

Ruben Kok

15-01-2018, Nijmegen, The Netherlands



# The Dutch infrastructure for personalized health research

# Health-RI addresses common challenges in the Health research environment

## Challenges and Issues



**Fragmentation** of infrastructures and funds



Infrastructures providers and researchers **operate in separate worlds**



The promise of **PM&H is not delivered**



**Lack of reproducibility** of research outcomes



Reward system for scientists conserves **the innovation gap**



**Return-on-investment** of research is **insufficient**



**Major investments** are done across the field

## Opportunities and Solutions



A **single top-of-the-bill** infrastructure



**Strong collaboration** between all stakeholders



A **learning healthcare system**



Implement **FAIR data** stewardship



Change incentives to **reward sharing**

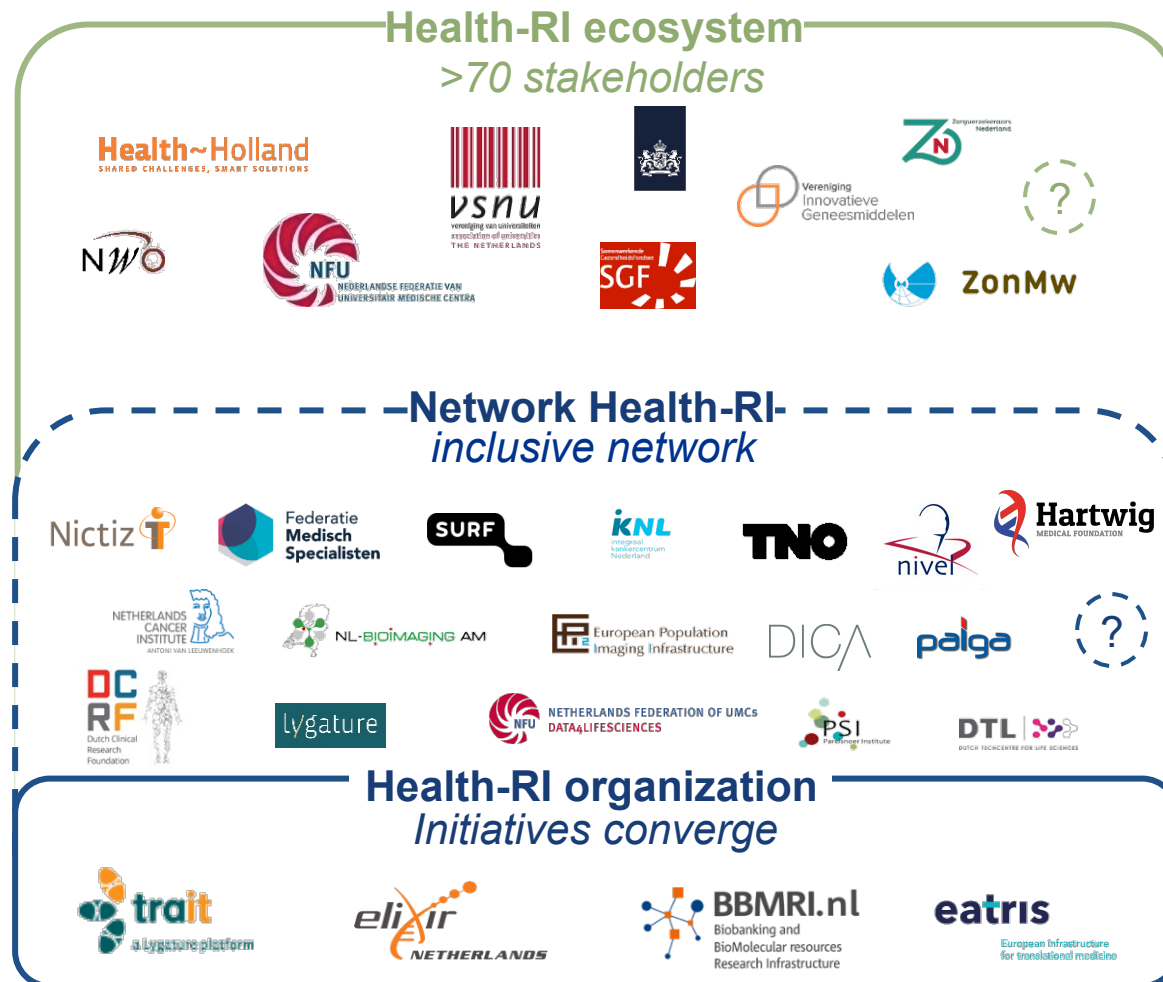


**Coordination of an investment agenda**



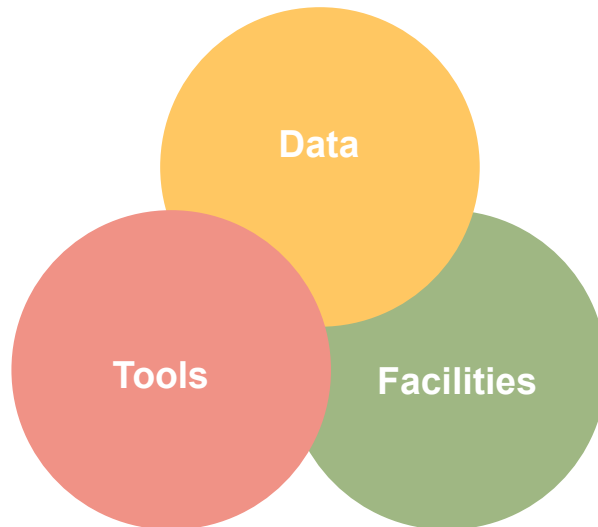
Shared infrastructure under **inclusive** governance

# Health-RI will build on existing infrastructures and attract new partners



# Health-RI will provide shared services and acts as the collective voice

**Provide shared services**



**Act as a collective voice**



# Health-RI services and activities will facilitates the entire research process

## Research Process

Define research question

Experimental design

Access to data & samples

Data generation

Analysis

Translation & dissemination

Improvement of research / care

Operational level  
(platform services)

Tactical level  
(connecting the network)

Strategic level  
(transforming the system)

Health-RI actions

The Health-RI platform will offer researchers solutions-on-demand for each step of the research process

