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What can we improve for the future?

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BBMRI.nl
Health-RI partner

10 YEARS

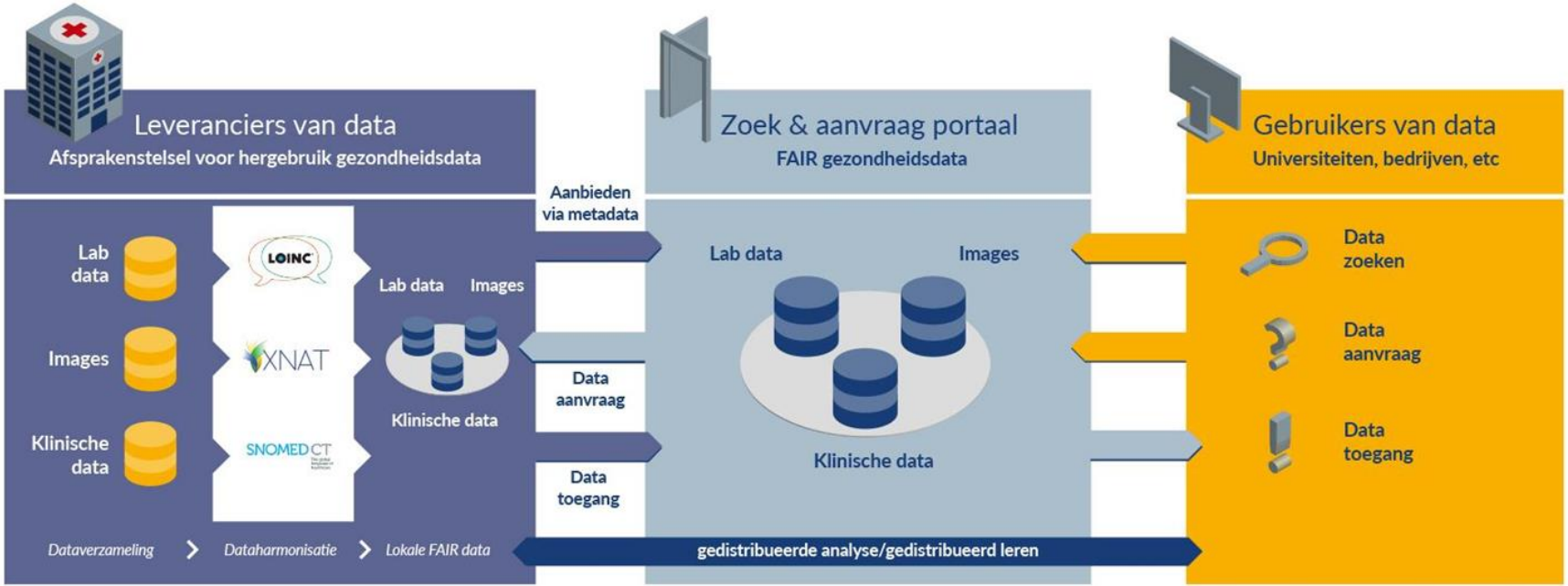
health RI
enabling data driven health

Expert Meeting Series 2021
The Next Step in Making Health Data Available for Research

Expert Meeting #3

07/10/2021

Building a National Health Research Infrastructure for optimal access to knowledge, tools, facilities, health data and samples



Data genereren volgens FAIR principes

Donderdag 9 september 13.00-14.30 uur

- Dr. Rob Hooft (DTL)
- Dr. Margreet Bloemers (ZonMw)
- Prof. Dr. Wiro Niessen (ErasmusMC)

Data vindbaar en koppelbaar maken

Donderdag 23 september 13.00-14.30 uur

- Prof. Dr. Sabine Siesling – (IKNL)
- Prof. Dr. Edwin Cuppen – (HMF)
- Dr. Jeroen Beliën - Amsterdam UMC

Data zoeken en toegankelijk maken

Donderdag 7 oktober 13.00-14.30 uur

- Sandra van den Broek (HMF)
- Dr. Aletta Debernardi (PALGA)
- Prof. dr. Folkert van Kemenade (ErasmusMC)

Folkert v Kemenade

Erasmus MC. Afd pathologie

Data zoeken & toegankelijk maken

Expertmeeting 7-10-2021

health RI research infrastructure

BBMRI.nl
Biobanking and
BioMolecular resources
Research Infrastructure
The Netherlands

FAIR Biobanking en Databanking

Research biobanken, Registraties, Zorg data banken

BBRMI 1.0 RB8 findable: Catalogus, PALGA portal

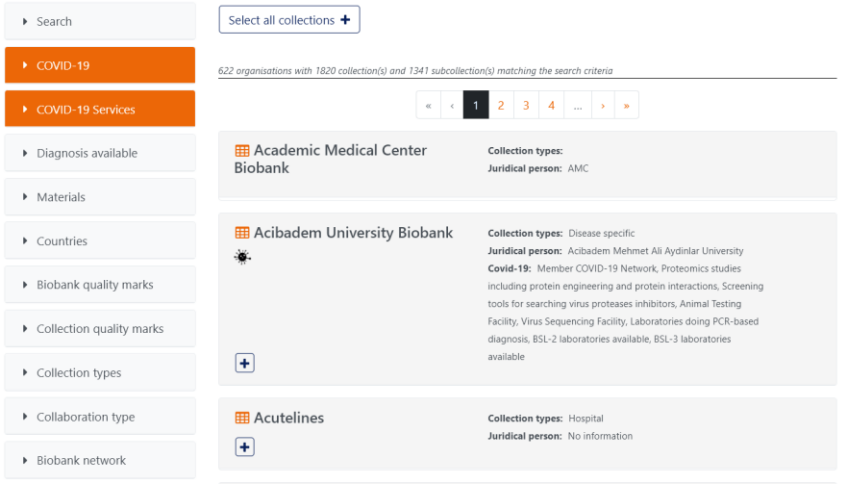
BBRMI 2.0 WP4 Accessible: Podium (catalogus+ uitbreiding met registraties en cohort data (bios)

Podium doel: vinden en toegang krijgen.

