

dr. ir. Mariska Bierkens

Goed Gebruik Geneesmiddelen 6 April 2017

Health-RI

Ondersteuning voor translationeel onderzoek

Als we betere behandelingen van patiënten willen, dan moeten we

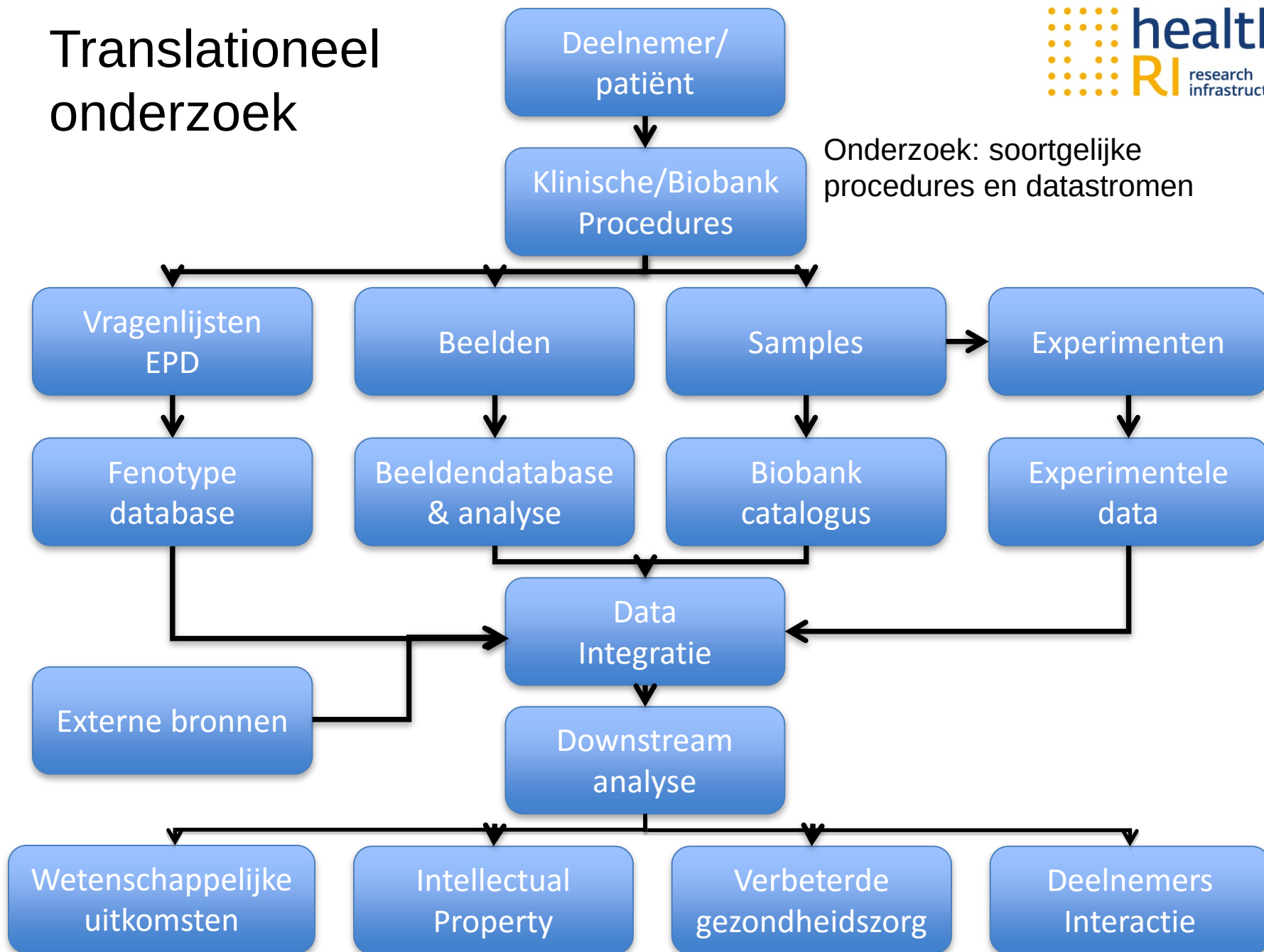
- de klinische praktijk veranderen
- richtlijnen aanpassen
- bewijs van hoge kwaliteit genereren
- daarvoor moet men onderzoek doen dat dit bewijs levert
- dat vergt een onderzoeksinfrastructuur van hoge kwaliteit



