

What does a modern laboratory need (e.g.,
tools/infrastructure) in order to be prepared to
implement the policy?

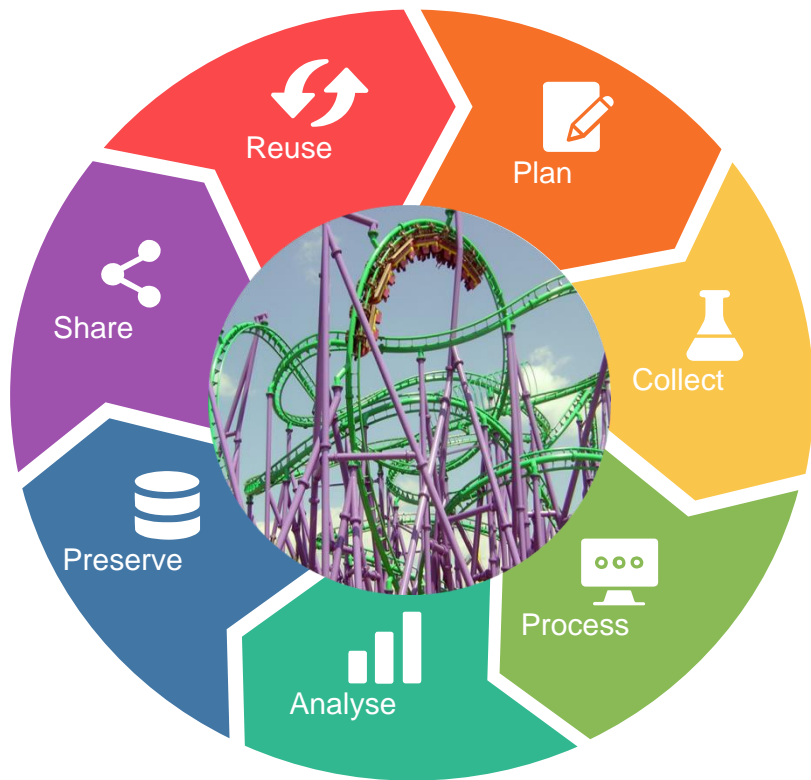
Routine Data RDM & Sharing at the Investigator level

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ELIXIR European Research Infrastructure

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Data and Metadata Journey

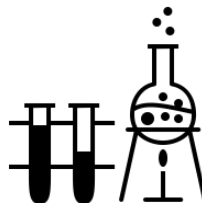
(Access to) support for (most of) the steps of data's life cycle and flow.

Multiple tools/platforms

(Ideally) managed platforms and resources that are smoothly joined up.

Mix of local & cloud based services to make an interlinked ecosystem of tools (a Research Commons).

Sociology of staged sharing



Lab-level RDM

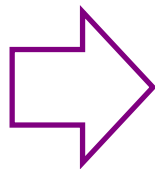
Files from facilities, instruments, trials
File stores, LIMS, Secure stores
Repositories,
Long term Preservation, Data movement



Team-level Cataloguing & Sharing

Catalogue & organise across repositories & studies
Metadata tracking, consent tracking
Deposition to shared (public) repositories
Data Brokering, Secure Gate-keeping

Data and metadata flows



Metadata Templates & Metadata Transactions

Spreadsheets, scripts and protocols
Data staging points, metadata standards
Reporting for you, friends & strangers

Sharing flows

Labs -> Team Hubs -> Public
Data Hubs



GLA - German Lymphoma Alliance

Description:

B-cell lymphoma is the most frequent lymphoid neoplasia accounting for one third of all lymphomas. R-CHOP (rituximab, cyclophosphamide, doxorubicin, vincristine and prednisolone) is the current treatment standard, leading to high cure rates especially in younger patients. Although the 3-year event-free survival is about 60% even for elderly patients between 60-80 years old, the remainder of patients eventually relapse and the majority die of their disease. T German Non-Hodgkin's Lymphoma Study Group (DSHNHL) was founded in 1993 and has since conducted more than 25 national and international trials including more than 8000 patients in first line and salvage therapies. The DSHNHL is a network of haematoncologists, pathologists, radiologists, radiotherapists, nuclear physicians, biologists, geneticists and biometricians. All results of clinical trials performed by the DSHNHL were published in international journals and could lead a contribution to improve the treatment results.