Deze expertmeetings zijn bedoeld om gebruik toe te lichten.

NB : Europees equivalent (BBMRI-ERIC): directory ≈ catalogus .

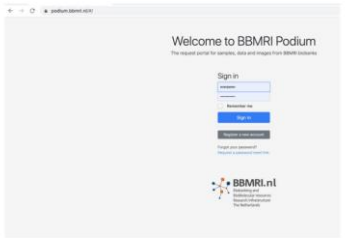
https://directory.bbmri-eric.eu



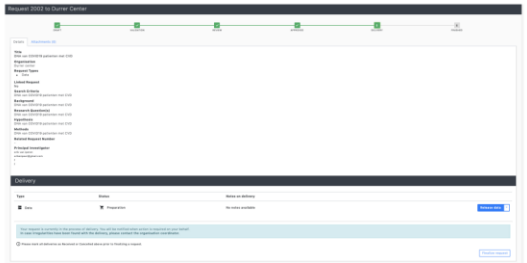
Een eerder voorbeeld was capacity (DCVA) (expertmeeting ‘20)

Investigating the role of cardiovascular disease in patients with COVID19: role of preexistent cardiac disease, role of ACE inhibitors, extent of cardiac damage → connecting with COVID isaric formatted data.

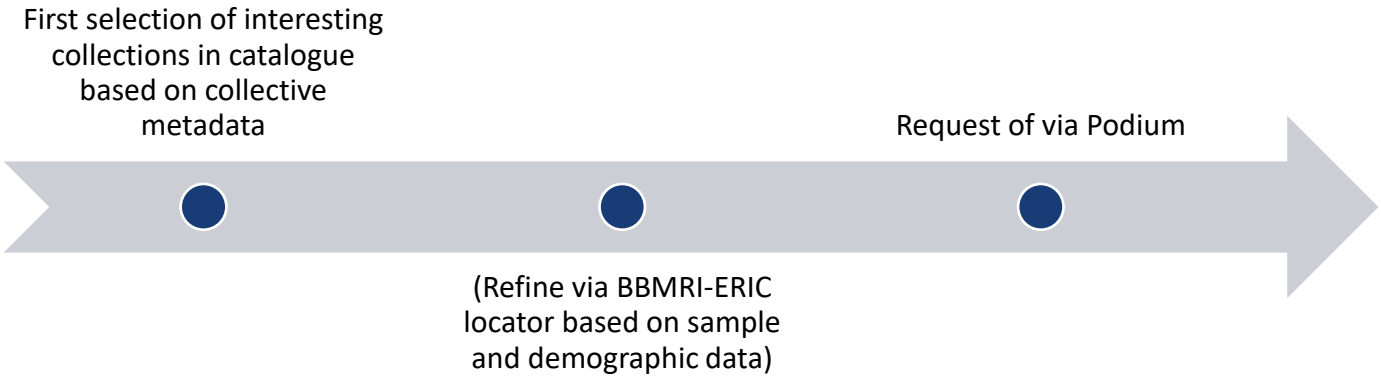
Login/Register in Podium



Release of data



Ideale situatie



Researcher:

- What to expect is clear
- Conditions and terms are clear
- Minimize paperwork
- No time delays

Bio/databank:

- Resources are being used
- Uniform procedures and forms
- Responsible use of resources
- Overview and management of requests

