Kidney Biopsy Codes for Pathologists

KBC
## Codes?

<table>
<thead>
<tr>
<th>Code</th>
<th>Concept</th>
<th>Coding system</th>
</tr>
</thead>
<tbody>
<tr>
<td>68779003</td>
<td>Primary IgA nephropathy</td>
<td>SNOMED CT</td>
</tr>
<tr>
<td>S67300</td>
<td>IgA nephropathy</td>
<td>SNOMED II</td>
</tr>
<tr>
<td>1128</td>
<td>IgA nephropathy</td>
<td>ERA-EDTA PRD</td>
</tr>
</tbody>
</table>
What exactly do we want to achieve?

We want
to develop a terminology
with corresponding codes (or “code values”)
applicable to every non-neoplastic kidney biopsy
for use by nephropathologists, nephropathology units or kidney biopsy registries.
• Describe coding systems: Kidney biopsy registries and nephropathology centres
• Describe international terminologies

• Define the requirements the KBC has to fulfill
• Build the principles for the solution

• Technical description of the basic design and a rational for choosing a specific system
• A complete code list and an example how to map an existing diagnosis list to the new codes

• Organize and conduct a review process
• Implement suggestions for improvement and comments

• Build structures for maintenance and further development; provide a economical model
• Online publication of the KBC
How do we intend to reach our goal?

Kidney Biopsy Codes

Amélie Dendooven
Antwerp, Belgium
FCGG

Sabine Leh
Bergen, Norway
NNR

Flemish Collaborative Glomerulonephritis Group

Norsk Nyreregister, seksjon for nyrebiopsi
How do we intend to reach our goal?

Mark Helbert
Antwerp, Belgium
As-is

- Describe coding systems: Kidney biopsy registries and nephropathology centres
- Describe international terminologies

Principles

- Define the requirements the KBC has to fulfill
- Build the principles for the solution

Design

- Technical description of the basic design and a rational for choosing a specific system
- A complete code list and an example how to map an existing diagnosis list to the new codes

Review

- Organize and conduct a review process
- Implement suggestions for improvement and comments

Governance

- Build structures for maintenance and further development; provide a economical model
- Online publication of the KBS
What have we accomplished so far?
Scope WP1: to learn what is

To describe

- medical kidney biopsy registries
- their coding systems
- international terminologies

Sources:

Scientific papers - PubMed search: ((Renal biopsy[Title/Abstract]) OR kidney biopsy[Title/Abstract]) AND registry[Title/Abstract]

Websites, SurveyMonkey
How do registries code?

<table>
<thead>
<tr>
<th>Registry</th>
<th>Coverage</th>
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<tbody>
<tr>
<td>British Columbia Glomerulonephritis Registry</td>
<td>regional</td>
</tr>
<tr>
<td>Flemish Renal Biopsy Registry</td>
<td>regional</td>
</tr>
<tr>
<td>Norwegian Renal Registry</td>
<td>nationwide</td>
</tr>
<tr>
<td>National Pathology Data Bank</td>
<td>nationwide</td>
</tr>
<tr>
<td>South-Eastern Romanian Renal Biopsy Registry</td>
<td>single center</td>
</tr>
<tr>
<td>Czech Registry of Renal Biopsies</td>
<td>nationwide</td>
</tr>
<tr>
<td>Japanese Renal Biopsy Registry</td>
<td>nationwide</td>
</tr>
<tr>
<td>Italian Registry of Renal Biopsies</td>
<td>nationwide</td>
</tr>
<tr>
<td>Polish Registry of Renal Biopsies</td>
<td>nationwide</td>
</tr>
<tr>
<td>Spanish Registry of Glomerulonephritis</td>
<td>nationwide</td>
</tr>
<tr>
<td>Scottish Renal Biopsy Registry</td>
<td>regional</td>
</tr>
</tbody>
</table>
How do registries code?