Programme: NHL

Health Atlas ID: 7RX4165T77-8

Funding codes:

- Deutsche Krebshilfe
- BMBF

Public web page: <https://www.dshnhl.org>

Organisms: Homo sapiens

Human Diseases: Non-hodgkin lymphoma, B-cell lymphoma

Health Atlas PALs: Markus Löffler

Project Coordinators: No Project coordinators for this Project

Project created: 16th Apr 2019

Project Hierarchy

- GLA - German Lymphoma Alliance
 - MMML - Molecular mechanisms in malignant lymphoma
 - MMML-MYC-SYS
 - MMML Demonstrators - Molecular Mechanisms in Malignant Lymphomas - Demonstrators of Personalized Medicine

Related items

[Institutions \(3\)](#) [Investigations \(17\)](#) [Studies \(15\)](#) [Resources \(16\)](#) [Publications \(74\)](#) [Data files \(91+1\)](#) [Models \(2\)](#) [People \(10\)](#)

Institute for Medical Informatics, Statistics and Epidemiology

imise.

Country: Germany
City: Leipzig
Web page: <http://www.imise.uni-leipzig.de>

Interdisciplinary Center for Bioinformatics

[Investigations \(17\)](#) [Studies \(15\)](#) [Resources \(16\)](#) [Publications \(74\)](#) [Data files \(91+1\)](#) [Models \(2\)](#) [People \(10\)](#) [Human Diseases \(3\)](#)

SEXIE-R-CHOP-14

Description:

Demographics, reference pathology diagnosis, Outcome (Event-free survival, Progression-free survival, Overall survival)

Health Atlas ID: 7WPDERG3ME-9

Projects: GLA - German Lymphoma Alliance

Selected: SEXIE-R-CHOP-14 (Investigation)

Description: Demographics, reference pathology diagnosis, Outcome (Event-free survival, Progression-free survival, Overall survival)

Tree Split Graph Fullscreen

- SEXIE-R-CHOP-14
 - SEXIE-R-CHOP-14 metadata
 - SEXIE-R-CHOP-14 metadata-ODM
 - SEXIE-R-CHOP-14 metadata-XLSX
 - SEXIE-R-CHOP-14 trial data
 - SEXIE-R-CHOP-14 trial data-ODM
 - SEXIE-R-CHOP-14 trial data-SPSS
 - SEXIE-R-CHOP-14 trial data-CSV

Optimization of rituximab for the treatment of DLBCL: increasing the dose for elderly male patients.

Related items

[Projects \(1\)](#) [Studies \(1\)](#) [Resources \(2\)](#) [Publications \(1\)](#) [Data files \(5\)](#) [People \(2\)](#)

SEXIE-R-CHOP-14 trial data

GLA - German Lymphoma Alliance



Demographics, reference pathology diagnosis, Outcome (Event-free survival, Progression-free survival, Overall survival)
Sample Size: 268

Submitter: René Hänsel
Resource type: Experimental Assay Type
Technology type: Technology Type
Snapshots: No snapshots

Investigation: SEXIE-R-CHOP-14
Study: SEXIE-R-CHOP-14
Organisms: No organisms
Human Diseases: diffuse large B-cell lymphoma
SOPs: No SOPs
Data files: SEXIE-R-CHOP-14 trial data-CSV, SEXIE-R-CHOP-14 trial data-ODM, SEXIE-R-CHOP-14 trial data-SPSS

Created: 16th May 2019 at 15:59, Last updated: 29th Oct 2019 at 10:57

FAIRDOM HUB

Home / Projects Index

Projects

59 Projects matching the given criteria: (Clear all filters)

Organisms: **Homo sapiens**

11 Last update date (Descending)

Search here... Go

Created At: Any time

Programme

Model repository for M4 (Make ... 12)

LSyM - Systems Medicine of th... 10

Independent Projects

RNA Systems Biology Lab

SARCHI: Mechanistic modelling ... 2

ERASysAPP

More...

