

Patient registries
in the BeNeLuxA
member countries –
A mapping exercise



Background

- Orientation Meeting on Patient Registries on 28 November 2017
 - Policy makers and national patient registry experts from BeNeLuxA countries, Hungary and the United Kingdom met in Vienna on 28 November 2017 to explore a possible collaboration in the field of patient registries in order to increase efficiency, and enhance evidence generation and information sharing.
- Mapping of patient registries
 - As a supportive exercise, a preliminary mapping of patient registries in the member countries of the BeNeLuxA collaboration was done and shared.

Disclaimer and citation policy

- The mapping exercise was conducted for internal BeNeLuxA purposes,
 - however, the BeNeLuxA is pleased to make findings publically available.
- Precautions have been taken to verify the information
 - but the mapping exercise does not pretend to be comprehensive.
- Interested researchers and experts are allowed to use information compiled in the mapping exercise,
 - however, the BeNeLuxA collaboration shall be acknowledged as author.
- Cite as follows:
 - BeNeLuxA Collaboration. Patient registries in the BeNeLuxA member countries – A mapping exercise. Available from: <http://www.beneluxa.org>

Purpose of registries

- Research and evidence
- Scientific publication

- Statistics
- Surveillance

- Quality assurance and quality improvement
- Overview and recruit patients for clinical trials

- Cost containment
- Looking for donors

- Monitoring
- Other (funding, quality control, etc.)

Patient registries (diseases/conditions)

Austria

CONDITION BASED REGISTRY: NAME OF THE REGISTRY - REGISTRY HOLDER

• Austrian acromegaly registry	Pr Harald DOBNIG, Medizinische Universität Graz, Österreichische Gesellschaft für Endokrinologie und Stoffwechsel	• Austrian Alpha-1 Antitrypsin Deficiency Registry	Wilhelminenspital der Stadt Wien
• Austrian Birth Registry	IET*	• Austrian Brain Tumor Registry	Obersteiner Institut, Klinische Institut für Neurologie
• Austrian Cancer Registry	Statistik Austria	• Austrian chronic myeloid leukemia registry	Pr Günther GASTL, Österreichische Gesellschaft für Hämatologie & Medizinische Onkologie
• Austrian dialysis and transplantation registry	ÖGN* , Austrotransplant Österreichische Gesellschaft für Transplantation, Transfusion und Genetik, ARGE ÖDTR*	• Autoimmune hemolytic anemia (AIHA) Registry	AGMT*
• Austrian Hemophilia Registry - Registry for patients with inborn coagulation defects	Pr Ingrid PABINGER-FASCHING, Universitätsklinik für Innere Medizin	• Austrian Myeloma registry	Oncotyrol
• AUSTRIAN NATIONAL CATH. LAB. REGISTRY	ÖKG*, ARGE	• Austrian registry for inborn errors of metabolism	Pr Daniela KARALL, Medizinische Universität Innsbruck
• Austrian Stroke Unit registry	Austrian Public Health Institute	• Biomarkers in Metastatic Colorectal Cancer	AGMT*

*IET = Institut für klinische Epidemiologie der Tirol Kliniken GmbH

* AGMT = Arbeitsgemeinschaft medikamentöse Tumorthherapie

* ÖGN = Österreichische Gesellschaft für Nephrologie

* ÖKG = Österreichische Kardiologische Gesellschaft

* ARGE ÖDTR = Arbeitsgemeinschaft Österreichisches Dialyse- und Transplantationsregister