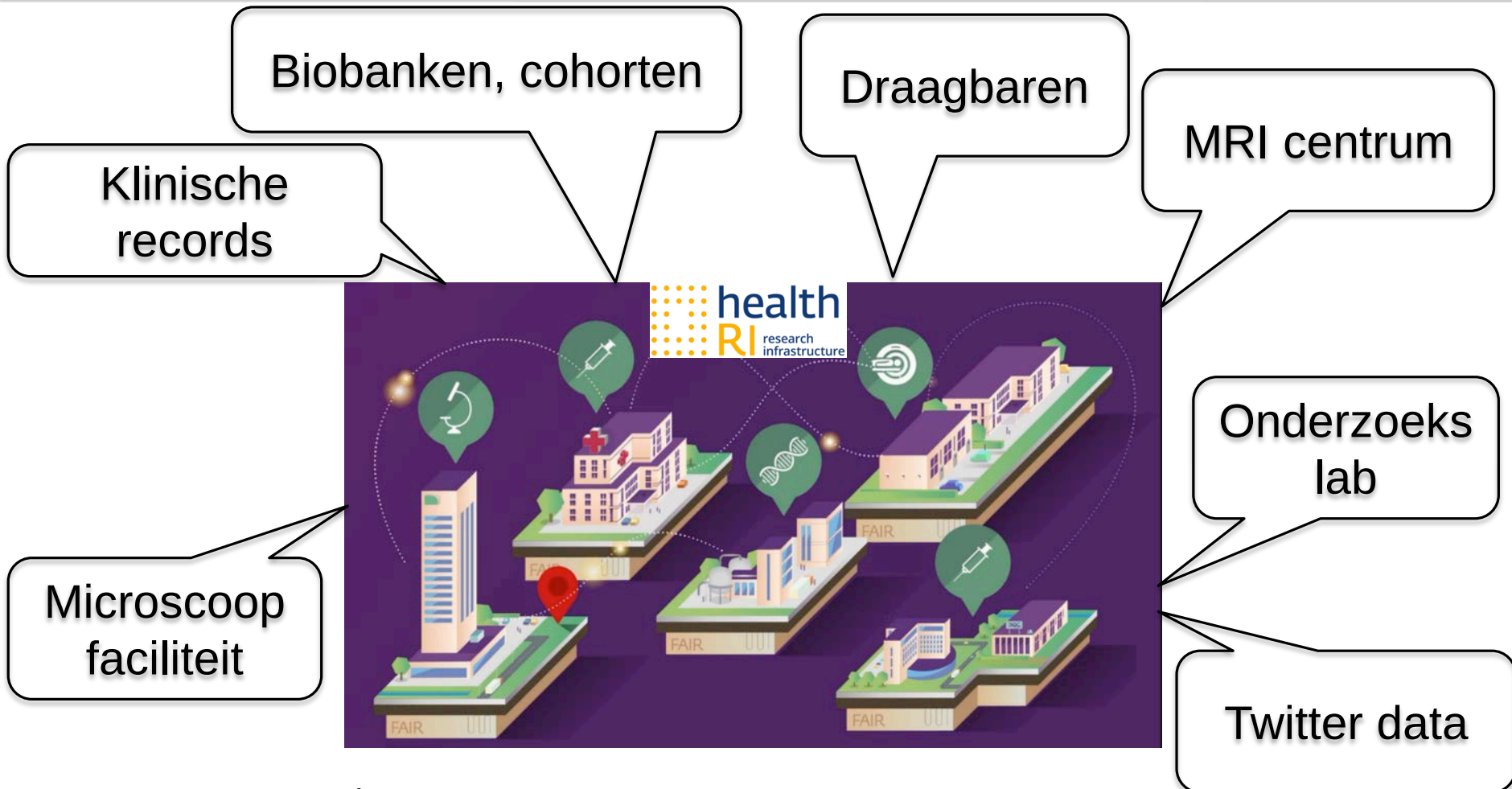
Bottleneck: versnippering!