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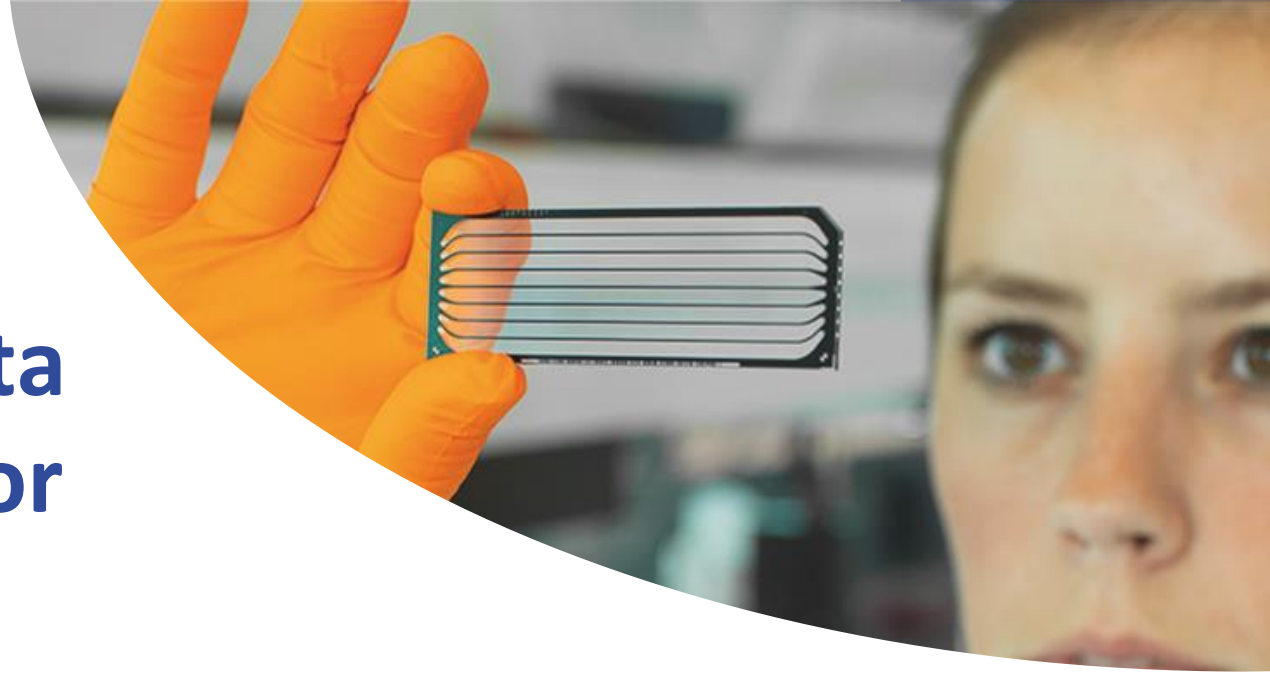
Hartwig
MEDICAL FOUNDATION

The more we know,
the better our care

Hartwig
MEDICAL FOUNDATION

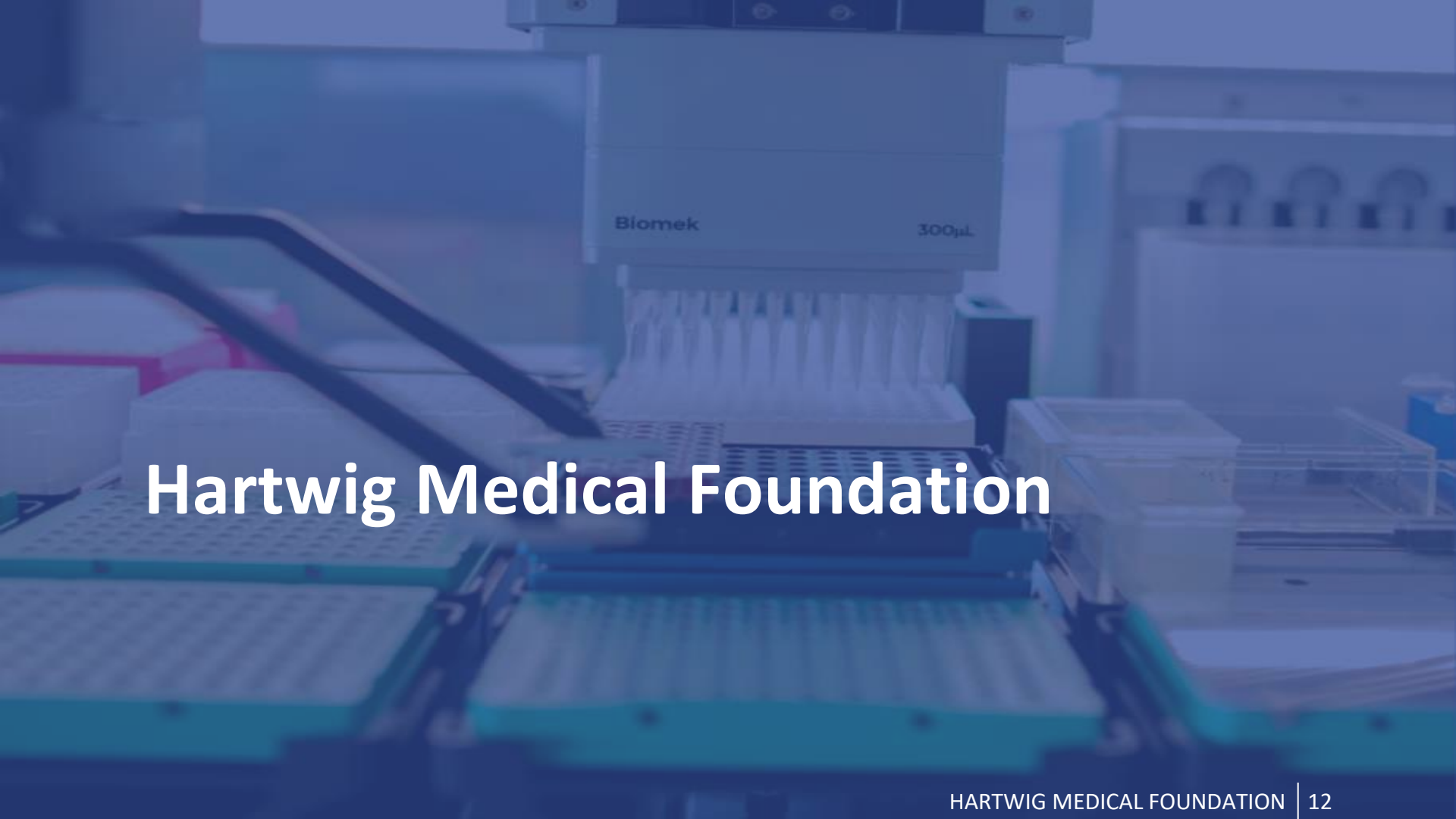


Making data available for research

Experiences and challenges

Sandra van den Broek

7 Oct 2021



Hartwig Medical Foundation

Hartwig Medical Foundation

Mission: to stimulate scientific research for improving prevention and treatment of cancer by enabling large-scale DNA analyses and systematic clinical data collection