# Health-RI offers solutions-on-demand

## Research Process



Health-RI actions

ELSI  
Servicedesk

Operational level  
(platform services)

Tactical level  
(connecting the network)

Strategic level  
(transforming the system)

# ELSI Servicedesk



[ProjectNet](#) [Vacatures](#) [Over ZonMw](#) [Veelgestelde vragen](#) [Contact](#) [English website](#)

[Subsidies](#) [Onderzoek & resultaten](#) [Actueel](#)

[Home](#) [Onderzoek & resultaten](#) [Geneesmiddelen](#) [Personalised Medicine](#) [Personalized medicine: servicedesk ethiek en recht](#)

Project

## Personalized medicine: servicedesk ethiek en recht

[Deel deze pagina](#) [in](#) [t](#) [f](#) [e](#)

### Projectomschrijving

Behandeling op maat, ontwikkeld en voorgeschreven met behulp van genetisch onderzoek, is sterk in opkomst. Tegelijk brengt het onderzoek naar en de implementatie van deze Personalised Medicine en Next-Generation Sequencing ethische, maatschappelijke en juridische vraagstukken met zich mee – bijvoorbeeld over privacy en de omgang met nevenbevindingen.

In dit project wordt een Servicedesk opgezet die de inzichten, expertise en normen op dit terrein bundelt en toegankelijk maakt. Onderzoekers, zorgverleners, patiëntvertegenwoordigers en beleidsmakers kunnen er terecht met vragen. Een online portal biedt toegankelijke informatie, een helpdesk beantwoordt eenvoudige vragen. Specialisten, zoals ethici en gezondheidsjuristen, zijn beschikbaar voor complexe vragen. Alle antwoorden worden zo snel mogelijk beschikbaar gemaakt voor andere geïnteresseerden.

De Servicedesk wordt opgezet in samenwerking met BBMRI-NL en Federa-COREON. Een eerste versie wordt verwacht per februari 2018.

### Inhoud van het project

[Projectomschrijving](#)