Translationeel onderzoek



Internet van Personalized Medicine&Health en Data&Things

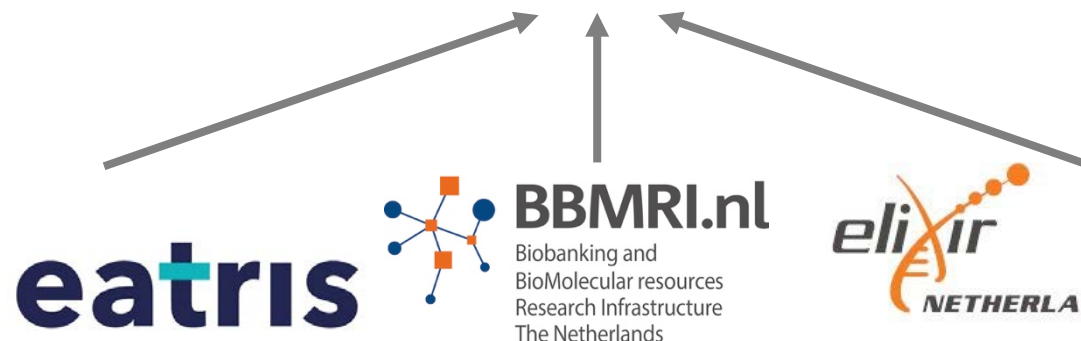


Meer weten, Youtube!

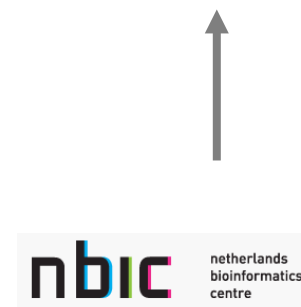
NL: <https://youtu.be/MRdB0Eh5hek>

ENG: <https://youtu.be/QEYKOk4bNxl> (forward naar internationale collega's!)

2016



2014



2009



200 biobanks



Service portfolio van Health-RI

- Catalogus
 - data
 - fenotype
 - omics
 - draagbaren
 - beelden
 - monsters