- Not-for-profit organization, financed through philanthropy
- Founded in 2015, now ~25 employees (lab, IT, medical)
- ISO accredited (IVDR-ready) sequencing lab in Amsterdam
- Performs routine WGS-based cancer diagnostics for hospitals
- Collaborates with a broad range of care and research organizations
- To realize a learning care system

Whole Genome Sequencing

Hartwig Medical OncoAct

Most complete diagnostics for today's cancer patient

Hartwig Medical Database

Improved care for tomorrow's cancer patient

Hartwig Medical Database

- Largest database worldwide of Whole Genome Sequencing data of metastatic cancer
- Genetic and clinical data of ~5500 patients (~2,500 with RNA-seq data)
- Informed consent from all patients for whom data is included in the database
- Continuously growing (studies, but now also including diagnostic patients)

- High quality data due to uniform process from sampling to bioinformatics
- Data available for free for academic research

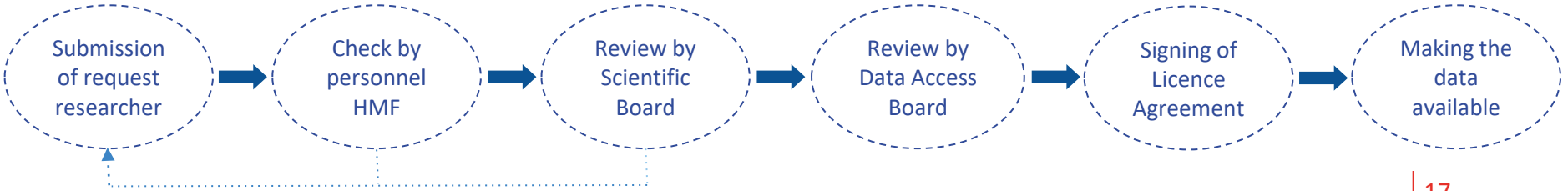
Data Access Request procedure

Data Access Request procedure

https://www.hartwigmedicalfoundation.nl/applying-for-data/

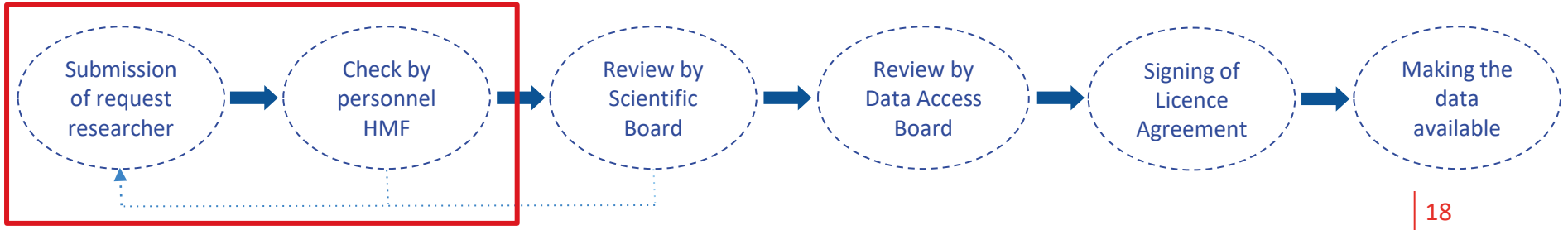
“One of the main goals is to make our data available for scientific research. This scientific research must contribute to the improvement of treatment of cancer and must serve the public interest within the boundaries of privacy legislation.”

- *GDPR proof procedure, including careful assessment as to whether the intended use of the data falls within the scope of the patient's informed consent*



Submission of a request

- Digital software for application and feedback (all steps are automated)
- Request for general (name, institute, legal entity) and scientific details - focus on motivation why the data is needed is for the specific research question
- Extra (legal) questions for institutions outside the EEA



Review process

- Review of request by (independent) Scientific Board:

  Assessment of the scientific validity

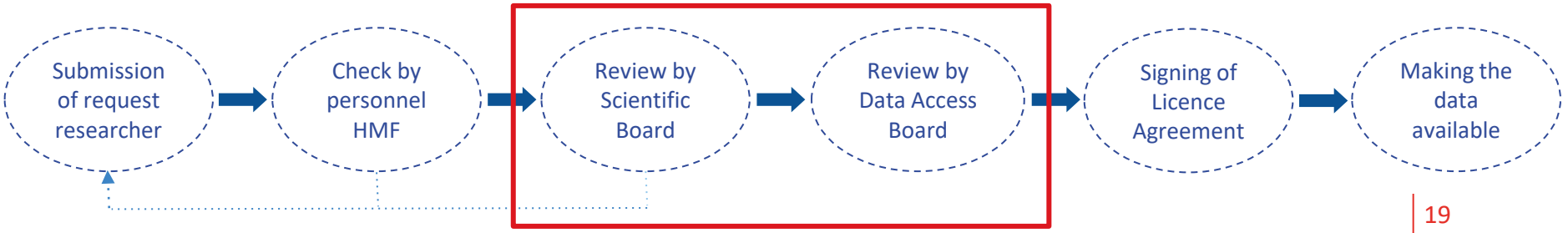
  Need of the requested data for the scientific question