**IgA nephropathy, mesangiproliferative GN**

- **15 glomeruli, 1 cellular crescent, 2 segmental sclerosis, 4 global glomerulosclerosis.**
- **Tubular atrophy in around 20% of the cortical area.**
- **Moderate arteriolosclerosis and arteriosclerosis.**

**IH:** 
Dominant IgA positivity

**EM:** 
Mesangial electron dense deposits

**Oxford classification:** M1 E0 S1 T0 C1

**FLEMISH COLLABORATIVE GLOMERULONEPHRITIS GROUP (FCGG-NBVN)**

- **FCGG-NBVN 3/3a**
  - IgA nephropathy / IgA nephropathy, primary
- **ERA-EDTA PRD 1128**
  - IgA nephropathy –histologically proven

**PATOBANK (DENMARK)**

- **T 71000**
  - kidney
- **M46862**
  - diffuse mesangial proliferative GN
- **S67300**
  - IgA nephritis
- **M53300**
  - glomerulosclerosis
- **M58000**
  - tubular atrophy

**SCOTTISH RENAL BIOPSY REGISTRY**

- **ERA-EDTA PRD 1128**
  - IgA nephropathy – histologically proven

**UK RENAL REGISTRY**

- **ERA-EDTA PRD 1128**
  - IgA nephropathy – histologically proven

**LIMBURG RENAL REGISTRY**

- Mesangiproliferative glomerulonephritis
- IgA nephropathy
- Interstitial fibrosis
- Arteriosclerosis

**POLISH REGISTRY OF RENAL BIOPSIES (PRRB)**

- **124 Class IV (diffuse proliferative) lesions in IgA nephropathy**

**CZECH REGISTRY OF RENAL BIOPSIES (CRRB)**

- **1730 IgA nephropathy with crescents**

**ROMANIA "Dr. Carol Davila"**

- IgA nephropathy

**BRITISH COLUMBIA GLOMERULONEPHRITIS NETWORK**

- **G23.1**
  - IgA nephropathy primary
- **V3**
  - Hypertensive/benign/ischemic nephrosclerosis

**JAPAN RENAL BIOPSY REGISTRY (J-RBR)**

- IgA nephropathy (histological diagnosis by pathogenesis)
- Mesangial proliferative glomerulonephritis (histological diagnosis by histopathology)

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- **NNR 2013**
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- **NNR 2011**
  - 3 IgA nefropati

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<th>Histological diagnosis by pathogenesis</th>
<th>Histological diagnosis by histopathology</th>
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<tbody>
<tr>
<td>Acute nephritic syndrome</td>
<td>Primary glomerular disease except IgA nephropathy</td>
<td>Minor glomerular abnormalities</td>
</tr>
<tr>
<td>Rapidly progressive nephritic syndrome</td>
<td>IgA nephropathy</td>
<td>Focal and segmental glomerulosclerosis</td>
</tr>
<tr>
<td>Recurrent or persistent hematuria</td>
<td>Purpura nephritis</td>
<td>Membranous nephropathy</td>
</tr>
<tr>
<td><strong>Chronic nephritic syndrome</strong></td>
<td>Lupus nephritis</td>
<td><strong>Mesangial proliferative glomerulonephritis</strong></td>
</tr>
<tr>
<td>Nephrotic syndrome</td>
<td>MPO-ANCA positive nephritis</td>
<td>Endocapillary proliferative glomerulonephritis</td>
</tr>
<tr>
<td>Renal disorder with metabolic disease</td>
<td>PR3-ANCA positive nephritis</td>
<td>Membranoproliferative glomerulonephritis (type I and III)</td>
</tr>
<tr>
<td>Renal disorder with collagen disease or</td>
<td>Anti-glomerular basement membrane antibody nephritis</td>
<td>Dense deposit disease</td>
</tr>
<tr>
<td>vasculitis</td>
<td></td>
<td></td>
</tr>
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<td>Hypertensive nephropathy</td>
<td>Hypertensive nephrosclerosis</td>
<td>Crescentic and necrotizing glomerulonephritis</td>
</tr>
<tr>
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<td>Thrombotic microangiopathy</td>
<td>Sclerosing glomerulonephritis</td>
</tr>
<tr>
<td>Acute renal failure</td>
<td>Diabetic nephropathy</td>
<td>Nephrosclerosis</td>
</tr>
<tr>
<td>Drug-induced nephropathy</td>
<td>Amyloid nephropathy</td>
<td>Acute interstitial nephritis</td>
</tr>
<tr>
<td>Renal transplantation</td>
<td>Alport syndrome</td>
<td>Chronic interstitial nephritis</td>
</tr>
<tr>
<td>Others</td>
<td>Thin basement membrane disease</td>
<td>Acute tubular necrosis</td>
</tr>
<tr>
<td></td>
<td>Infection-related nephropathy</td>
<td>Others</td>
</tr>
<tr>
<td></td>
<td>Transplanted kidney</td>
<td></td>
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WP2: Principles