CONDITION BASED REGISTRY: NAME OF THE REGISTRY - REGISTRY HOLDER

• Ceprotrin Treatment Registry	Pr Paul KNÖBL, Universitätsklinik für Innere Medizin	• Epidermolysis bullosa registry	DEBRA* Austria
• Echinococcosis registry	Pr Michael RAMHARTER, Allgemeines Krankenhaus der Stadt Wien	• Head and neck tumour registry Austria	AGMT*
• European Leukemia Net (ELN)	European Leukemia Network, Ludwig-Maximilians-Universität München	• Injury Database Austria	KfV*
• Hepatitis C Registry	Main Association of Austrian Social Security Institutions	• Langerhans cell histiocytosis registry	Medical University of Vienna
• Innsbruck registry for Adamantiades- Behcet disease	Pr Michael SCHIRMER, Medizinische Universität Innsbruck	• MDS Austrian myelodysplastic syndromes patient registry	Pr Reinhard STAUDER, Universitätsklinik für Innere Medizin Innsbruck
• Metastatic breast cancer in Austria	AGMT*	• NF-10 - Prospective collection of potentially prognostically relevant data in patients with indolent non-follicular B-cell lymphoma	Pr Markus RADERER, Allgemeines Krankenhaus der Stadt Wien
• Premature Infants Outcome Registry	Austrian Public Health Institute	• PTCL registry (T-cell lymphoma in Austria)	AGMT*
• Diabetes Registry Tyrol	IET*	• Registry and Biobank for the collection of clinical data and biomaterial from adult acute lymphoblastic leukemia	AGMT*

*IET = Institut für klinische Epidemiologie der Tirol Kliniken GmbH

*DEBRA = Dystrophic Epidermolysis Bullosa Research Association

* AGMT = Arbeitsgemeinschaft medikamentöse Tumorthapie

*KfV = Kuratorium für Verkehrssicherheit

CONDITION BASED REGISTRY: NAME OF THE REGISTRY - REGISTRY HOLDER

• Registry for Philadelphia chromosome-positive acute lymphoblastic leukemia in childhood and adolescence	Pr Andishe ATTARBASCHI, St. Anna Kinderspital, Wien	• Upshaw-Schulman-Syndrome registry	Pr Paul KNÖBL, Universitätsklinik für Innere Medizin
• Registry for relapsing acute lymphoblastic leukemia in childhood and adolescence	Pr Georg MANN, St. Anna Kinderspital, Wien	• Registry of the NHL-BFM study group for all subtypes of Non-Hodgkin lymphoma in children and adolescents	Pr Andishe ATTARBASCHI, St. Anna Kinderspital, Wien
• Salzburg Cancer Registry	Hospital Association of Salzburg, University Hospital Salzburg	• Screening for human epidermal growth factor receptor 2 (HER2) positivity in patients with inoperable locally advanced or metastatic gastric or gastro-esophageal junction cancer	AGMT*
• Skin cancer syndrome registry Graz	Pr Harald DOBNIG, Medizinische Universität Graz, Österreichische Gesellschaft für Endokrinologie und Stoffwechsel	• Styrian registry of congenital anomalies	Pr Martin HÄUSLER, Forschungsverein zur Registrierung steirischer Geburtsfehlbildungen, Medizinische Universität Graz
• Surgical Resection of Solitary Metastases in Patients with Metastatic Breast Cancer	AGMT*	• The Use of Genomic Testing and the Resulting Medical Decisions According to Target Identification	AGMT*
• Traumaversorgung	DGU*, AUC*	• Tumor Registry Kärnten	KABEG
• Tumor Registry Salzburg	SALK*	• Tumor Registry Tyrol	AGO*, IET*

*AGMT = Arbeitsgemeinschaft medikamentöse Tumortherapie

*AGO = Arbeitsgemeinschaft für Gynäkologische Onkologie

* KABEG = Kärntner Landeskrankenanstalten-Betriebsgesellschaft

* DGU Deutsche Gesellschaft für Unfallchirurgie

* IET = Institut für klinische Epidemiologie der Tirol Kliniken GmbH

* AUC Akademie der Unfallchirurgie GmbH

* Salk Institute for Biological Studies

SERVICE BASED REGISTRY: NAME OF THE REGISTRY - REGISTRY HOLDER

• Austrian Invitro fertilisation registry	Austrian Public Health Institute	• Prosthesis Registry Tyrol	IET*
• Quality assurance in vascular surgery	Austrian Public Health Institute	• Registry for adult heart surgery	Austrian Public Health Institute (BIQG)
• Registry for breast implants	Gesellschaft für plastische, ästhetische und rekonstruktive Chirurgie	• Sacrocolpopexy registry	Österreichische Arbeitsgemeinschaft für Urogynäkologie & Rekonstruktive Beckenbodenchirurgie
• Stem Cell Registry	Austrian Public Health Institute (GÖG)	• Surgical Resection of liver methastases	AGMT*