- Review of request by independent Data Access Board:

  Assessment of ethical, legal and societal validity

  e.g. extra focus when commercial party involved

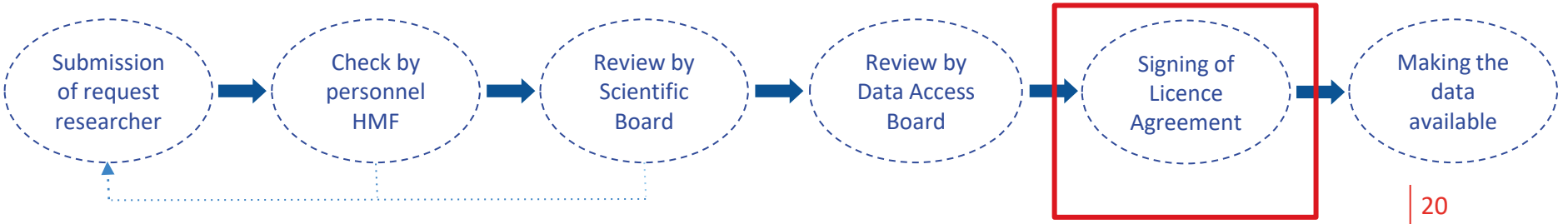
  e.g. no sharing of data to 'sensitive' countries



Licence Agreement

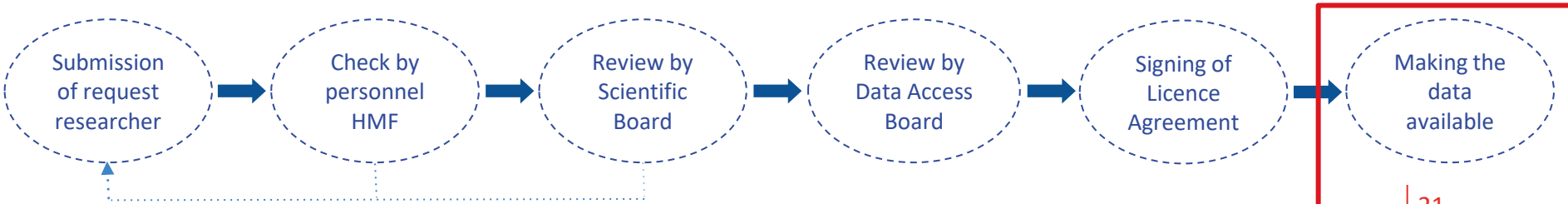
Signing of Licence Agreement that is entered into by and between Hartwig, and the requesting party (legal entity (institute) & researcher).

- *To make sure they commit to comply with strict requirements governing the use and protection of the data made available by Hartwig Medical Foundation*
- *After ending of the Licence Agreement the shared data must be deleted*
- *Renewals allowed (after positive review by Data Access Board)*
- *In keeping with European privacy legislation, specific arrangements apply for providing data to parties residing in a country outside the EEA*



Making the data available

After approval, Hartwig only makes a specific set of data (not the whole database) available, that may only be used for the approved, relevant and specific research purpose. This is a prerequisite for GDPR-compliance.



Making the data available

The Google Cloud Platform

- The Hartwig Medical Database consists of ~1 Petabyte of data
- The data is stored in the Google Cloud Platform (GCP)
- Primary storage in Eemshaven, back up in Finland (hot storage), plus cold storage op tape
- GCP meets the requirements of the GDPR regarding data privacy
- DPIA performed
- Own encryption used (not available for Google)
- Making the data available also trough GCP