- Principles are fundamental rules (foundation) on which KBC is based.
- The principles are designed to ensure that the system meets the needs of the various interested parties.
Workshop WP 2 principles Maastricht 21.06.2018

Participants:
First row (left to right): Tri Nguyen (Netherlands), Evelyne Lerut (Belgium)
Second row: Han Peetermans (Belgium), Thorsten Wiech (Germany), Candice Roufousse (UK), Myrurgia Abdul Hamid M.A. (Netherlands), Amélie Dendooven (Belgium), Joris Roelofs (Netherlands), Sabine Leh (Norway)
<table>
<thead>
<tr>
<th>Coding</th>
<th>System</th>
<th>Environment</th>
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<tbody>
<tr>
<td>State of the art knowledge</td>
<td>Simple and quick to use</td>
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<td>systems possible</td>
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<tr>
<td>morphological pattern</td>
<td>user’s needs</td>
<td></td>
</tr>
<tr>
<td>Coding of multiple diagnoses</td>
<td>Synonyms</td>
<td>Mapped to widely used terminologies</td>
</tr>
<tr>
<td>Codes for every conceivable</td>
<td>Definitions</td>
<td>Governance</td>
</tr>
<tr>
<td>scenario</td>
<td>KBC is multilingual</td>
<td></td>
</tr>
<tr>
<td>Unambiguous coding</td>
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</tr>
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KBC
Principles

1. Coding of more than one morphological pattern is possible
2. KBC allows coding along several axes
3. Coding multiple diagnoses is possible with KBC
4. KBC provides for unambiguous coding
5. Governance is established
6. KBC reflects state-of-the-art knowledge
7. KBC is simple and quick to use
8. KBC is freely accessible
9. Use of KBC is flexible according to the user’s needs
10. Mapping of KBC to existing coding systems is possible
11. KBC provides synonyms for concepts
12. The workload in production, maintenance and governance is minimised
13. KBC allows for various operating modalities such as coding on paper, but also coding in digital systems and databases
Principles

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What comes next?

Design and content!
This is, where the idea for the new system gets a little bit complicated.
Kidney biopsy diagnosis

- Diagnosis
  - Class
    - 1..*
- Pathogenesis
- Morphological pattern
- Certainty
  - 0..1
Kidney biopsy diagnosis

- Diagnosis
  - Pathogenesis
  - Morphological pattern
  - Certainty

- Diagnosis code
- Pathogenesis code
- Pattern code
- Certainty code
Kidney biopsy diagnosis

- Diagnosis
  - Class
    - 1..*
- Pathogenesis
  - 0..1
- Morphological pattern
  - 0..?
- Certainty
  - 0..1

- Diagnosis code
- Pathogenesis code
- Pattern code
- Certainty code

Combined code
Discussion

- How to align efforts?
- Describe coding systems: Kidney biopsy registries and nephropathology centres
- Describe international terminologies

- Define the requirements the KBC has to fulfill
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Italian Registry of Renal Biopsies
Scottish Renal Biopsy Registry
Spanish Registry of Glomerulonephritis
The Polish Registry of Renal Biopsies
British Columbia Glomerulonephritis Registry
UK Renal Registry
Limburg Renal Registry
Japan Renal Biopsy Registry
Czech Renal Biopsy Registry
South-Eastern Romanian Renal Biopsy Registry
Swedish Renal registry
Nederlandstalige Belgische Vereniging voor Nefrologie (NBVN)

Niels Marcussen
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Fergus Caskey
Myurgia Abdul Hamid
Michio Nagata
Eva Jancova
Cristina Capusa
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