This webinar will be recorded
Recordings can be made available for knowledge dissemination.

Questions or remarks?
Join us at www.slido.com and enter eventcode datasharing or scan the QR code. Or use the chat.

Mute your microphone
Please mute your microphone to minimize background noise by clicking on the “mute”-symbol on the top of your screen.

What can we improve for the future?
We are happy to hear any additional questions or feedback for our next expert meeting. Please contact us by mail: robin.verjans@lygature.org
Virtual Expert Meeting Series: How to Make Health(care) Data Available for Research?

12th of November 2020
BBMRI 2.0 Work programme 4

Linking registries and biobanks findable and accessible
2012-2015 BBMRI 1.0: A tissue block delivery service was the basis for the DNTP

1. Researchers
2. PALGA
3. Block.com
4. Delivery
The PALGA portal/DNTP tissue block services for researches gave insight in the block traffic.

<table>
<thead>
<tr>
<th>Aantal aanvragen:</th>
<th>2017</th>
<th>2018</th>
</tr>
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<tbody>
<tr>
<td>Alleen verslagen</td>
<td>5403</td>
<td>2410</td>
</tr>
<tr>
<td>Alleen FFPE blokken</td>
<td>8838</td>
<td>9069</td>
</tr>
<tr>
<td>Alleen klinische gegevens</td>
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<td>1730</td>
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<tr>
<td>Verslagen en FFPE blokken</td>
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<td>Verslagen, FFPE blokken en klinische gegevens</td>
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<td>Verslagen en klinische gegevens</td>
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<tr>
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<tr>
<td>Totaal aantal lab verzoeken</td>
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<tr>
<td>Totaal aantal PA nrs</td>
<td>24.163</td>
<td>17.874</td>
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</table>
Tussen 2015-2019

- Consolideer de portal /DNTP met zgn. hub-medewerkers op 8 UMC’s afd pathologie die services verleende aan laboratoria
- Bouw BBMRI 2.0 podium tool voor alle registries & biobanks
BBMRI 2.0 → Health-RI

- **F**indeable
- **A**ccessible
- **I**nteroperable
- **R**euseable
Virtual Expert Meetings Series

Goal

- To create a **discussion platform** to discuss current hurdles, experiences and best practices how to make health(care) data available for scientific (re)use.

Program

<table>
<thead>
<tr>
<th></th>
<th>Thursday October 29th</th>
<th>CBS - Fatima El Messlaki &amp; Ivo Gorissen</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>14.00-15.00</td>
<td>NHR - Saskia Houterman</td>
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</table>

<table>
<thead>
<tr>
<th></th>
<th>Thursday November 12th</th>
<th>Durrer Center - Erik van Iperen &amp; Wanda Hermans-Van Ast</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>14.00-15.00</td>
<td>IKNL - Peter Prinsen &amp; Vincent Ho</td>
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<table>
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<th>Thursday November 26th</th>
<th>LifeLines - Trynke de Jong</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>14.00-15.00</td>
<td>DataHub – Pascal Suppers</td>
</tr>
</tbody>
</table>
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Request procedure

Erik van Iperen, datamanager IT
Wanda van Ast, manager
Netherlands Heart Institute/ Durrer Center
Registry of patients with COVID-19 including cardiovascular risk and complications

CAPACITY is a registry of patients with COVID-19 and has been established to answer questions on the role of cardiovascular disease in this pandemic. It is an extension of the Case Record Form (CRF) that was released by the ISARIC (International Severe Acute Respiratory and Emerging Infection Consortium) and WHO (World Health Organisation) in response to the emerging outbreak of COVID-19.

The aim of CAPACITY is to collect data regarding the cardiovascular history, diagnostic information and occurrence of cardiovascular complications in COVID-19 patients. By collecting this information in a standardized manner, CAPACITY can aid in providing more insight in (1) the incidence of cardiovascular complications in patients with COVID-19, and (2) the vulnerability and clinical course of COVID-19 in patients with an underlying cardiovascular disease.

