

# 13th DTL DTL Partner Advisory Committee meeting

October 29th 2020

## Participants

Name/Affiliation
John Schmitz/TUD
Ronald van Schijndel/Amsterdam UMC
Rick van Nuland/Lygature
Cees Hof - DANS-KNAW
Filip Pattyn/ONTOFORCE
Patrick Kemmeren (Princess Máxima Center for Pediatric Oncology)
Bas de Waard/ZonMw
Eva van Ingen - Elevate Health
Erik Schultes, GO FAIR / DTL
Dimitris Koureas / Naturalis
Jeroen Belien/Amsterdam UMC
Peter Hilbers(TU/e)
Marielle Gallegos Ruiz (Roche) (first hour only)
Lars Ridder (eScience Center)
Jet Zoon (Princess Máxima Center for Pediatric Oncology)
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Louis Ter Meer, Erasmus University - IOSpress Amsterdam
Barend Mons (LUMC rep) and GO FAIR
Solon Pissis (CWI)
Martijn van Rooijen (RIVM)

Jantine Dirksen (Quaero Systems)
Eric Kuijt (GenNovation)
Jaap Heringa (VU)
Renger Jellema (DSM)
Hans Niendieker (Ivido and HINQ)
Henk-Jan van den Ham (ENPICOM)
Rita Azevedo (Lygature and Health-RI)
Harry van Haaften (The Hyve)
Inez Joung (RIVM)
Jet Zoon (Princess Máxima Center for Pediatric Oncology)
Jildau Bouwman (TNO)
Lars Ridder (eScienceCenter)
Frits van Merode (MUMC)
Han Bakker (Lab Servant)
Alain van Gool (Radboudumc)

DTL team: Ruben Kok, Frederike Schmitz, Mijke Jetten, Rob Hooft, Merlijn van Rijswijk

## Useful information:

The slides from the meeting can be found here.

**Annexes:** <https://www.dtls.nl/about/organisation/pac/documents-pac-meetings/>

1. Report 12<sup>th</sup> meeting DTL Partner Advisory Committee May 28<sup>th</sup> 2020  
Exhibits: presentations of previous PAC meeting

The report of the 12th meeting has been approved without modifications

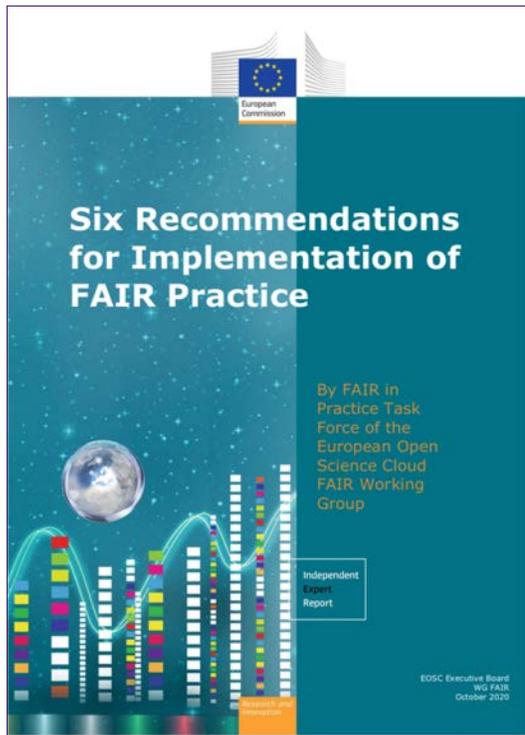
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## 1. Short updates by Ruben Kok (DTL)

Ruben summarized recent developments from within and outside DTL's network.

- [The Annual bioinformatics and systems biology research community conference BioSB 2020](#) took place Oct 27-28 2020. The conference was co-organised by BioSB, Utrecht Bioinformatics Centre and DTL. More than 300 participants and 3 keynote speakers joined this online conference.
- [Data Sharing Coalition](#): DTL is exploring to set up a Life Sciences branch as part of the The Data Sharing Coalition. DTL's partners DSM, Roche, the Hyve have already expressed interest and a group is currently being set up. If you are interested to join, please contact Ruben Kok.
- [National Programme Open Science \(NPOS\)](#): The NPOS is under NWO, VSNU and NFI governance. It runs two projects in the field of FAIR data, including NPOS-E which aims to strengthen the national FAIR data landscape, and NPOS-F aimed to develop a "Competence & Training Framework for Data Stewards". In the coming years 2021-2030, NPOS will work towards a strong national cross-science FAIR data programme, for which Ruben Kok will take the lead. The work process is now being formalized, and it will strongly connect its efforts to existing science infrastructures and Digital Competence Centers (DCC's).
- [The European Open Science Cloud \(EOSC\) has launched five working groups](#) amongst which a FAIR Working group: "Implementing the FAIR data principles by defining the corresponding requirements for the development of EOSC services, in order to foster cross-disciplinary interoperability Research performing, funding and supporting organisations all all members of EOSC." EOSC is creating a European data layer on top of the European e-infrastructures and will therefore also affect the Dutch research data landscape. DTL has applied as an observer to the EOSC Association, to represent the Dutch Life Science perspective. Rob Hooft has been leading the FAIR in Practice Taskforce, leading to [a publication with six recommendations for Implementation of FAIR Practice](#).



