Kidney Biopsy Codes for Pathologists

KBC

Codes?

Code	Concept	Coding system
68779003	Primary IgA nephropathy	SNOMED CT
S67300	IgA nephropathy	SNOMED II
1128	IgA nephropathy	ERA-EDTA PRD

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.

As-is

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

Principles

- Define the requirements the KBC has to fullfill
- 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

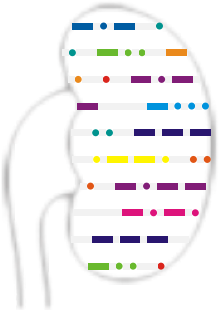
- Organize and conduct a review process
- Implement suggestions for improvement and comments

Governance

- Build structures for maintenance and further development; provide a economical model
- Online publication of the KBC

How do we intend to reach our goal?

Kidney Biopsy Codes



KBC

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How do we intend to reach our goal?

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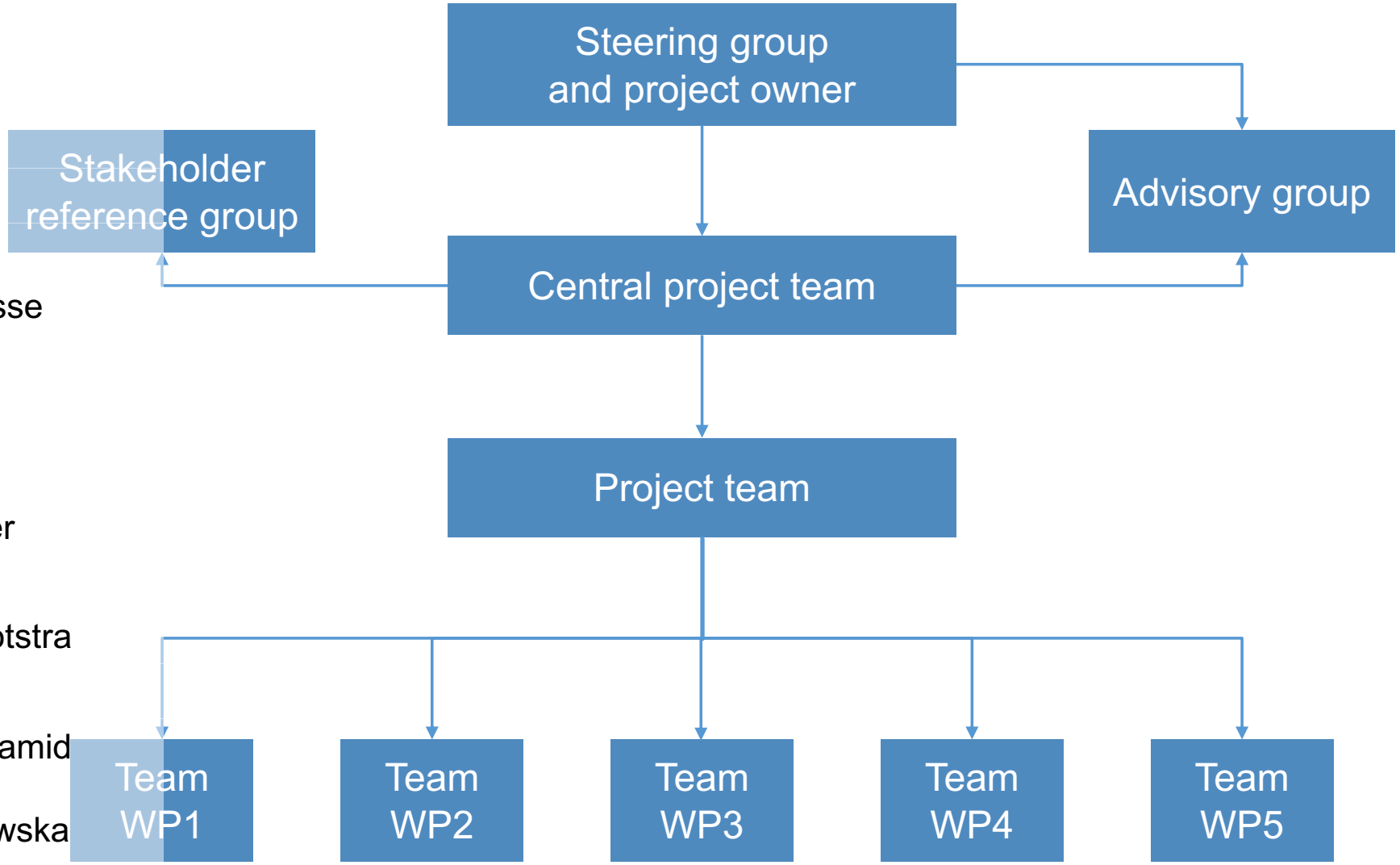

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What have we accomplished so far?