Does your center want to participate? Join us! Please see our infographic on which steps you have to take.
Design of CAPACITY

• Case Record Form of ISARIC (WHO)

• Additional instruments:
  • cardiovascular history
  • diagnostic information
  • occurrence of cardiovascular complications in COVID-19 patients

• Aim to provide insight in:
  (1) the establishment and incidence of cardiovascular complications in patients with COVID-19, and
  (2) the vulnerability and clinical course of COVID-19 in patients with an underlying cardiovascular disease.
7321 Total number of inclusions
6643 Total number of patients with follow-up
75 Total number of centres currently including
13 Total number of countries currently including
Governance

• Complex project – two weeks to organise
• Review by METC: 24 hrs!
• Informed consent: opt-out for limited period of time
• Coordinating center: UMC Utrecht
Delivery of data from centers to coordinating center

Each participating center

Signed DTA by legal representative of hospital

Research protocol: appoint local coordinator + involved researchers

Confirm agreement with Data Access Policy

Coordinating center
Data access

• Data Access Policy
• Data Access Committee
• Data Access Procedure

• Check for overlapping proposals (see site)
Together we are investigating the role cardiovascular disease in the COVID-19 pandemic. We sincerely invite our international colleagues and researchers to apply for data access or to join efforts that are already ongoing. The following six research questions have formulated by the Data Access Committee and are being assessed:

1. What is the incidence and pattern of cardiovascular complications in patients with COVID-19?
2. Does the clinical presentation of COVID-19 differ between patients with and without a history of cardiovascular disease?
3. What is the extent of cardiac damage in patients with COVID-19?
4. Do patients with COVID-19 and cardiovascular risk factors or underlying cardiovascular disease have a worse disease course? If this is the case, which cardiovascular risk factors and types of cardiovascular diseases are especially associated with a poor outcome?
5. Does the use of medication that influence ACE-2 expression worsen the course of COVID-19 (ACEI, ARBs, NSAIDs and thiazolidinediones)?
6. What is the effect of therapy for COVID-19 on patients with cardiac complications or underlying cardiovascular disease? E.g. chloroquine and effect on QT-interval.

The following requests for data access have been approved:

1. Oral anticoagulation and COVID-19 outcome – Disease modifiers
2. Sex differences in COVID-19
3. Effect of diabetes on COVID-19 cardiovascular complications
4. Acute cardiac injury and ACS in COVID-19
5. Arrhythmias and conduction disorders in COVID-19
7. Disease-specific ECG features in patients with COVID-19

Contact us to join already ongoing projects

How to apply for data access:

- First check the overview of applications to avoid overlap with an existing project.
- Start your application by filling in the application form via https://podium.bbmri.nl. By sending this form the request will go to info@capacity-covid.eu
- To gain access, this form including your research questions, required data and/or samples, financing, and timeline of the research must be submitted
- Make your data selection using this specific CAPACITY REDCap codebook. Please select your variables with corresponding variable names and labels. This file must be submitted as well alongside the application form using https://podium.bbmri.nl.
- The submitted application will be reviewed within one week by the CAPACITY Data Access Committee.
- Once an application is approved, CAPACITY will prepare a Data Transfer Agreement (DTA) for you to sign.
- Data will be released after signing the DTA.
- The data will be released in a digital research environment (the CAPACITY workspace).
- For further information regarding data access see this file.
Login/Register in Podium
Create a new request
<table>
<thead>
<tr>
<th>Research Proposal</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Background</strong></td>
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<tr>
<td><strong>Research Question(s)</strong></td>
</tr>
<tr>
<td><strong>Hypothesis / Goals</strong></td>
</tr>
<tr>
<td><strong>Methods</strong></td>
</tr>
<tr>
<td><strong>Related Request Number</strong></td>
</tr>
</tbody>
</table>
Principal Investigator Details

Name
Name of the principal investigator

Email
Email of the principal investigator

Function
Function of the principal investigator

Affiliation
Affiliation of the principal investigator

Attachments

Drag here or browse to upload.

<table>
<thead>
<tr>
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<th>Uploader</th>
<th>Size</th>
<th>Upload Date</th>
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Reset  Save draft  Submit
## Data Dictionary Codebook