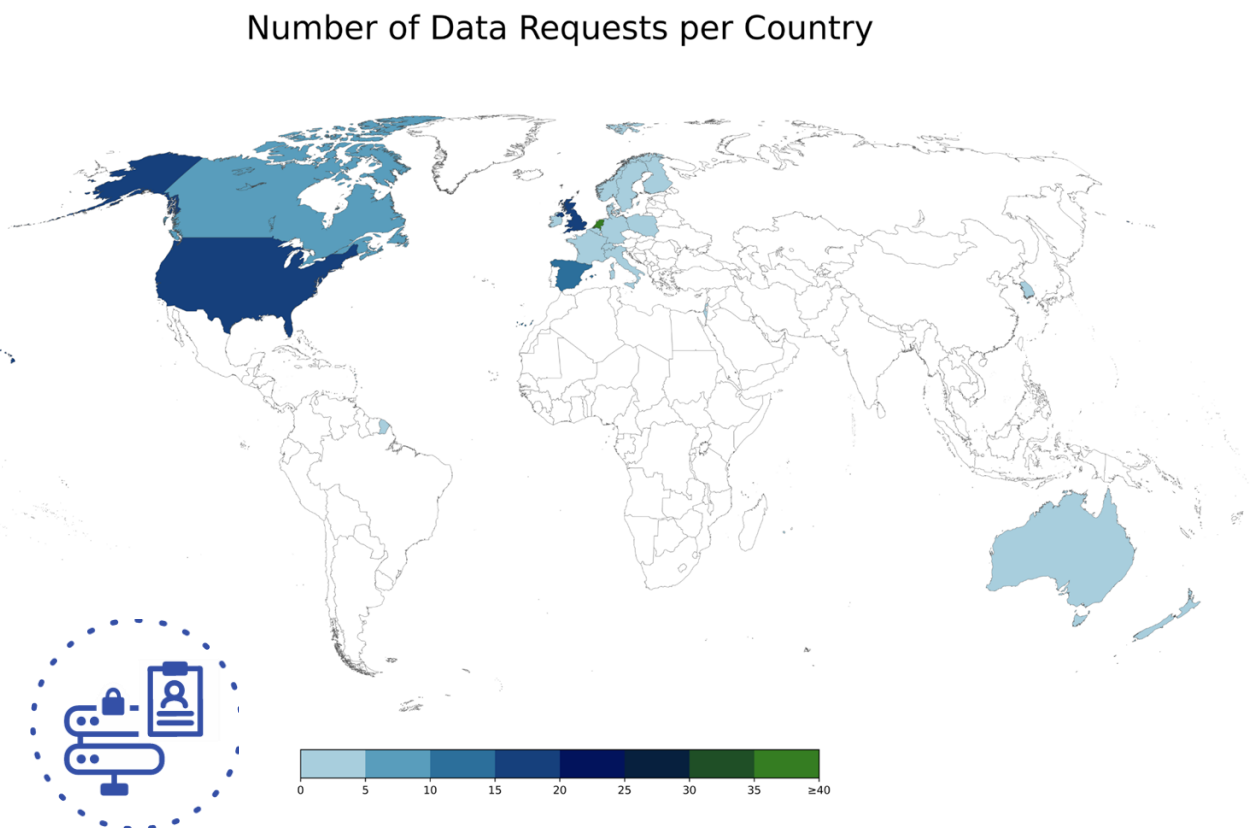
  **data is stored and made available pseudonymised*

  **efforts to make data less identifiable (date shifting; GENONCO)*

Bringing the researcher to the data

- Researcher needs a GCP account
- In-house developed tooling to add the account of the researcher to the ‘Access Control (permission) list’ of the specific files the researcher got approval for
    + *No copying of the files*
    + *Always latest-greatest available*
    + *No over-use of costly resources*
- Downloading the data is costly and unwanted (previous points); moreover, traditional computers used within institutes do not have enough storage or computation resources to process the amount of data
- We therefore advise researchers to process the data within the Google Cloud
- Compute costs are charged to the researchers, but storage costs of the source data is covered by Hartwig

Current data use



Netherlands	110
UK	19
USA	18
Spain	10
Canada	8
Poland	4
Australia	3
France	2
Denmark	2
Norway	2
Israel	2
Finland	1
Korea	1
Italy	1
Ireland	1
Belarus	1
New Zealand	1
Hong Kong	1
Switzerland	1
Sweden	1
Singapore	1
Germany	1
Total	191

Searching for the balance between meeting with all (GDPR) requirements *versus* making it feasible for the researcher

Experiences of researchers

Continues evaluation of our procedures and process of making the data available

- Regular email contact with researchers
- Input through questionnaires

Although all researchers are very appreciative of the value of the data,
feedback on the procedures/making the data available is contradictory:

- Some researchers are very happy and find using the cloud easy
- Some researchers are less happy (see next slide)…

Difficult to find a solution that suits everyone, and also meets all (GDPR) requirements

Identified difficulties and challenges

- Extensive Data Access Request Procedure: long procedure with several contracts to be signed to comply with GDPR

- Researcher needs a specific GCP account, but setting this up correctly within the institute is challenging (legal, IT department, billing)
- Vendor lock-in because of choice HMF (no ‘free’ vendor transfer)
- High Performance Computing facility available within institute; using this is/feels ‘free’ for researcher - getting funding for cloud computing not taken into account
- Specific knowledge needed of programming and working within the cloud
- **Distrust of cloud and big data companies (such as Google)**

Most researchers still download the data...

The solution?

We believe that using the Cloud is needed for the (growing) amounts of data we as (research) community process

Contracts and smart use of the Cloud to be sure to have appropriate data protection

Use collaborations to combine our efforts and **find the balance between meeting all requirements *versus* feasibility for researchers**

Very near-future:

- Education/workshops

Future:

- One central point for requesting data (a lot of overlap in questions; GENONCO/HealthRI)?
- Vendor-agnostic cloud environment?
- Data portal on the cloud for more easy access?