- Ethisch/juridische service
 - regelgeving compliance by design
 - privacy
 - initiatief voor wetgeving
 - mybiobank enz
- IT services
 - standaardisatie
 - online digitale onderzoeksomgeving
 - “office 365” voor personalized medicine & health research
 - geavanceerde technologie
 - ‘deep learning pipelines’ voor beeld analyse
 - ‘multi-omics pipelines’
 - enz

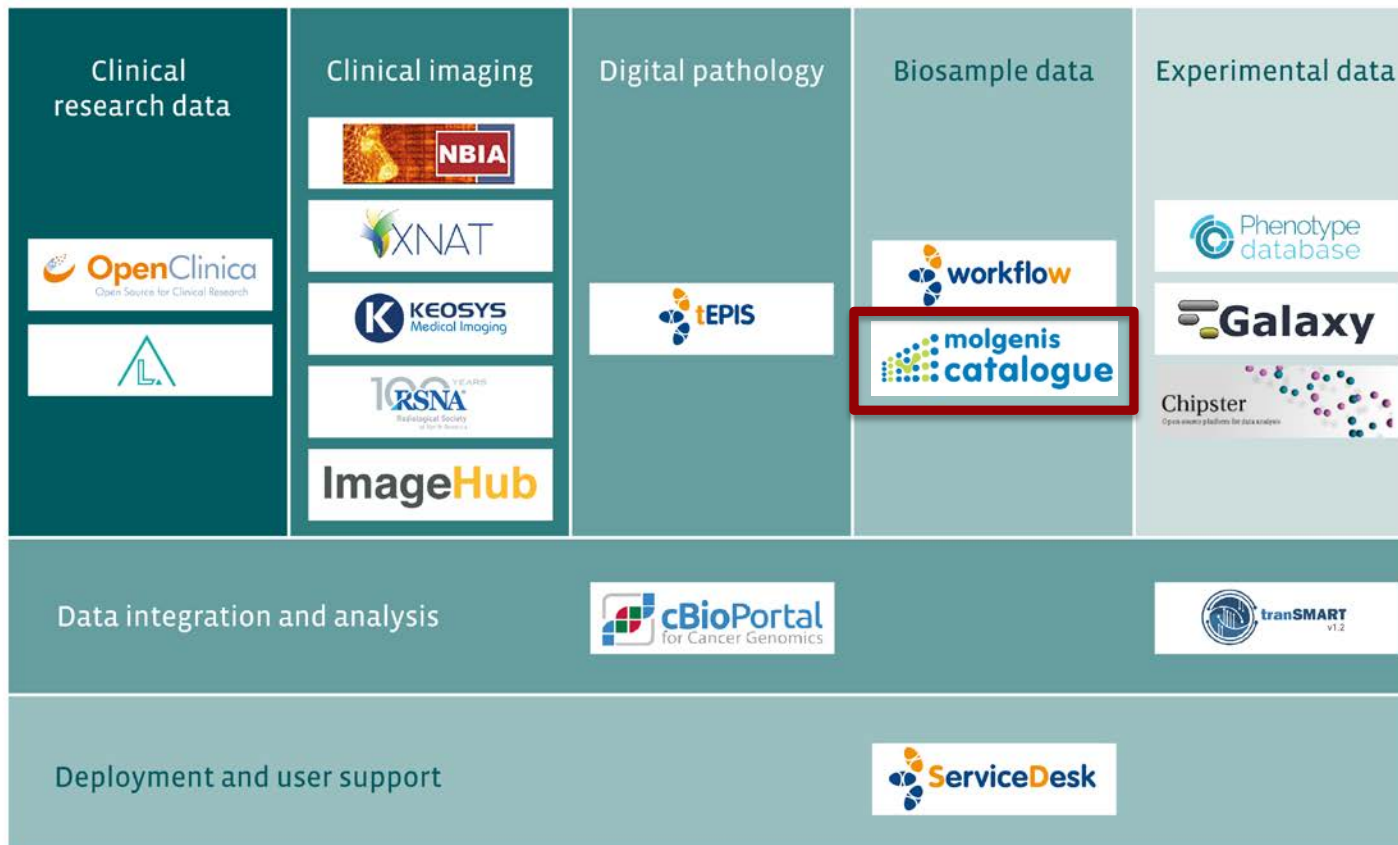
open
data
is about
MORE
THAN
DISCLOSURE
it must be
“Fair”