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<th>Field Label</th>
<th>Field Attributes (Field Type, Validation, Choices, Calculations, etc.)</th>
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<td></td>
</tr>
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<td>subjid</td>
<td>Participant Identification Number (PIN): 999-9999 (plasma-HIV)</td>
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<td>studyid</td>
<td>Please contact your local study coordinator for the STUDY ID.</td>
<td>descriptive</td>
</tr>
<tr>
<td>3</td>
<td>datcreated</td>
<td></td>
<td>text (date_dmy), Field Annotation: @TODAY @HIDDEN</td>
</tr>
<tr>
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<td>Section Header: Form Status Complete?</td>
<td>dropdown</td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>2: Complete</td>
</tr>
<tr>
<td></td>
<td><strong>ISARIC/CAPACITY - Inclusion Criteria (REQUIRED)</strong> (inclusion_criteria_required)</td>
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<td>distdat</td>
<td>Date of Enrollment</td>
<td>text (date_dmy), Required</td>
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<td>Site name</td>
<td>dropdown</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>11: Admiraal de Ruyter Ziekenhuis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>22: Albert Schweitzer Ziekenhuis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>32: Airline ziekenhuis</td>
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<tr>
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<td></td>
<td></td>
<td>11: Amphia Ziekenhuis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3: Amsterdam UMC, locatie AMC</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4: Amsterdam UMC, locatie VU</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>33: Antonius Ziekenhuis, Sneeek</td>
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<tr>
<td>Request id</td>
<td>Title</td>
<td>Request type(s)</td>
<td>Organisation(s)</td>
</tr>
<tr>
<td>------------</td>
<td>--------------------------------------------</td>
<td>-----------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>1945</td>
<td></td>
<td>Data</td>
<td>CAPACITY COVID</td>
</tr>
<tr>
<td>1936</td>
<td></td>
<td>Data</td>
<td>CAPACITY COVID</td>
</tr>
<tr>
<td>1910</td>
<td></td>
<td>Data</td>
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</tr>
<tr>
<td>1891</td>
<td></td>
<td>Data</td>
<td>CAPACITY COVID</td>
</tr>
<tr>
<td>1865</td>
<td></td>
<td>Data</td>
<td>CAPACITY COVID</td>
</tr>
<tr>
<td>1855</td>
<td>The Impact of Anticoagulation Therapy with COVID-19</td>
<td>Data</td>
<td>CAPACITY COVID</td>
</tr>
<tr>
<td>1851</td>
<td>Diabetes on COVID-19 cardiovascular complications</td>
<td>Data</td>
<td>CAPACITY COVID</td>
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2 step validation

Request 2002 to Durrer Center

Details

Title
DNA van COVID-19 patiënten met CVD
Organisation
Durrer center
Request Types
- Data
Linked Request
No
Search Criteria
DNA van COVID-19 patiënten met CVD
Background
DNA van COVID-19 patiënten met CVD
Research Question(s)
DNA van COVID-19 patiënten met CVD

I hereby validate this request. Upon sending for review all organisation reviewers will be notified.

Principal Investigator

Your request is currently waiting for validation by the organisation coordinator.

I hereby validate this request. Upon sending for review all organisation reviewers will be notified.
**Request details including review comments**

### Request 1791 to CAPACITY COVID

#### Title
- University of XYZ
- 2020-01-01 to 2020-12-31

#### Hypothesis

#### Methods

#### Results Request Number
- Principal Investigator: [Name]

#### Review

<table>
<thead>
<tr>
<th>Date</th>
<th>Result</th>
<th>Comment</th>
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<tr>
<td>2020-01-01</td>
<td>10/10</td>
<td>note 1</td>
</tr>
<tr>
<td>2020-01-02</td>
<td>10/10</td>
<td>note 2</td>
</tr>
<tr>
<td>2020-01-03</td>
<td>10/10</td>
<td>note 3</td>
</tr>
<tr>
<td>2020-01-04</td>
<td>10/10</td>
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</tr>
<tr>
<td>2020-01-05</td>
<td>10/10</td>
<td>note 5</td>
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</tbody>
</table>

Note: This review is a summary of the proposed study design and methodology, including any potential ethical considerations and the rationale behind the proposed study. Further details and site-specific information will be provided upon successful review.
Review by Data Access Committee

1. Discuss submitted requests and review comments
2. Look for overlap with approved projects
3. Evaluation of data request
   • Approve
   • Reject (data not available)
   • Adjust (data partly not available / overlapping question, suggest to cooperate with other researchgroup)
Based on DAC meeting: decision
Release data: start delivery process

### Request 1788 to CAPACITY COVID

<table>
<thead>
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<th>Attachments</th>
<th>OS</th>
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<tbody>
<tr>
<td><strong>Title</strong></td>
<td>Capacity mand</td>
<td>Focus Type</td>
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<tr>
<td><strong>Search Criteria</strong></td>
<td>All patients with &quot;discharge&quot; link completed in the CAPACITY-COVID Registry</td>
<td>N/0 of patients per site being treated with intermittent Peritoneal dialysis (including peritoneal discharge)</td>
</tr>
<tr>
<td><strong>Background</strong></td>
<td>Research Question(s)</td>
<td>Hypothesis</td>
</tr>
<tr>
<td></td>
<td>Methods</td>
<td>Related Request Number</td>
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#### Review