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


Denmark
Norway
Sweden
Poland
Scotland
Limburg
Czech Republic
Japan
British Columbia
Belgium
Romania
Spain
Italy
Malaysia
Uruguay

How do registries code?

	2 Coverage
British Columbia Glomerulonephritis Registry	regional
Flemish Renal Biopsy Registry	regional
Norwegian Renal Registry	nationwide
National Pathology Data Bank	nationwide
South-Eastern Romanian Renal Biopsy Registry	single center
Czech Registry of Renal Biopsies	nationwide
Japanes Renal Biopsy Registry	nationwide
Italian Registry of Renal Biopsies	nationwide
Polish Registry of Renal Biopsies	nationwide
Spanish Registry of Glomerulonephritis	nationwide
Scottish Renal Biopsy Registry	regional

How do registries code?

IgA nephropathy, mesangioproliferative GN glomerulonephritis. 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

NORWEGIAN RENAL REGISTRY (NNR)

ERA-EDTA PRD	1128	IgA nephropathy-histologically proven
NNR 2013	300	IgA nefropati
NNR 2011	3	IgA nefropati

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)

ITALIAN REGISTRY OF RENAL BIOPSIES (IRRB)

ERA-EDTA PRD 1128 IgA nephropathy – histologically proven

SPANISH REGISTRY OF GLOMERULONEPHRITIS

? IgA nephropathy

FLEMISH COLLABORATIVE GLOMERULONEPHRITIS GROUP (FCGG-NBVN)

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

LIMBURG RENAL REGISRTY

Mesangioproliferative glomerulonephritis
IgA nephropathy
Interstitial fibrosis
Arteriosclerosis

UK RENAL REGISRTY

ERA-EDTA PRD 1128 IgA nephropathy – histologically proven

SCOTTISH RENAL BIOPSY REGISRTY

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

How do registries code?

IgA nephropathy, mesangioproliferative GN glomerulonephritis. 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
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Japan Renal Biopsy Registry

Clinical diagnosis	Histological diagnosis by pathogenesis	Histological diagnosis by histopathology

Sugiyama H, Yokoyama H, Sato H, et al. Japan Renal Biopsy Registry: the first nationwide, web-based, and prospective registry system of renal biopsies in Japan. *Clin Exp Nephrol* 2011; **15**(4): 493-503.

Japan Renal Biopsy Registry

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

Sugiyama H, Yokoyama H, Sato H, et al. Japan Renal Biopsy Registry: the first nationwide, web-based, and prospective registry system of renal biopsies in Japan. *Clin Exp Nephrol* 2011; **15**(4): 493-503.

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)

Coding	System	Environment
State of the art knowledge	Simple and quick to use	Freely accessible
Coding along several axes	Various operation modalities	Mapping to self-made coding systems possible
Coding of more than one morphological pattern	Flexibility according to the user's needs	Mapped to widely used terminologies
Coding of multiple diagnoses	Synonyms	Governance
Codes for every conceivable scenario	Definitions	Minimised workload to run the system
Unambiguous coding	KBC is multilingual	
Hierarchy of coding axes	Coding roules are provided	