Hartwig
MEDICAL FOUNDATION

The right treatment for each cancer patient

A Science Park 408 - 1098 XH Amsterdam - The Netherlands
T +31 (0)20 235 2640 E info@hartwigmedicalfoundation.nl W hartwigmedicalfoundation.nl

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Data search and accessibility

PALGA's approach of a next generation find and request portal

Dr. Aletta Debernardi, director PALGA

7 October 2021, BBMRI.nl & Health-RI expert meeting #3

palga

The best treatment begins with the best diagnosis

PALGA

- Independant foundation, started by pathologists
- Pathology reports, archiving since 1971
- Country wide coverage since 1991 (> 45 pathology departments/labs in NL)
- >75 M records of >13 M patients
- >2,0 M new records per year
- Funding comes from the Ministry VWS

palga

The best treatment begins with the best diagnosis

PALGA

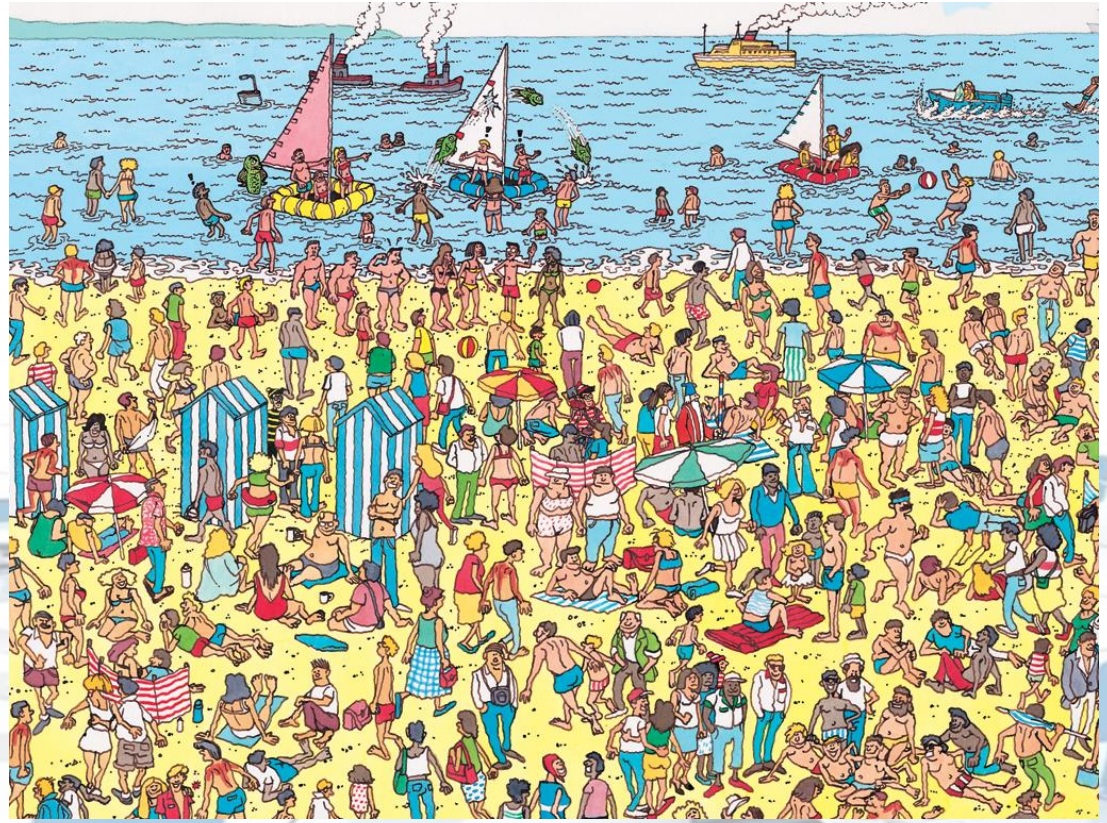
The best treatment begins with the best diagnosis

PALGA, two roles

1. Provide excellent support to the pathologist to make the best possible diagnosis and to contribute decisive information to the patient's treatment plan.
2. Excel at the collection, management and provision of structured pathology data in order to promote data quality and patient safety and to enable scientific research.