<table>
<thead>
<tr>
<th>Name</th>
<th>Date</th>
<th>Result</th>
<th>Comment</th>
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</thead>
<tbody>
<tr>
<td>n/a</td>
<td>4/18/2020, 7:46 PM</td>
<td>Approved</td>
<td>1st review hypothesis: important topics, but the hypothesis as formulated in the present application is not adequate. This may introduce difficulties in comparing with other applications.</td>
</tr>
<tr>
<td>n/a</td>
<td>4/18/2020, 7:44 PM</td>
<td>Approved</td>
<td>Staff can list needs/wanted patient data: list the data set required for the COVID-19 patients with vascular complications or underlying congestive heart disease.</td>
</tr>
<tr>
<td>n/a</td>
<td>4/18/2020, 7:45 PM</td>
<td>Approved</td>
<td>1st review hypothesis: writing group to discuss statistical powers, methodologies to harmonize across different drug questions and present overview.</td>
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<tr>
<td>n/a</td>
<td>4/18/2020, 7:46 PM</td>
<td>Approved</td>
<td>Sample size: sample size requirement not applicable, data cannot be reviewed.</td>
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<tr>
<td>n/a</td>
<td>4/18/2020, 7:47 PM</td>
<td>Approved</td>
<td>Cell under consideration to enhance care.</td>
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<td>n/a</td>
<td>4/18/2020, 7:46 PM</td>
<td>Approved</td>
<td>Other: Involving in CAPACITY: observational study is evaluate the effect the effect of...19 patients.</td>
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Release of data

Request 2002 to Durrer Center

Details | Attachments (0)
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**Title**
DNA van COVID19 patienten met CVD

**Organisation**
Durrer Center

**Request Types**
+ Data

**Linked Request**
No

**Search Criteria**
DNA van COVID19 patienten met CVD

**Background**
DNA van COVID19 patienten met CVD

**Research Question(s)**
DNA van COVID19 patienten met CVD

**Hypothesis**
DNA van COVID19 patienten met CVD

**Methods**
DNA van COVID19 patienten met CVD

**Related Request Number**

**Principal Investigator**

**Delivery**

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<tr>
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<th>Status</th>
<th>Notes on delivery</th>
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<tbody>
<tr>
<td>Data</td>
<td>Preparation</td>
<td>No notes available</td>
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Your request is currently in the process of delivery. You will be notified when action is required on your behalf. In case irregularities have been found with the delivery, please contact the organisation coordinator.

Please mark all deliveries as Received or Cancelled above prior to finalising a request.

Release data
Delivery and finalize request
Approved request

Requestor:
• Sign DTA

CAPACITY datamanager:
• Prepare dataset in digital research environment (DRE)
  • DRE workspace per approved request -> data uploaded
  • Researchers involved in this request get access to this specific workspace:
    • Analysis + document sharing in virtual environment
    • Necessary statistical programs can be installed
    • Data doesn’t have to leave this virtual environment
Requester

- Discuss performed analysis with DAC
- Publication send to DAC
- CAPACITY collaboration -> last authorship
- Acknowledgements -> provided by DAC
Results

• Number of requests: 26
• Approved: 15
• Rejected: 2
• Revision: 4
Questions?
ICRF: hoe gangbaar is zoiets in de cardiologie? Of was dit geen probleem?

Wie voerde de data in of hoe kwamen de data in Capacity?
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The Netherlands Cancer Registry

BBMRI.nl & Health-RI Expert meeting

*How to make health(care) data available for research?*
Table of Contents

• Data collection
  - content
  - legal basis

• Data request
  - procedure
  - lead times

• Challenges & the way forward
Netherlands Cancer Registry (1/2)

- National data since 1989 (regional from 1955)
Netherlands Cancer Registry (2/2)

- National data since 1989 (regional from 1955)
- Coverage: 90-95%
- Incidence: >115,000 cases per year
- Database: >2 million cases
- Data managers
Data collection (1/3)

- Pathology laboratories
- Hospital discharge
- Other databases

NCR
Data collection (3/3)

- diagnosis
- primary treatment
- follow-up

Death
Minimal data set (WHO/IARC)
- demographics (birth date, sex, postal code, vital status)
- basic tumor characteristics (topography, morphology, stage)

Additional data
- diagnosis
- treatment (type, hospital)
- follow-up (progression)

Additional data on tumor types
- e.g. molecular markers, complications, pathology review
## Coloncarcinoom
Laatste update: januari 2019