Organism

Homo sapiens

Arabidopsis thaliana 17

Mus musculus 15

Rattus norvegicus 11

Escherichia coli 9

Saccharomyces cerevisiae 9

More...

COVID-19 related studies and tools in Germany

This project bundles information about COVID-19 related studies and tools in Germany. It intends to provide an information hub for the different initiatives, their aims, their processes, standards and study protocols, as well as their available data and metadata. It is initiated by the German National Research Data Infrastructure for Personal Health Data (nfd4health), a consortium that plans to establish a concept for a federated research data infrastructure for personal health data in Germany.

Programme: nfd4health - German National Research Data Infrastructure for Personal Health Data

Organisms: Homo sapiens, Severe acute respiratory syndrome coronavirus 2

Public web page: <https://www.nfd4health.de/index.php/de/task-force-covid-19/>

nfd4health - German National Research Data Infrastructure for Personal Health Data

nfd4health aims to create the most comprehensive inventory of German epidemiological, public health and clinical trial data to date. It builds a centralised data catalogue with elaborate search functionalities, sophisticated data access management, and a data analysis toolbox, while respecting stringent requirements for privacy concerning personal health data. Standardisation services ensure a high degree of interoperability. Use cases covering prototypical study types and areas of research show.

Programme: nfd4health - German National Research Data Infrastructure for Personal Health Data

Organisms: Homo sapiens

Public web page: <https://www.nfd4health.de>

Start date: 1st Jul 2020

COVID-19 Disease Map

Here we share resources and best practices to develop a disease map for COVID-19. The project is progressing as a broad community-driven effort. We aim to establish a knowledge repository on virus-host interaction mechanisms specific to the SARS-CoV-2. The COVID-19 Disease Map is an assembly of molecular interaction diagrams established based on literature evidence.

Programme: Disease Maps

Organisms: Severe acute respiratory syndrome coronavirus 2, Homo sapiens

Public web page: <http://dx.doi.org/10.17811/covid19-disease-map>

PolMIR - Polymers in the Liver: Metabolism and Regulation

PolMIR is funded through the EU Marie Skłodowska-Curie Innovative Training Network (ITN), which drives scientific excellence and innovation. ITNs bring together universities, research institutes, industry and clinical partners from across the world to train researchers to doctorate level. Metabolic diseases are a burden on the European population and health care system. It is increasingly recognised that individual differences with respect to history, lifestyle, and genetic make-up affect disease.

Programme: This Project is not associated with a Programme

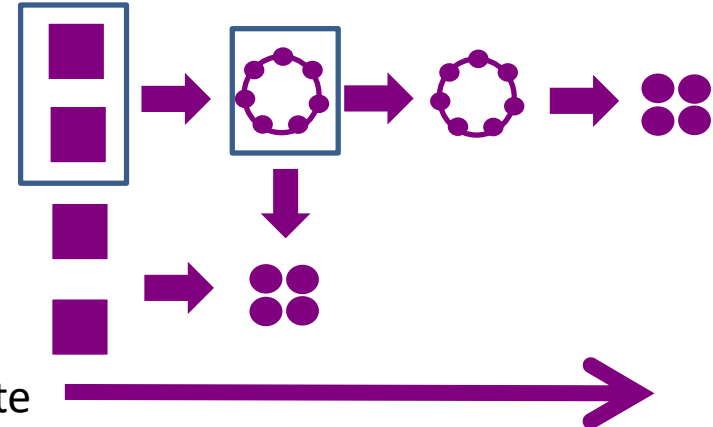
Organisms: Homo sapiens, Mus musculus, Rattus norvegicus