DISEASE/CASE BASED REGISTRY: NAME OF THE REGISTRY - REGISTRY HOLDER

• Austrian Registry for Biologic Agents	BioReg*	• Biologika in der Kinderrheumatologie	BIKER*
• Central data registry of the European Competence Network on Mastocytosis	Medical University Vienna	• European central hypoventilation syndrome registry	European CHS Network
• European Cystic Fibrosis Society Patient Registry	- European Cystic Fibrosis Society	• European Database for Multiple Sclerosis	EDMUS, Hôpital Neurologique, Lyon
• European Haemophilia Safety Surveillance System	University of Sheffield	• European Multicentre Bronchiectasis Audit and Research Collaboration	University of Dundee

*IET = Institut für klinische Epidemiologie der Tirol Kliniken GmbH

*AGMT = Arbeitsgemeinschaft medikamentöse Tumorthherapie

*BIKER = Biologic Registry for Pediatric Rheumatology

*BioReg = Biologika-Register

DISEASE/CASE BASED REGISTRY: NAME OF THE REGISTRY - REGISTRY HOLDER

• European Network and Registry for Homocystinurias and Methylation Defects - E-HOD	VU University Medical Centre VUMC (in NL)	• European patient registry on TRAPS syndrome	EUROTRAPS
• European prospective cohort on thrombophilia	Leiden University	• European registry and network for intoxication type metabolic diseases	E-IMD (University of Heidelberg)
• European Registry for Children on Renal Replacement Therapy	European Society for Paediatric Nephrology	• European Society for Immunodeficiencies	University Freiburg
• European surveillance of congenital anomalies EUROCAT	Joint Research Centre , JRC-EUROCAT Central Registry European Commission, Institute for Health and Consumer Protection	• Galactosemia Patient Registry	Maastricht University
• RD-Connect: Patient registries integrated platform	International Centre for Life, Newcastle University	• Translational Research in Europe: Assessment and Treatment of Neuromuscular Diseases	University of Newcastle

PRODUCT BASED REGISTRY: NAME OF THE REGISTRY - REGISTRY HOLDER

• Austrian Brentuximab Vedotin Registry	AGMT*	• Austrian registry for pacemakers, ICD and looprecorder	Austrian Public Health Institute
• Austrian Registry on Hypomethylating Agents in Myeloid Neoplasms	AGMT*		

*AGMT = Arbeitsgemeinschaft medikamentöse Tumorthherapie

Patient registries (diseases/conditions)

Belgium

REGISTRIES FOR THE FOLLOWING DISEASES/CONDITIONS:

• Cancer	• Cardiac Incidents
• Chronic Kidney Disease	• Diabetes Mellitus
• Fetal Chromosomal Abnormalities	• Healthcare Associated Infections > Clostridium Difficile Infections, Septicemia, Methicillin resistant Staphylococcus aureus
• Infectious diseases > HIV-AIDS, Sexually Transmittable Infections, Hepatitis C	• Metabolic Diseases
• Rare Diseases > Cystic Fibrosis Registry, Hemophilia, Multiple Sclerosis, Lynch Syndrome	• Rheumatoid arthritis
• Severe Acute Respiratory Illness	• Tuberculosis
• Medical Devices	• Medication
• Testing	• Treatment

Patient registries (diseases/conditions)