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<th></th>
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<td>overlijdensdatum/laatste contactdatum</td>
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<td>ASA classificatie</td>
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<tr>
<td>co-morbiditeit bij diagnose (standaard)</td>
<td></td>
<td>(vanaf 1993, regionaal)</td>
<td>(regionaal)</td>
<td>(regionaal)</td>
</tr>
</tbody>
</table>

| Brongegevens                    |          |           |           |           |
| instelling van diagnose/behandeling |          |           |           |           |
• Legitimate interest (*gerechtvaardigd belang*)
  - one of the lawful bases for processing personal data
    a lawful basis is required in order to process personal data in line with
    the ‘lawfulness, fairness and transparency’ principle

• Special category data (*bijzondere persoonsgegevens*)
  - statutory exception to the General Data Protection Regulation (GDPR):
    scientific research and statistical purpose (*wetenschappelijk onderzoek
    en statistiek*)

• Hospitals
  - contracts / data processing agreements etc.
Legal basis (2/2)

• Review
  - privacy protection (patients / doctors)
  - sensitive company information

Supervisory board of the NCR

• Members
  - jurist
  - patient representative
  - medical profession
  - hospital representative

Data request
<table>
<thead>
<tr>
<th>Tumour group</th>
<th>Scientific committee</th>
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<tbody>
<tr>
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<td>NABON (Nationale Borstkanker Overleg Nederland)</td>
</tr>
<tr>
<td>Hematology</td>
<td>HOVON (Hemato-Oncologie voor Volwassenen Nederland)</td>
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<tr>
<td>Bone &amp; soft tissue</td>
<td>DSSG (Dutch Sarcoma Study Group)</td>
</tr>
<tr>
<td>Neuro-oncology</td>
<td>DBTR (Dutch Brain Tumour Registry)</td>
</tr>
<tr>
<td>Endocrine cancers</td>
<td>DTCG (Dutch Thyroid Study Group)</td>
</tr>
<tr>
<td>Upper GI</td>
<td>DUCG (Dutch Upper GI Cancer Group)</td>
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<tr>
<td></td>
<td>DPCG (Dutch Pancreatic Cancer Group)</td>
</tr>
<tr>
<td></td>
<td>DHCG (Dutch Hepatocellular &amp; Cholangiocarcinoma Group)</td>
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<tr>
<td>Lower GI</td>
<td>PLCRC (Prospectief Landelijk CRC-cohort)</td>
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<tr>
<td>Head &amp; neck</td>
<td>NWHHT (Nederlandse Werkgroep Hoofd-HalsTumoren)</td>
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<tr>
<td>Urogenital cancers</td>
<td>DUOS (Dutch Uro-Oncology Studygroup)</td>
</tr>
<tr>
<td>Gynaecology</td>
<td>DGOG (Dutch Gynaecological Oncology Group)</td>
</tr>
</tbody>
</table>
Data request (1/2)

• Website IKNL.nl
  - procedure
  - contact form

• Mail: gegevensaanvraag@iknl.nl

• Data request form
  - contract between applicant and IKNL
Data request (2/2)
Lead times (1/5)

Lead time: type of request

- quick-info: 1 week
- regular: 5 weeks
- linkage: 6 weeks
- complex linkage: 14 weeks
Lead times (2/5)

Lead time: regular requests & linkages

<table>
<thead>
<tr>
<th>Quarter</th>
<th>2019q4</th>
<th>2020q1</th>
<th>2020q2</th>
<th>2020q3</th>
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<tbody>
<tr>
<td>Lead time (weeks)</td>
<td>4</td>
<td>5</td>
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median
Data request

Preparation of contracts

Supervisory board of the NCR

Signing of the contract

Preparation time

Lead time

<table>
<thead>
<tr>
<th>Tumour group</th>
<th>Scientific committee</th>
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<tr>
<td>Breast cancer</td>
<td>NABON (Nationale Borstkanker Overleg Nederland)</td>
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<tr>
<td>Hematology</td>
<td>HOVON (Hematologie-Oncologie voor Volwassenen Nederland)</td>
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<tr>
<td>Bone &amp; soft tissue</td>
<td>DSSG (Dutch Sarcoma Study Group)</td>
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<tr>
<td>Neuro-oncology</td>
<td>DBTR (Dutch Brain Tumour Registry)</td>
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<tr>
<td>Endocrine cancers</td>
<td>DTGG (Dutch Thyroid Study Group)</td>
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<tr>
<td>Upper GI</td>
<td>DUGC (Dutch Upper GI Cancer Group)</td>
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<tr>
<td></td>
<td>DPRGG (Dutch Pancreatic Cancer Group)</td>
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<tr>
<td>Lower GI</td>
<td>DHCG (Dutch Hepatocellular &amp; Cholangiocarcinoma Group)</td>
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<td>Head &amp; neck</td>
<td>PLORC (Prospectief Lokaal CRC-cohort)</td>
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<td>Urogenital cancers</td>
<td>NWHT (Nederlandse Werkgroep Hoofd-HalsTumoren)</td>
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<tr>
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<td>DGOG (Dutch Gynaecological Oncology Group)</td>
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</tbody>
</table>
Lead times (4/5)