Public web page: <http://polmire-db.eu/>

Support and encourage incremental staged sharing & permission control

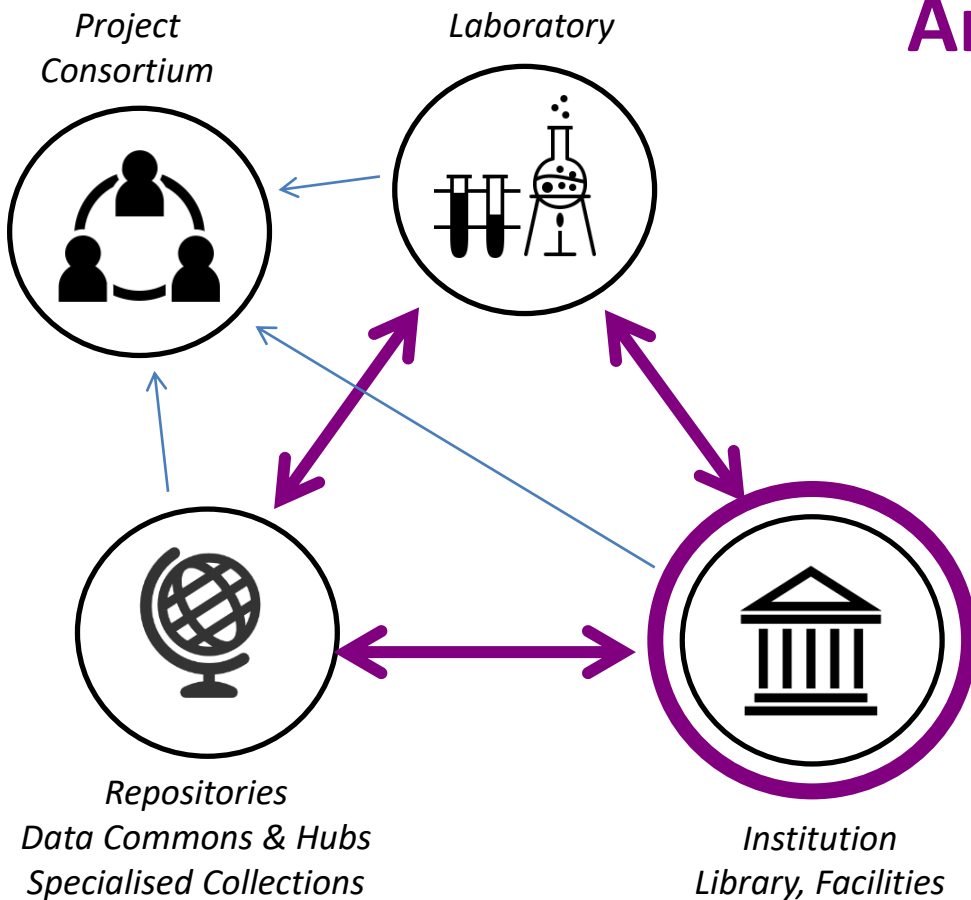
- To get trust in data sharing and support team sharing