Luxembourg

REGISTRIES FOR THE FOLLOWING DISEASES/CONDITIONS – RESPONSIBLE AUTHORITY

• Causes of death	Ministry of Health	• Maternal and newborn health (SUSANA)	Ministry of Health / Luxembourg Institute of Health
• National Cancer Registry (RNC)	Ministry of Health / Luxembourg Institute of Health	• Traumatism and injuries (RETRACE)	Ministry of Health / Luxembourg Institute of Health
• Nosocomial infection surveillance system (NOSIX)	Ministry of Health / Luxembourg Institute of Health	• Infectious diseases (compulsory notification)	Ministry of Health
• Breast cancer screening program	Ministry of Health	• Colorectal cancer screening program	Ministry of Health
• Individualized support and integration plan (PAI) for children with specific health needs in educational or care establishments	Ministry of Health / Ministry of Education, Children and Youth	• HIV, AIDS, HCV	Luxembourg Institute of Health
• Newborn screening program <ul style="list-style-type: none"> - Phenylketonuria - Congenital hypothyroidism - Congenital adrenal hyperplasia - MCADD - Cystic fibrosis 	Laboratoire national de santé		

Patient registries (diseases/conditions)

The Netherlands

REGISTRIES FOR THE FOLLOWING DISEASES/CONDITIONS

• Cancer: Pancreatic – Lung – Breast cancer	• Cystic Fibrosis	• Diabetes
• Early psoriatic arthritis	• Fabry disease	• Gaucher
• Growth Hormon	• Gynaecological oncology	• Hemato-Oncology
• Hemophilia	• HIV	• Immuno therapy
• Inflammatory Bowel Disease	• Long Fibrose	• Melanoma
• MS	• Psychiatric case registry	• Reumatic diseases & arthrises
• Severe Asthma	• SLE	• Viral Hepatitis

Who is in charge of/maintains the registries?

AUSTRIA

- | | | |
|-------------------|----------------|----------------------|
| • Medical society | • Hospital | • Research companies |
| • Authority | • Universities | • Association |

BELGIUM

- | | | |
|----------------------------|-------------------------------|-----------------|
| • Scientific organizations | • Professional organizations | • SME |
| • Patient organizations | • Governmental administration | • Healthdata.be |
| • Industry | • Payers | • Universities |

LUXEMBOURG

- | | | |
|-------------------------------|----------------------------------|---------------------------------|
| • Governmental administration | • Luxembourg Institute of Health | • Laboratoire national de santé |
| • Hospitals | | |

THE NETHERLANDS

- | | | |
|---------------------------|-----------------------|--------------|
| • Society of doctors | • Knowledge institute | • Insurers |
| • Pharmaceutical industry | • Hospitals | • Government |

Which data is collected and how?

AUSTRIA

- | | | |
|--|--|--|
| <ul style="list-style-type: none">• Adverse events• Complications• Death• Diagnosis• Discharge | <ul style="list-style-type: none">• Laboratory values• Mortality• Operation techniques• Outcome• Overdoses | <ul style="list-style-type: none">• Procedures• Symptoms/signs• Treatment data |
|--|--|--|

How:

- Depends on Registry
- Sources: PARENT, Orphanet, EnCPP, RD-Connect, Austrian Public Health Institute, Publications, Austrian medical society

BELGIUM

- | | | |
|---|--|---|
| <ul style="list-style-type: none">• Encounters• Functional Status• Identifiers• Immunization | <ul style="list-style-type: none">• Medical Devices• Medication• Problems• Procedures | <ul style="list-style-type: none">• Results<ul style="list-style-type: none">> Laboratory and Text Results• Social and Family history• Vital Signs |
|---|--|---|

How:

- Technical solutions: fax, email, web application
- Semantics and information architecture
- Treatment of identifiers: anonymization or pseudonymization
- Since 2015 standardized and centralized by healthdata.be

Which data is collected and how?