### Projectgegevens



# Health-RI offers solutions-on-demand

## Research Process



Health-RI actions

Catalogue  
facilities &  
expertise

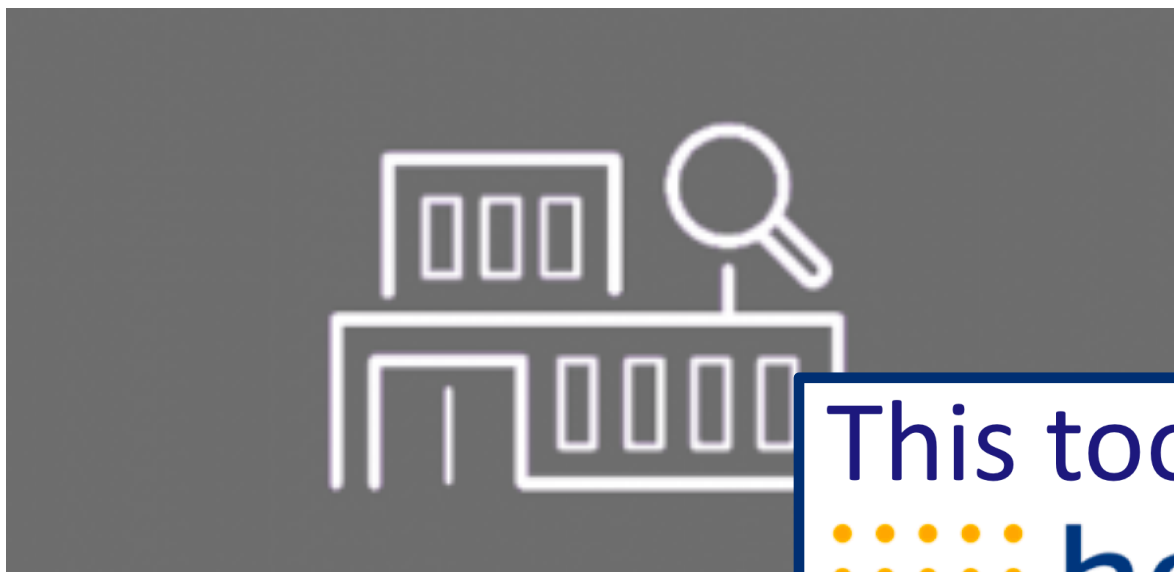
Tactical level  
(connecting the network)

Strategic level  
(transforming the system)



# Overview expertise and facilities

DTL | 



This too is .....

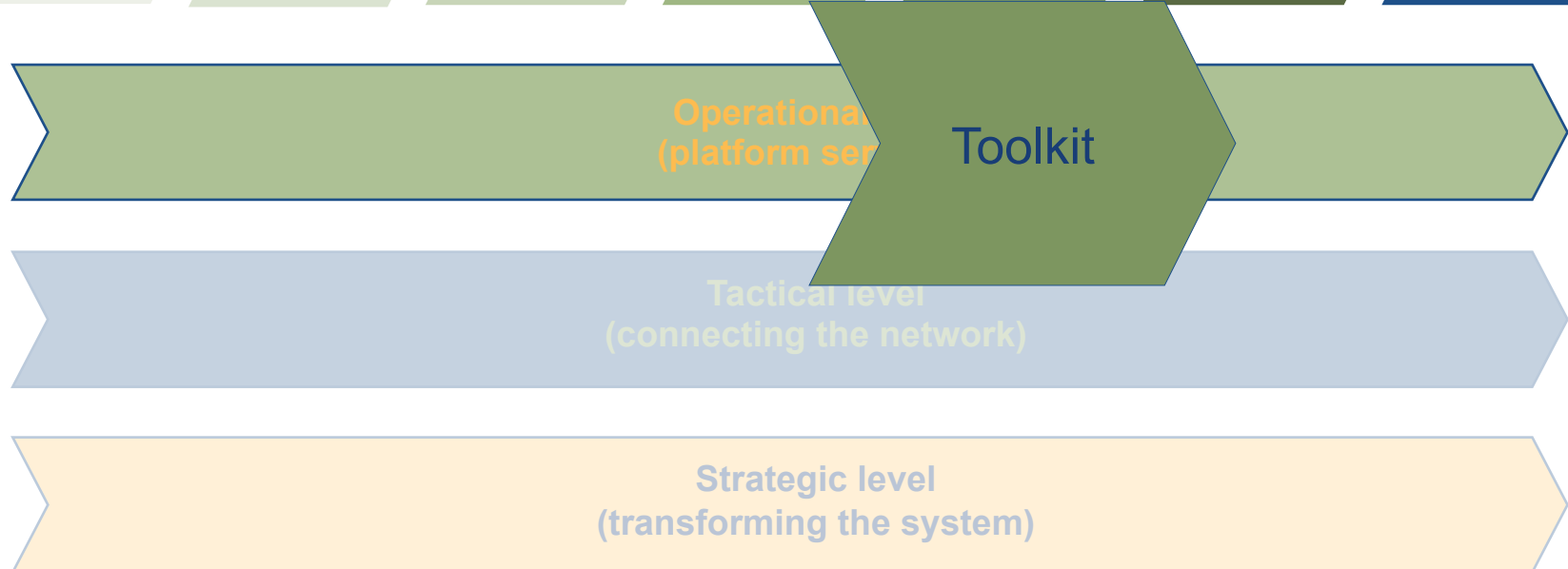
 **health**  
**RI** research  
infrastructure