Coding

State of the art knowledge
● ● ● ● ● ● ●

Coding along several axes
● ● ● ● ● ● ● ●

Coding of more than one morphological pattern ● ● ● ●
● ● ● ● ● ● ● ● ● ● ● ● ●

Coding of multiple diagnoses
● ● ● ● ● ● ● ●

Codes for every conceivable scenario
● ● ● ● ● ●

Unambiguous coding
● ● ● ● ● ● ● ●

Hierarchy of coding axes

System

Simple and quick to use
● ● ● ● ●

Various operation modalities

Flexibility according to the user's needs
● ● ● ●

Synonyms
● ● ●

Definitions

KBC is multilingual

Coding roules are provided
● ● ● ● ●

Environment

Freely accessible
● ● ● ● ●

Mapping to self-made coding systems possible
● ● ●

Mapped to widely used terminologies
● ●

Governance
● ● ● ● ● ● ● ●

Minimised workload to run the system
●

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

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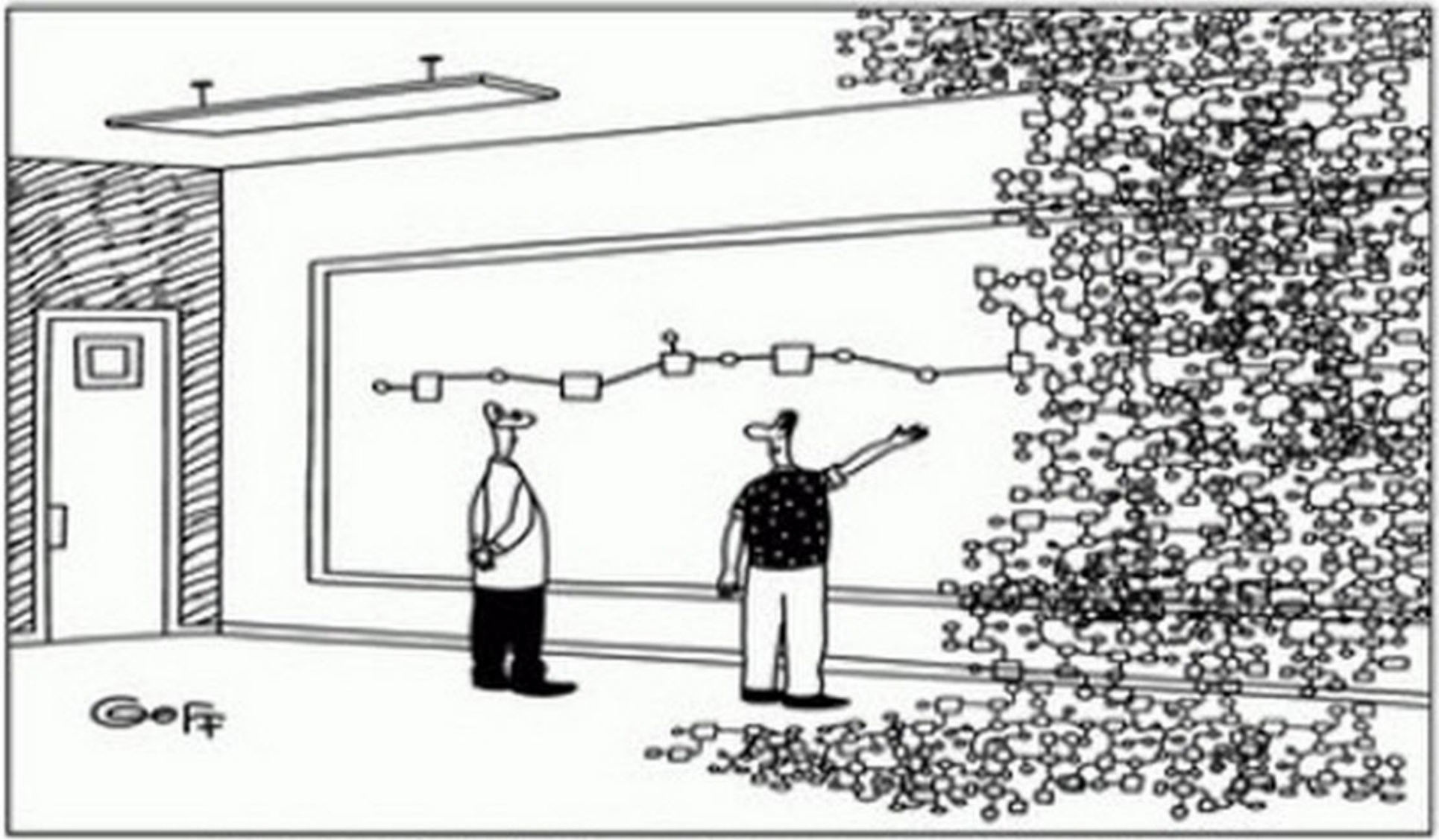
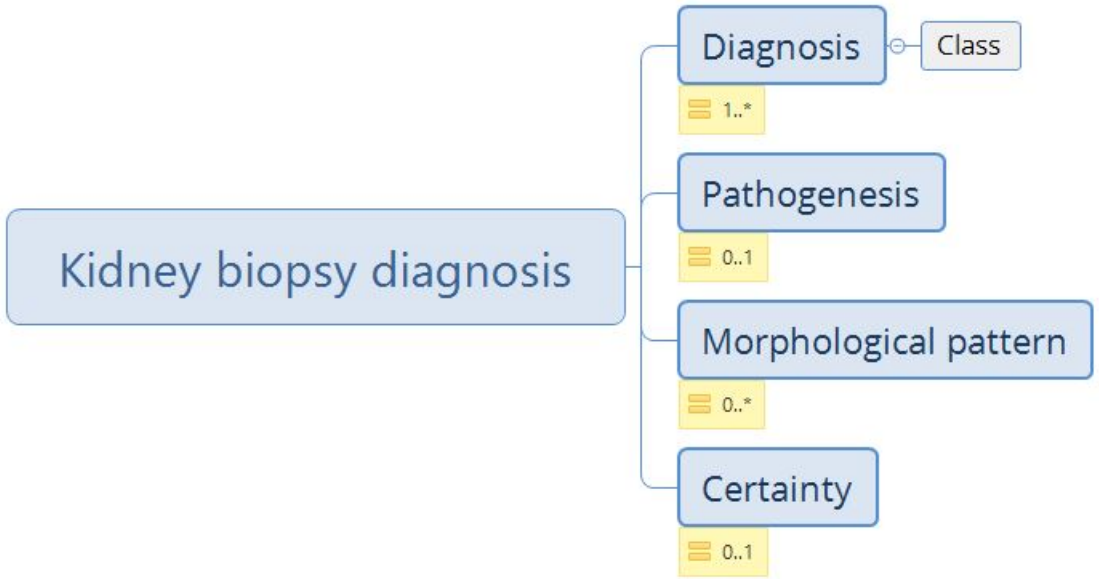
What comes next?