Support Data Staging & pipelines



Investigation-Study-Assay/Analysis





An interlinked triangle



Trusted Research
Environments



Access to analysis
platforms

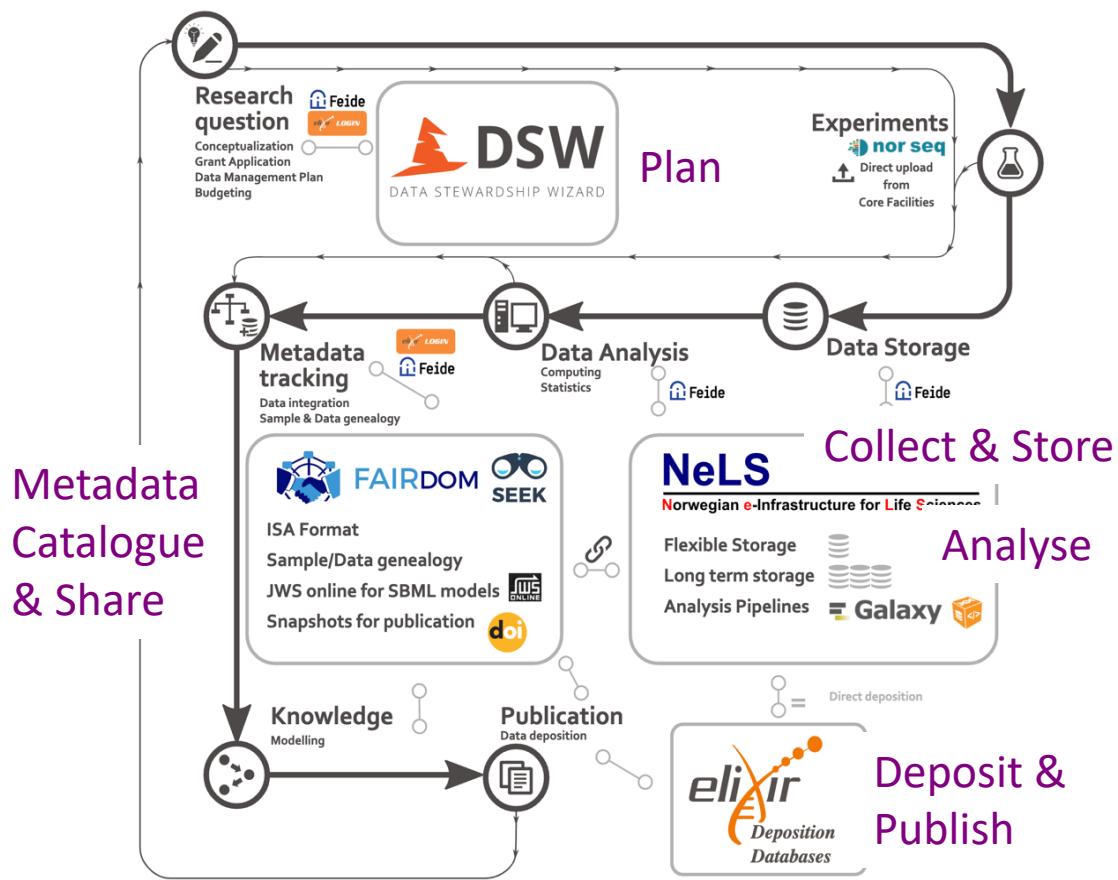


Cloud Store, Synch and
Share services, AAI
Frictionless connections

**Reduce the friction of data brokering,
data visiting**

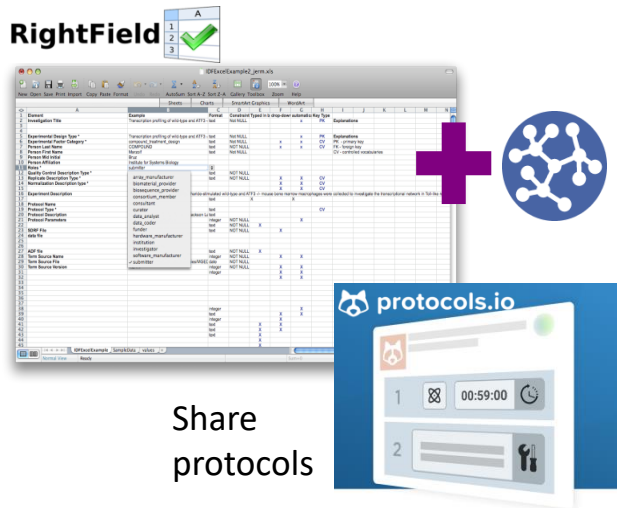
Leverage the resources and people

Blueprints & Examples



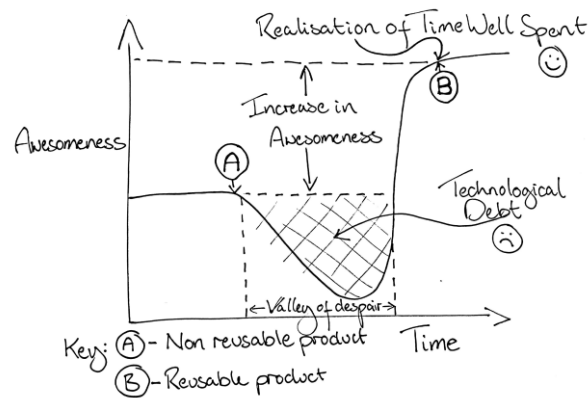
Norwegian e-Infrastructure for Life Sciences Data Management Tool Assembly

Nudge Points



Data Stewardship in the Lab

What can be automated?
Understand the (meta)data and its flows
Build in the processes and get them followed