Preparation time: type of request

- Quick Info: 7 weeks
- Regular: 2 weeks
- Linkage: 10 weeks
- Complex Linkage: 12 weeks
Preparation time: complex linkages

Weeks

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<tr>
<th>Quarter</th>
<th>Median</th>
<th>Minimum</th>
<th>Maximum</th>
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<tr>
<td>2020q2</td>
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<tr>
<td>2020q3</td>
<td>13</td>
<td>12</td>
<td>20</td>
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</tbody>
</table>
Customer evaluations

Evaluatie onder aanvragers (n=23)

- Het aanvraagprocedure is goed verlopen.
- De gegevens zijn snel geleverd.
- Het formulier is makkelijk in te vullen.
- De gegevens zijn goed bruikbaar.
- De toelichting op de gegevens is duidelijk.
- Mijn contactpersoon was deskundig.
- Mijn contactpersoon was goed bereikbaar.
- Mijn contactpersoon was klantvriendelijk.

IkNL: Netherlands comprehensive cancer organisation
Challenges

• Lead times
  - full customization versus standard delivery?

• Transparency of the data request process

• Preparation times
  - legal basis for linkages

• Information on data sets
  - completeness
  - addition / removal of data sets
  - changes over time
The way forward…
A catalogue for the NCR

• Current situation:
  • Pdf with item set for each tumor type on IKNL website

• Desired situation:
  • Online catalogue with overview of items and details per item (definition, details, values, collection period, quality, etc.)
  • Integration with data request procedure? Complex: “variabelen op maat”, selection criteria

• Planning:
  • Proof of concept (PoC) for one tumor type in Q2 2021
  • Second tumor type in Q4 2021
  • Collection of feedback on PoC for further development
A catalogue for the NCR: PoC

Based on Norwegian Cancer Registry catalogue ELVIS (https://metadata.kreftrregisteret.no/)

- Shopping basket
- Data request
- Variable selection by tumor type
- Variable (+ details)

More details
Add to shopping basket
In Norwegian and English
Questions?
www.iknl.nl

www.linkedin.com/company/iknl

twitter.com/iknl
Bij NHR en Capacity studie is de data invoer (variabelen, definities) gestandaardiseerd aan de hand van het NHR handboek en codeboek. Hoe werkt dit bij IKNL?
What is your key takeaway from this expert meeting?

- Mooie voorbeelden van hoe het in de praktijk gaat
- Professioneel en zorgvuldig. Doorlooptijd is wel een issue
- Interessant te horen hoe anderen met data aanvragen omgaan!
- Capacity toont aan: t kan snel
- Meer Samenwerking
- (koppelen van) catalogus data zou een mooie stap in de richting van F (FAIR) zijn.
### Program Expert Meeting Series:

<table>
<thead>
<tr>
<th></th>
<th>Date</th>
<th>Location</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Thursday October 29&lt;sup&gt;th&lt;/sup&gt; 14.00-15.00</td>
<td>CBS – Fatima El Messlaki &amp; Ivo Gorissen</td>
<td>NHR – Saskia Houterman</td>
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<tr>
<td>2</td>
<td>Thursday November 12&lt;sup&gt;th&lt;/sup&gt; 14.00-15.00</td>
<td>Durrer Center – Erik van Iperen &amp; Wanda Hermans-Van Ast</td>
<td>IKNL – Peter Prinsen &amp; Vincent Ho</td>
</tr>
<tr>
<td>3</td>
<td>Thursday November 26&lt;sup&gt;th&lt;/sup&gt; 14.00-15.00</td>
<td>LifeLines – Trynke de Jong</td>
<td>DataHub – Pascal Suppers</td>
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</tbody>
</table>

**WE HOPE TO SEE YOU NEXT EXPERT MEETING!**