1. Fund awareness-raising, training, education and community-specific support
2. Fund development, adoption and maintenance of community standards, tools and infrastructure
3. Incentivise development of community governance
4. Translate FAIR guidelines for other digital objects
5. Reward and recognise improvements of FAIR practice
6. Develop and monitor adequate policies for FAIR data and research objects

- [1+Million Genomes Initiative has published it's roadmap in late September 2020.](#) It's aim is to build a cross-border European genomic cohort of 1+M citizens. So far, 23 countries have signed its declaration. The 1+MG project is a strong use case for a federated FAIR data approach. In the Netherlands it has strong connections to ELIXIR-NL and Health-RI.
- [The Trusted World of Corona](#) (TWOC project) was awarded and is a Life Sciences & Health project with several DTL partners (LUMC, Radboud, TNO, Roche, LACDR, Euretos, GO FAIR foundation, DTL-Projecst, etc.)
- Recapitulating from the last PAC meeting, Ruben emphasized DTL's mandate to "form a collective voice in digital life sciences". Together with the community of bioinformaticians and computational life scientists (assembled in research school BioSB) and ELIXIR-NL (data infrastructure), DTL aims to combine its agenda on data stewardship and data infrastructure into a more comprehensive agenda towards 'Digital Life Sciences'.

## DIGITAL LIFE SCIENCES LANDSCAPE IN NL

Digital Life Sciences (technical & biological aspects)	Key initiatives, projects, organisations
Training & Capacity Building	Universities (of applied sciences), UMC's, T02, BioSB, ELIXIR, the Carpentries, Goblet, companies
FAIR Data Stewardship	RDA, 4TU.ResearchData, local DCCs, LCRDM, GO FAIR, DANS, NPOS, Data Sharing Coalition, companies,
Biobanks & Collections	Universities, UMC's, Institutes, BBMRI, (ELIXIR)
Access to Real World Data	hospitals, farms, companies, citizens & patients (eHealth)
Enabling Technology Hotels (Core Facilities)	universities (of applied sciences), UMC's, T02, NPC, NMC, X-Omics, NL-Bioimaging, NEMI, medical imaging, companies
Data Science & Analytics (Bioinfo, Sysbio, A.I.)	BioSB, DSPN, AI Coalition, companies
Software & Models	eScience center, BioSB, ELIXIR
Computing, storage & workspaces	SURF, companies



## 2. Presentation: Data in your food. Community-based initiatives to realise a data infrastructure for lifestyle and prevention. Jildau Bouwman (TNO)

Jildau Bouwman introduced the work of communities which are doing research within 'lifestyle and prevention' at TNO. She mentioned that there is a global diabetes 'epidemic', mainly caused by the increase in obesity. There is an urgent need to invest in prevention. Our healthcare today is focused on treating diseases and not maintaining health. This should be changed by including prevention into the healthcare system. We should also understand more about the behaviour of individuals and provide guidance to live a healthy lifestyle. For this to happen, information needs to be collected in the areas of biology (including the microbiome), sociology, environmental sciences, behaviour, psychology and many others. Nowadays, numerous people are already collecting data about themselves in apps (wearables, eHealth), but it is difficult to combine data with other data sources and reuse it. On top of that, it is crucial that the consumers are in control of their own data.

Jildau introduced several initiatives TNO is currently working on.

- 'Connect2HealthConsumer'. In this project data from wearable devices covering food (intake) and activity is added to the medical data currently available, all complying with the ethical legal requirements.
- '[Lifestyle4Health](#) Innovation Center'. This initiative was started by the LUMC and TNO and its goal is to make lifestyle part of the current healthcare system in the

Netherlands. This center will be expanded beyond the initial founding institutes, to become a national center and all DTL partners are welcome to join ([please contact Jilda Bouwman](#)).