Design and content!

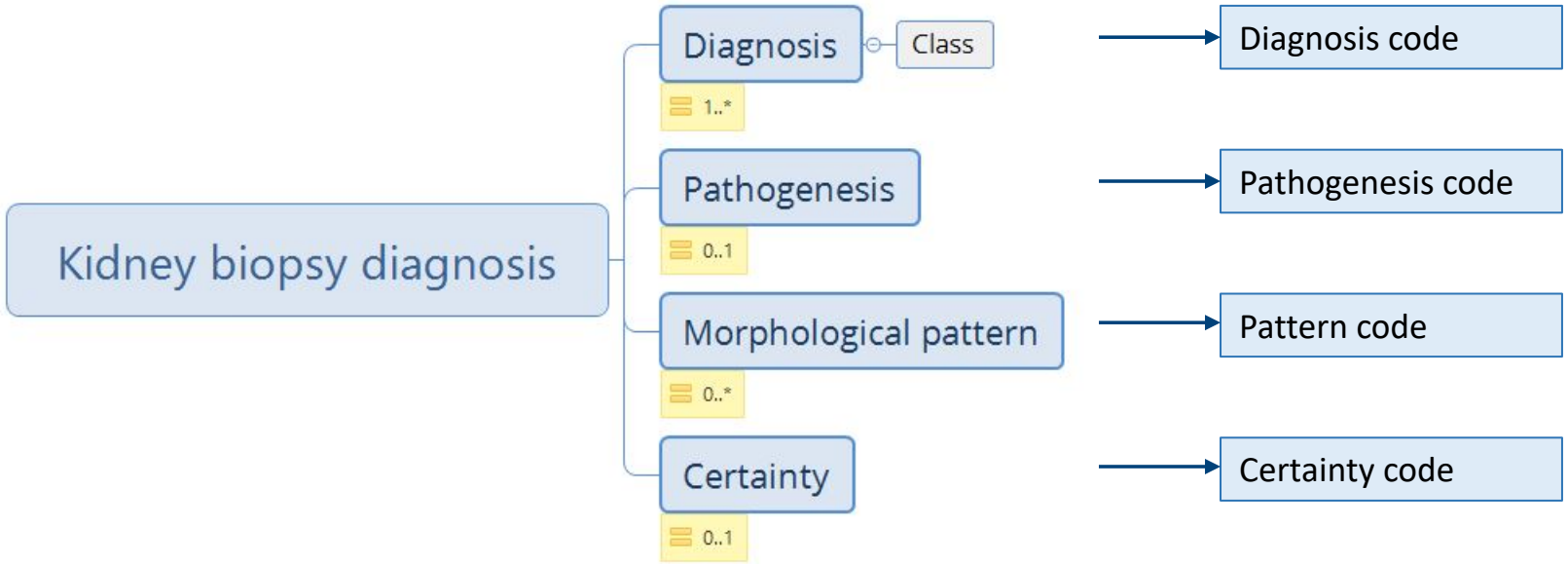


This is, where the idea for the new system gets a little bit complicated

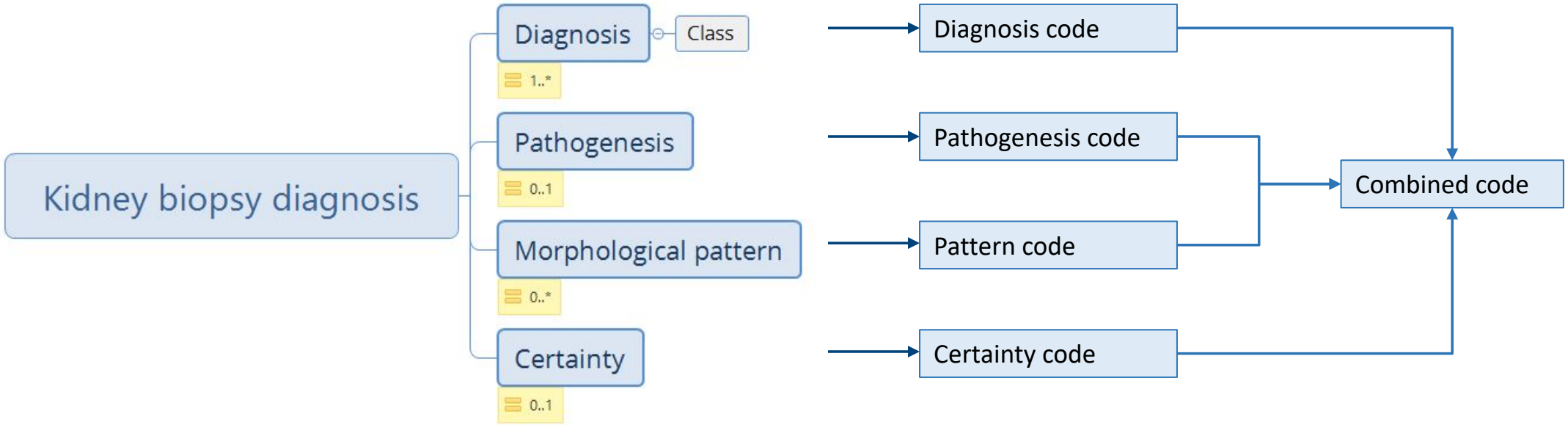
Kidney biopsy diagnosis



Kidney biopsy diagnosis



Kidney biopsy diagnosis



Discussion

- How to align efforts?

As-is

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Acknowledgements

National Pathology Data Bank	Niels Marcussen
Italian Registry of Renal Biopsies	Loreto Gesualdo
Scottish Renal Biopsy Registry	Colin Geddes
Spanish Registry of Glomerulonephritis	Juan Manuel Lopez Gomez
The Polish Registry of Renal Biopsies	Agniezka Perkowska
British Columbia Glomerulonephritis Registry	Sean Barbour
UK Renal Registry	Fergus Caskey
Limburg Renal Registry	Myurgia Abdul Hamid
Japan Renal Biopsy Registry	Michio Nagata
Czech Renal Biopsy Registry	Eva Jancova
South-Eastern Romanian Renal Biopsy Registry	Cristina Capusa
Swedish Renal registry	Marten Segelmark
Nederlandstalige Belgische Vereniging voor Nefrologie (NBVN)	

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