- Findable
- Accessible
- Interoperable
- Reusable

Een 'office' pakket



“Office 365” pakket voor translationeel onderzoek



Een praktisch voorbeeld

FAIR: Findable

Stap 1: Oriënteren en zoeken:

- Catalogus:

- [Palga Openbare Databank](#)
- [Nederlands Kanker Register \(NKR\) / Integraal Kankercentrum Nederland \(IKNL\)](#)
- [Centraal Beheer Statistiek \(CBS\) statline](#)

Studie: borstkanker bij mannen

Vraag: van hoeveel mannen (leeftijd 18-50 jaar) is materiaal beschikbaar?

→ data, samples, behandeling en follow-up

PALGA Openbare Databank

Toegepaste filters

Zoekterm: (('borstklier man,mamma man,mannelijke borstklier') or ('m.inv.c,microinvasief carcinoom')) ✕

Geslacht: ('Man') ✕

Leeftijdscategorie: ('18-50') ✕

 Wijzig zoekvraag

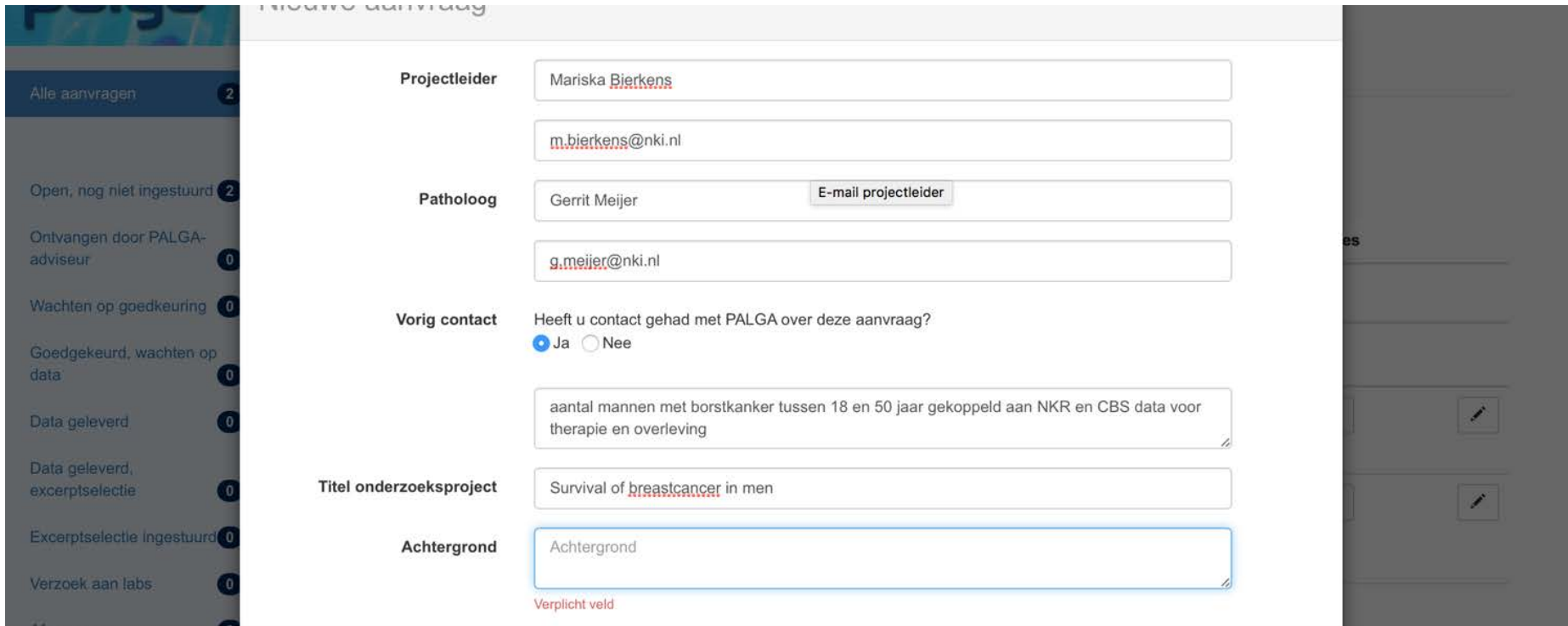
Sorteren op Materiaal x Geslacht

	Man	Aantal excerpten
Cytologie	≤10	≤10
Histologie	1951	1951
Aantal excerpten	≤1961	≤1961

Een praktisch voorbeeld

FAIR: Accessible

Stap 2: Aanvraag online indienen



The screenshot shows the 'Nieuwe aanvraag' (New request) form in the PALGA system. On the left is a sidebar with a progress indicator showing the status of the request: 'Alle aanvragen' (2), 'Open, nog niet ingestuurd' (2), 'Ontvangen door PALGA-adviseur' (0), 'Wachten op goedkeuring' (0), 'Goedgekeurd, wachten op data' (0), 'Data geleverd' (0), 'Data geleverd, excerptselectie' (0), 'Excerptselectie ingestuurd' (0), and 'Verzoek aan labs' (0). The main form contains the following fields:

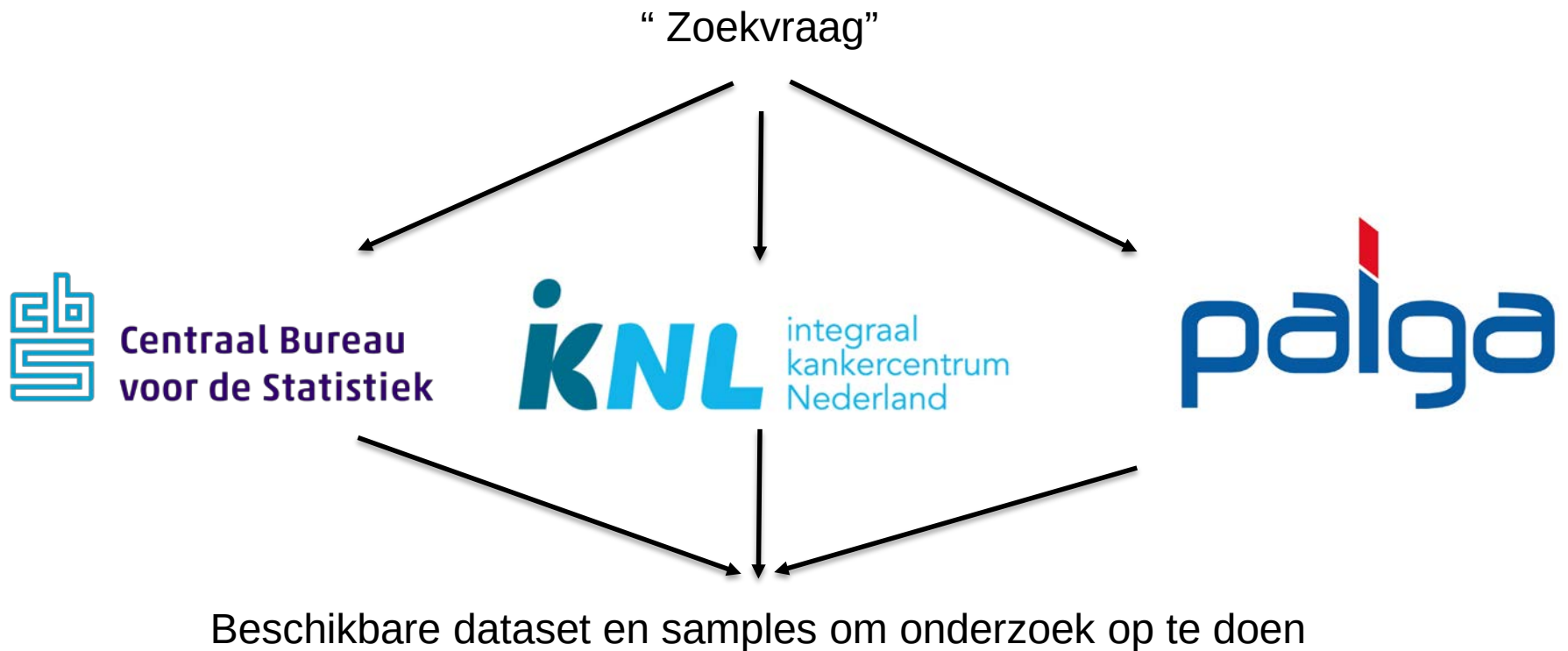
- Projectleider**: Mariska Bierkens (with a redacted email address) and m.bierkens@nki.nl
- Patholoog**: Gerrit Meijer (with a redacted email address) and g.meijer@nki.nl. There is an 'E-mail projectleider' button.
- Vorig contact**: Heeft u contact gehad met PALGA over deze aanvraag? (Ja ☒ Nee ☐)
- Titel onderzoeksproject**: Survival of breastcancer in men (with a redacted title)
- Achtergrond**: Achtergrond (with a redacted background text)

A red 'Verplicht veld' (Required field) message is visible below the 'Achtergrond' field.

Een praktisch voorbeeld

FAIR: Interoperable

Stap 3: Wachten op gekoppelde data set



health
RI research
infrastructure

trial

powered by

OpenClinica

Computing Solution

[CAIRO \(CAIRO\)](#) | [Change Study/Site](#)

[Home](#) | [Subject Matrix](#) | [Add Subject](#) | [Notes & Discrepancies](#) | [Tools](#)

Alerts & Messages

Your current active study has been changed successfully.

Instructions

If needed you may change the study/site or request access to a new study with a different role.

Other Info

Study: CAIRO

Start Date: 03-Oct

End Date: N/A

PI: Kees Punt and G Reijer

Title: CAIRO Study Data

Subtitle: Baseline: Tumor information

Instructions:

Pages: 1

General

Patient ID CAIRO study

NJM_CAIRO_CRC_002

Pathology

Primary tumor:

colon

T stage:

T4 Tumor directly invades other organs or structures and/or perforates visceral peritoneum

Tumor diameter:

Tumor diameter NULL

N stage:

N1 Metastasis in 1 to 3 regional lymph nodes

Number of lymph nodes removed:

Number of lymph nodes removed NULL

HGI status (based on IHC data):

MSS

Details pathology

Histopathology of the primary tumor:

Adenocarcinoma

Mucinous:

no

Desmoplastic stroma reaction:

no information

Metastases

Metastases:

no

Metachronous or synchronous (within 6 months) metastases:

no information

Number of organs involved (inclusive primary tumor when not removed):

0

Laboratory results

LDH:

normal

Previous treatment:

Previous adjuvant therapy:

yes

Welcome to CAIRO

Notes & Discrepancies Assigned to Me: 0

15

Show More

Select An Event

Add New Subject

Study Subject ID	CAIRO_Found	Actions
NJM_CAIRO_CRC_002	☒	Apply Filter Clear Filter
NJM_CAIRO_CRC_004	☒	Apply Filter Clear Filter