LUXEMBOURG

- | | | |
|--|---|---|
| <ul style="list-style-type: none">• Patient characteristics• Mortality• Adverse events• Complications | <ul style="list-style-type: none">• Follow up status• Nature of injury• Diagnosis | <ul style="list-style-type: none">• Risk factors• Treatment• Medication |
|--|---|---|

How:

Depends on registry, electronic and paper based data collection

THE NETHERLANDS

- | | | |
|---|--|--|
| <ul style="list-style-type: none">• Adverse events• Diagnostics• Medication | <ul style="list-style-type: none">• Outcome• Patients• QoL | <ul style="list-style-type: none">• Treatments |
|---|--|--|

• How:

- IT-Solution: new software, regular ict, unknown, spreadsheet

Who has access to the data? How?

AUSTRIA

Depends on the registry:	<ul style="list-style-type: none"> Some registries have a standardised process and a committee (e.g. BioReg-Austria)
--------------------------	---

BELGIUM

Who:	<ul style="list-style-type: none"> Sponsor: raw data Other research: raw aggregate data on request 	<ul style="list-style-type: none"> Data provider: feedback reports Government: reports
------	--	--

How:	<ul style="list-style-type: none"> Currently, no common user and access policy > Federal initiative to implement FAIR (<i>findable, accessible, interoperable, re-usable</i>) data policy
------	--

LUXEMBOURG

Who:	<ul style="list-style-type: none"> Depends on the registry 	<ul style="list-style-type: none"> Raw data for internal use / scientific use Aggregate data for public / health professionals
------	---	--

How:	<ul style="list-style-type: none"> Depends on the registry 	<ul style="list-style-type: none"> Standardized procedure Written request
------	---	---

THE NETHERLANDS

Who → Privacy of data through:	<ul style="list-style-type: none"> Coded data Patient informed consent 	<ul style="list-style-type: none"> Trusted third party Combination
--------------------------------	--	--

How → Commission for access of data:	<ul style="list-style-type: none"> 75% Yes 5% No 	<ul style="list-style-type: none"> 20% Unknown
--------------------------------------	--	---

Is there mandatory reporting to authorities in place?

AUSTRIA

Depends on the registry:

- Some are implemented by law

BELGIUM

Only if project is:

- Part of national or international obligation
- Funded by national or international authority

LUXEMBOURG

Depends on the registry, it is mandatory if....

- Legal basis
- Founded by national authority

What is done with the data?

Is the data used for MEA?

AUSTRIA

- No registry in place for MEA (out-patient sector)

BELGIUM

- | | | |
|---|---|---|
| <ul style="list-style-type: none"> • Use and re-use need to be specified by original authorisation by private commission | <ul style="list-style-type: none"> • Initiatives to re-use data from patient registries for MEA > Point of attention: <ul style="list-style-type: none"> • Many patient registries do not cover all required content • For extensions, the MEA-client always depends on approval by research consortium of the patient registry (uncertain outcome, timing) | <ul style="list-style-type: none"> • Data collection often only once a year/only the most recent data/only a summary • Practical issue: is researcher of patient registry also responsible for data quality or MEA-client |
|---|---|---|

LUXEMBOURG

- | | | |
|---|---|--|
| <ul style="list-style-type: none"> • Elaboration and evaluation of national plans and guidelines | <ul style="list-style-type: none"> • Data used at National and EU level: scientific papers, reports, fact sheets, newspaper articles | <ul style="list-style-type: none"> • General monitoring of health indicators, benchmarking, injury risks of products, services, etc |
| <ul style="list-style-type: none"> • Indicators for national public health discussion | <ul style="list-style-type: none"> • Health care assessment | <ul style="list-style-type: none"> • International comparison (WHO, OECD) |

THE NETHERLANDS

- | | | |
|--|--|--|
| <ul style="list-style-type: none"> • Monitoring | <ul style="list-style-type: none"> • Scientific publication | <ul style="list-style-type: none"> • Cost containment |
| <ul style="list-style-type: none"> • Lareb (adverse events) | <ul style="list-style-type: none"> • Health insurance board | |

Contact:

Info@beneluxa.org

For more information go to:

www.beneluxa.org