# Health-RI offers solutions-on-demand

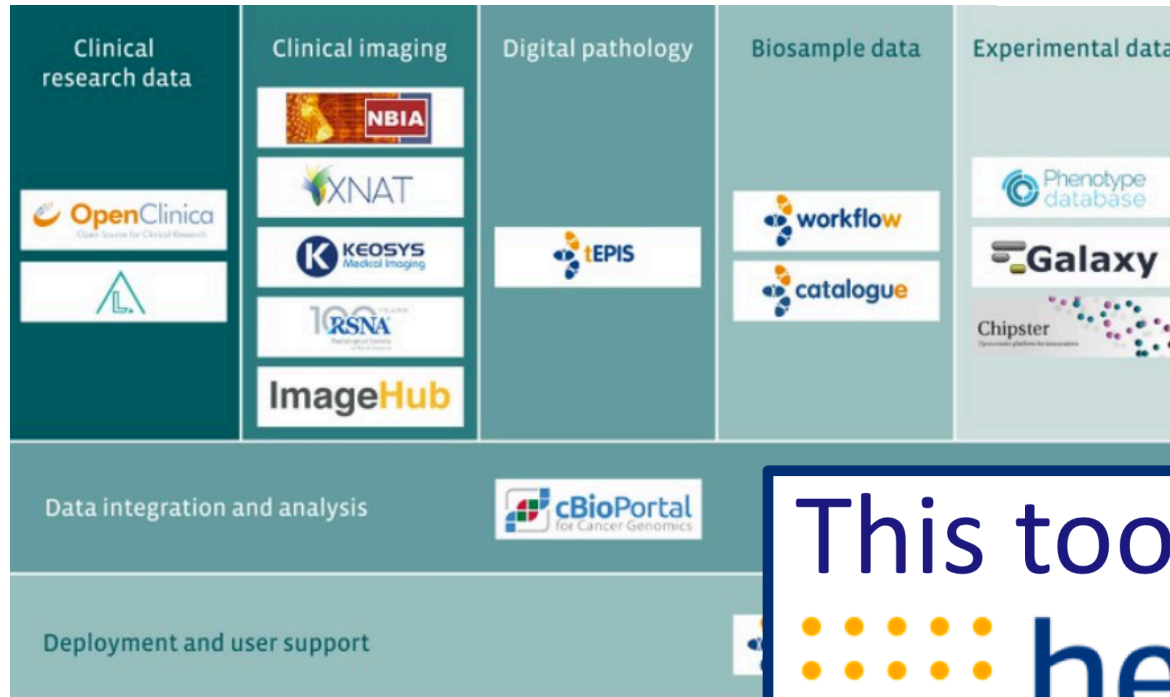
## Research Process



## Health-RI actions



# Toolkit



This too is .....



# Health-RI activities to transform the system

## Research Process

Define research  
question

Experimental  
design

Access to  
data &  
samples

Data  
generation

Analysis

Translation &  
dissemination

Improvement  
of research /  
care

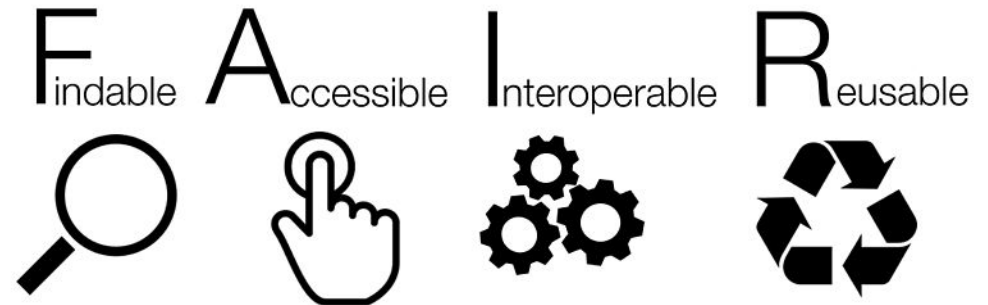
Operational level  
(platform services)

Tactical level  
(connecting the network)

Personal  
Health Train  
Strategic level  
(transforming the system)

Health-RI actions

# Personal Health Train & FAIR



This too is .....