	Images:	
L_005	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_004	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_003	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_002	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_001	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_017	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_016	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_015	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_014	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_013	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_012	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_400	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_399	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_398	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_011	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_024	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_023	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_403	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	
L_022	https://hepiz.c.tmn-trait.nl/443/fmsClient?images=1.3.46.670589.45.1.1.118866034784496.1.6000.1443050532175.2	



DB	Aggregates	Charts							
Specimen type (code)	Specimen type	Specimen ID	Anatomic source (code)	Preservation (code)	Anatomic source	Preservation	Unit	Age	
DNA	DNA	NUM_CAIRO_CRC_002_1	Colon	Frozen Specimen,buffered	Colon, NOS	Frozen specimen in a buffer	year	60	
DNA	DNA	NUM_CAIRO_CRC_002_2	Colon	Frozen Specimen,buffered	Colon, NOS	Frozen specimen in a buffer	year	60	
DNA	DNA	NUM_CAIRO_CRC_004_1	Rectum	Frozen Specimen,buffered	Rectum	Frozen specimen in a buffer	year	62	
DNA	DNA	NUM_CAIRO_CRC_004_2	Rectum	Frozen Specimen,buffered	Rectum	Frozen specimen in a buffer	year	62	
DNA	DNA	NUM_CAIRO_CRC_005_1	Rectum	Frozen Specimen,buffered	Rectum	Frozen specimen in a buffer	year	58	
DNA	DNA	NUM_CAIRO_CRC_005_2	Rectum	Frozen Specimen,buffered	Rectum	Frozen specimen in a buffer	year	58	
DNA	DNA	NUM_CAIRO_CRC_005_3	Colon	Frozen Specimen,buffered	Colon, NOS	Frozen specimen in a buffer	year	68	
DNA	DNA	NUM_CAIRO_CRC_006_2	Colon	Frozen Specimen,buffered	Colon, NOS	Frozen specimen in a buffer	year	68	
DNA	DNA	NUM_CAIRO_CRC_009_1	Colon	Frozen Specimen,buffered	Colon, NOS	Frozen specimen in a buffer	year	75	
DNA	DNA	NUM_CAIRO_CRC_009_2	Colon	Frozen Specimen,buffered	Colon, NOS	Frozen specimen in a buffer	year	75	
DNA	DNA	NUM_CAIRO_CRC_010_1	Rectum	Frozen Specimen,buffered	Rectum	Frozen specimen in a buffer	year	54	
DNA	DNA	NUM_CAIRO_CRC_010_2	Rectum	Frozen Specimen,buffered	Rectum	Frozen specimen in a buffer	year	54	
DNA	DNA	NUM_CAIRO_CRC_011_1	Colon	Frozen Specimen,buffered	Colon, NOS	Frozen specimen in a buffer	year	59	
DNA	DNA	NUM_CAIRO_CRC_011_2	Colon	Frozen Specimen,buffered	Colon, NOS	Frozen specimen in a buffer	year	78	
DNA	DNA	NUM_CAIRO_CRC_012_1	Rectum	Frozen Specimen,buffered	Rectum	Frozen specimen in a buffer	year	44	
DNA	DNA	NUM_CAIRO_CRC_012_2	Rectum	Frozen Specimen,buffered	Rectum	Frozen specimen in a buffer	year	44	
DNA	DNA	NUM_CAIRO_CRC_014_1	Colon	Frozen Specimen,buffered	Colon, NOS	Frozen specimen in a buffer	year	70	
DNA	DNA	NUM_CAIRO_CRC_014_2	Colon	Frozen Specimen,buffered	Colon, NOS	Frozen specimen in a buffer	year	70	
DNA	DNA	NUM_CAIRO_CRC_015_1	Rectum	Frozen Specimen,buffered	Rectum	Frozen specimen in a buffer	year	65	
DNA	DNA	NUM_CAIRO_CRC_015_2	Rectum	Frozen Specimen,buffered	Rectum	Frozen specimen in a buffer	year	65	

Een praktisch voorbeeld

FAIR: Reusable

Stap 5: Publiceren en delen!