palga
The best treatment begins with the best diagnosis

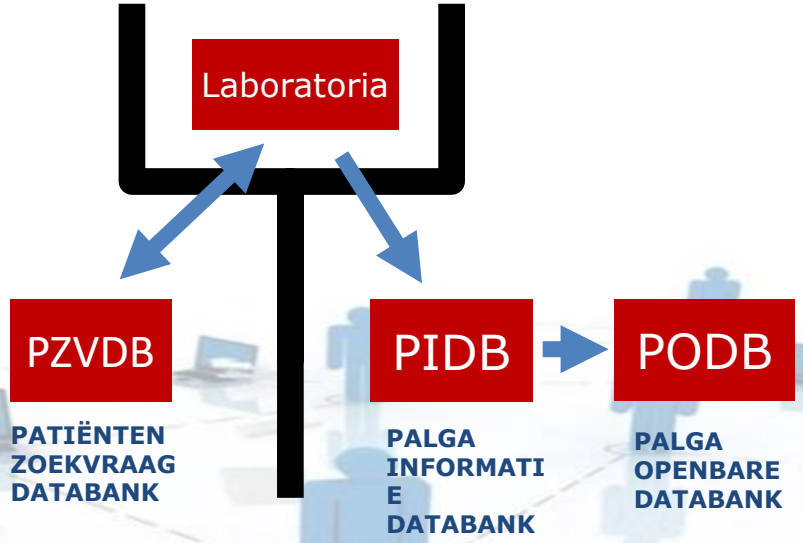
Find what you are looking for



palga

The best treatment begins with the best diagnosis

Databanks



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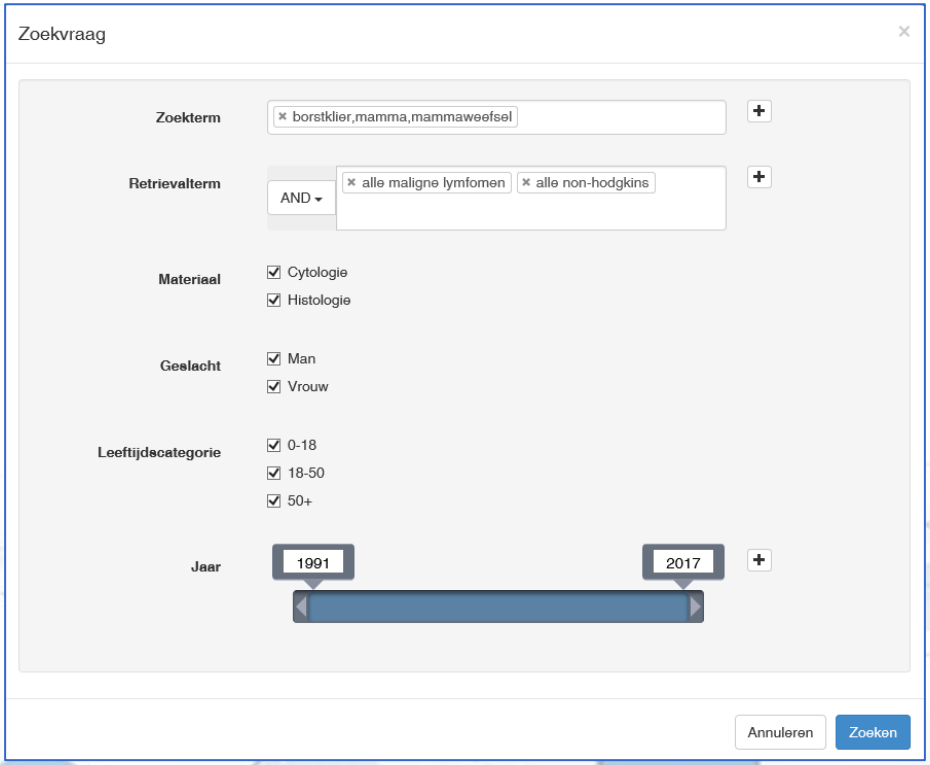
The best treatment begins with the best diagnosis

Public database: PODB



palga
The best treatment begins with the best diagnosis

PALGA portal

- Portal: data (and tissue)

palga
The best treatment begins with the best diagnosis

Patholoog	Patho Loog
	Patho@loog.nl
Vorig contact	Heeft u contact gehad met PALGA over deze aanvraag? ○ Ja ◉ Nee
Titel onderzoeksproject	"Sed ut perspiciatis"
Achtergrond	quisquam est, qui dolorem ipsum quia dolor sit amet, consectetur, adipisci velit, sed quia non numquam eius modi tempora incidunt ut labore et dolore magnam aliquam quaerat voluptatem.
Onderzoeksvraag	Ut enim ad minima veniam, quis nostrum exercitationem ullam corporis suscipit laboriosam, nisi ut aliquid ex ea commodi consequatur?
Hypothese	Quis autem vel eum iure reprehenderit qui in ea voluptate velit esse quam nihil molestiae consequatur, vel illum qui dolorem eum fugiat quo voluptas nulla pariatur?"
Methode	voluptatum deleniti atque corrupti quos dolores et quas molestias excepturi sint occaecati cupiditate non provident, similique sunt in culpa qui officia deserunt mollitia animi, id est laborum et dolorum fuga.
Zoekcriteria	Itaque earum rerum
Studieperiode	2000-2010
Biobank aanvraagnummer	nvt
Laboratoriumtechnieken	IHC, NGS
Kiembaanmutatieanalyse	Kiembaanmutatieanalyse? ○ Ja ◉ Nee
Benodigde data en/of materialen	○ Alleen aantallen; oriënterende zoekvraag ◉ Excerpten, PA-verslagen, PA-materiaal en/of klinische gegevens ☑ Excerpten ☑ Complete *anonieme* PA-verslagen ☑ PA materiaal blokje ☑ PA materiaal HE coupe(s) ☐ PA materiaal overig ☐ Klinische gegevens via behandelaar

Experts on pathology data and research

What do we have now and how to make the most of it.

- To get reliable data fitting with the research question: filtering and interpretation
- Differences in data, when linking with other data sources
- Build up of knowledge, improvement of research

You need experts!: Adviseur gegevensaanvragen

palga

The best treatment begins with the best diagnosis

Adviseurs gegevensaanvragen

Annette Gijsbers-Bruggink

Bert Siebers

Ivette Deckers

Rinus Voorham

Chantal Epskamp-Kuijpers

palga

The best treatment begins with the best diagnosis

Future plans

- Digital research environment

  -Data at the source, data integrity

  -AVG compliant

  Workable for the researcher

  Link with data of other sources

  Always with support of experts for the researcher

palga

The best treatment begins with the best diagnosis

It not just about researchers

- Stakeholders: patients, researchers, health organisations, pathologists
- AVG: patient
- Information security:

CIA Confidentiality, Integrity en Availability

or BIV: Beschikbaarheid (service for pathologists and researchers), Integriteit (data at the source) and Vertrouwelijkheid

- PALGA is data processor (for patient data, via the PALGA-Raad) and controllor (for research data)

palga

The best treatment begins with the best diagnosis

National request portal

PALGA has more than 50 years experience, thanks to the pathologists.

- We like to be a best practise for other fields, for other countries

palga

The best treatment begins with the best diagnosis