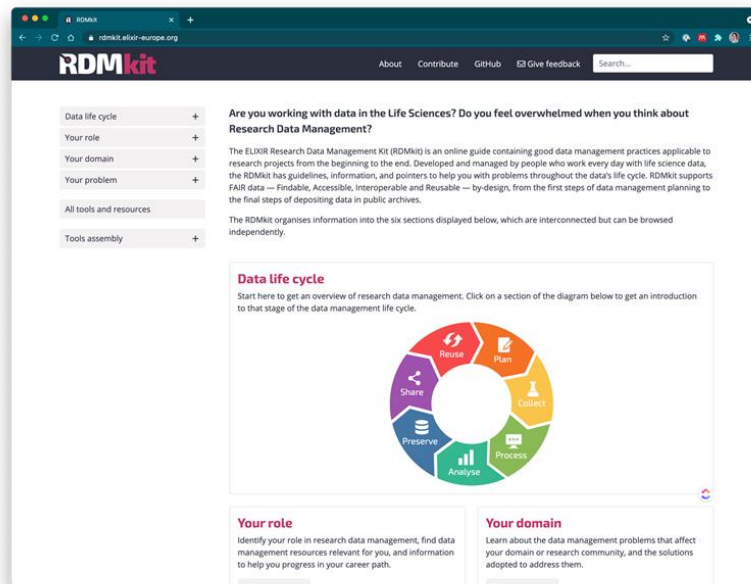
<http://www.rightfield.org.uk>
<http://protocols.io>

Some help



<https://rdmkit.elixir-europe.org>

Guides, examples, tools, pointers, assembled
and written by Life Science researchers and
data stewards



Data life cycle

Your role

Your domain

Your problem

All tools and resources

Tools assembly

Reusing

Edit me

- What is data reuse?
- Why is data reuse important?
- What should be considered for data reuse?
- Problems to be addressed at this stage
- Where can training materials and events about data reuse be found?

What is data reuse?

Data reuse means using data for other purposes than it was originally collected for. Reuse of data is particularly important in science, as it allows different researchers to analyse and publish findings based on the same data independently of one another. Reusability is one key component of the FAIR principles.

Data that is well-described, curated and shared under clear terms and conditions is more likely to be reused. Integration with other data sources is also important, since that can enable new, yet unanticipated, uses for the data.

Data life cycle

Your role

Your domain

Your problem

All tools and resources

Tools assembly

NeLS

Covid-19 Data Portal

COVID-19 Data Portal

Edit me

- What is the European COVID-19 Data Portal?
- How the portal is useful for researchers and how it is supposed to fit into their processes?
- What are the components for the COVID-19 Data Portal?
- What country specific instances are there and how new instances are deployed?

What is the European COVID-19 Data Portal?

The European COVID-19 Data Platform was launched to facilitate the urgent need to share and analyse COVID-19 data and thus accelerate research that will provide responses and build solutions, such as vaccines, treatments and public health interventions. The Platform comprises three core components, the SARS-CoV-2 Data Hubs, the Federated European Genome-phenome Archive and the COVID-19 Data Portal. The COVID-19 Data Portal brings together and continuously updates relevant COVID-19 datasets from a breadth of analytical platforms. Data are submitted using the SARS-CoV-2 Data Hubs functions or via other major centres

Data life cycle

Your role

Your domain

Plant sciences

Marine metagenomics

Human data

Biomolecular simulation data

Intrinsically disordered proteins

Microbial biotechnology

Your problem

All tools and resources

Tools assembly

Human data

Edit me

- Introduction
- Planning for, and collection of, human research data
- Processing and analysing human research data
- Preserving human research data
- Sharing & reusing of human research data
- Relevant tools and resources
- Training materials on the management of human-subject data

Introduction

When you do research on data derived from human individuals, there is the data life cycle. Note that much of the topics discussed on this page

Take home points

- Know (meta)data flows and identify metadata nudge points
- Stores AND Catalogue
- Processes + Templates go with the Tools
- Lab + Institution + Public Commons triangle
- Support the staging of sharing
- RDM help by folks who in labs and facilities