- Klinische data
- Pathologie data
- Imaging data
- Biobank data
- Experimentele data

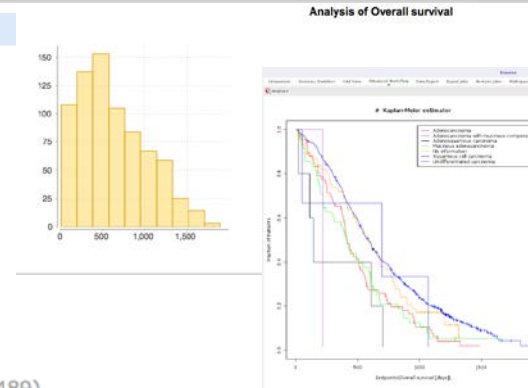
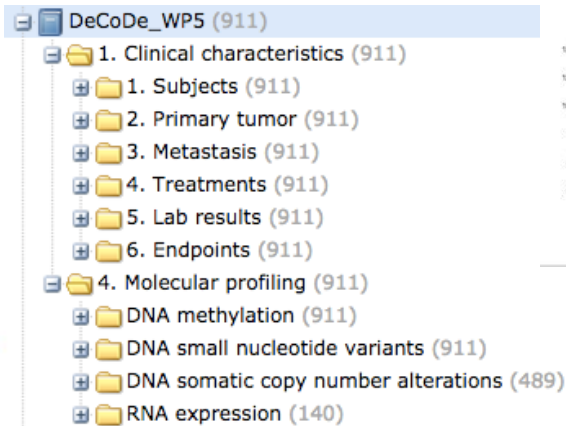
ClinicalTrials.gov



*Ook de 'final' data zelf
publiceren en delen*

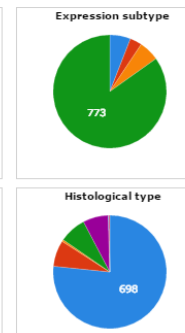
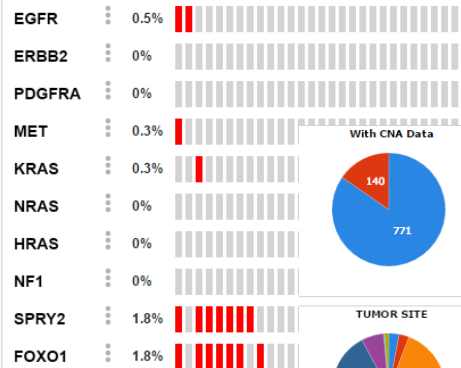
*Toegankelijk en bevraagbaar
voor niet data-experts*

'Final' data beschikbaar via data-integratieplatformen



Case Set: all (386 patients / 386 samples)

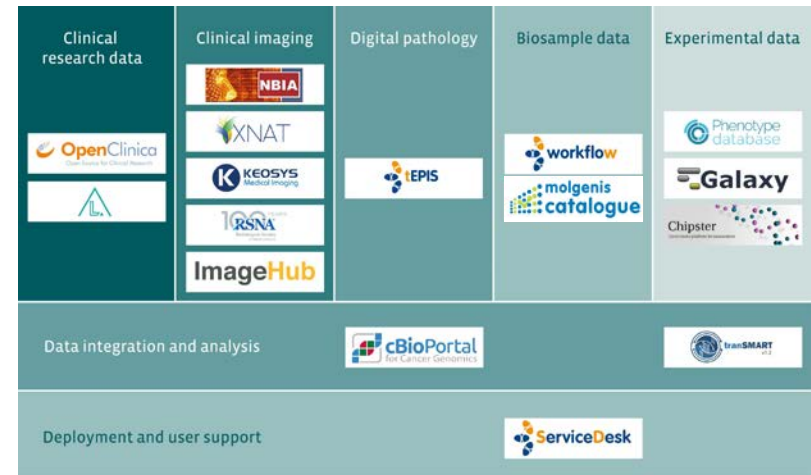
Altered in 10 (2.6%) of 386 cases/patients



Mogelijk om bestaande data te bekijken, bevragen en te analyseren binnen deze platformen.

Ten slotte

- Toegang tot bestaande data
- Snel inzicht beschikbaar materiaal
- Tijdens uitvoering studie:
→ gebruik Health-RI tools
- Dit leidt tot verrijking datasets



Investeringsen in data = rendement in de toekomst



The logo for Health Research Infrastructure (HRI) features a stylized grid of orange dots to the left of the text. The word "health" is in a dark blue, lowercase sans-serif font. Below it, "RI" is in a large, bold, orange sans-serif font, followed by the words "research" and "infrastructure" in a smaller, dark blue, lowercase sans-serif font, stacked vertically.