- [Food, Nutrition and Health-Research Infrastructure](#) (FNH-RI) (Dutch node: DISH-NL). This is a research infrastructure currently being built (scheduled to start 2025). A proposal for inclusion of FNH-RI on the ESFRI Roadmap 2021 has been submitted recently and is currently under review.
- The [NL-AI coalition](#) started a working group ‘health and care’ (gezondheid & zorg) with a team working on lifestyle and prevention. This team covers aspects of data integration, validation of models and thinks about a new health economy.
- A Food and Nutrition Community has been proposed within ELIXIR. A paper is prepared and will be reviewed by the Heads of Nodes of ELIXIR.
- ENPADASI ([European Nutritional Phenotype Assessment and Data Sharing Initiative](#)) is a project under the Joint Programming Initiative Healthy Diet for a Healthy Life (JP HDHL) which aims to FAIRify nutritional studies and make this FAIR data available to be reused. The knowledge platform on food, diet, intestinal microbiomics and human health also makes use of insights from this particular ENPADASI project.

Jildau Bouwman promotes the inclusion of these presented initiatives in Health-RI, or alternatively to establish a similar structure aimed at prevention aspects of health. Jildau suggests that DTL could be an important linking pin. It could link the agro-food area, biotech and health areas. It could also align the efforts of FAIRness which are undergoing in all communities in a similar manner. This could prevent building silos of communities further (she called this ‘a system in a system approach’).

**Questions/remarks/ answers raised during the presentation:**

- Remark: “Now that the ‘Trusted World of Corona (TWOC)’ was awarded by Life Sciences and Health, one of ‘the rooms’ is reserved for behavioural sciences and external influences (called the exposome). We have to extend to much more than the classical biomedical/clinical data, including behavioral data and other types of data. DTL could play an important role here in linking the different domains from which the data could be integrated.”
- Question: “What is the relation between FNH-RI and the ESFRI MetroFood (Infrastructure for Promoting Metrology in Food and Nutrition?)” Answer: “Metro Food is directed towards a very specific area of food availability/safety. FNH-RI

is much broader (sociology, food, etc). Nevertheless, we should be careful to align what has been done in other infrastructures (such as metro food) and not reinvent the wheel.

### 3. Presentation: Implementing FAIR data in the Dutch life sciences ecosystem. Picture a web of life science FAIR data. Rob Hooft (DTL)

Rob Hooft addressed the question on how we are getting FAIR off the ground, to be using the FAIR principles in practice?

He mentioned that we are facing a lot of silos. In traditional silos data is stored, together with tools that operate on that data. The tools cannot operate on data elsewhere, and it is also hard to analyse the data in the silo with other tools. One solution to address this issue could be to make the silos bigger. The better solution is to make data and tools FAIR. During the FAIR meeting in 2014 it was proposed to set this up according to an hourglass model, in which tools (at the top) and data (at the bottom of this hourglass) can communicate with each other, though a very narrow (standard) connection. The 'communicating middle layer' in this hourglass model depicts the definition of FAIR. If all data is made available in a FAIR way, and all tools talk with the data through this FAIR technique, there are no more silos. However, the concept of building silos is still strong: as seen in recent developments, new Covid-19 data portals again establish more silos: as the user can only search the data and then download it.

A proposed solution to break out of such silos and implement the hourglass model, is to make FAIR Digital Objects. Instead of offering "download" for "open" data, a (validated) user would get (certain) rights to access the data and could then be able to directly *operate* on the data. This is similar to how a programmer would work on a single computer or cluster, except that now it should not matter where the data is stored on the internet (as long as it is specified by Digital Object Identifiers (DOI)), as access is distributed and the data is well described according to specified (semantic) metadata standards. [The FAIR data point](#) can support this view by aggregating FAIR metadata. [FAIR Data Points can describe data sets in a FAIR way, using standard metadata and making them available through simple WWW protocols.]

Rob also explained what a FAIR research project would look like, yielding FAIR data as a result of its research. It is of essence to plan this up front before a researcher starts collecting data. Questions like 'Where should the data be stored?' and 'Who can help

me with implementing the FAIR principles such as data stewards in my institute or company', should be addressed before the studies begin.

#### 4. Presentations: Building a competent Dutch network of data stewards to create a national web of FAIR Covid-19 data resources. Mijke Jetten (DTL), Erik Schultes (DTL/GO FAIR), Bas de Waard (ZonMw) and Martijn van Rooijen (RIVM)

Bas de Waard (ZonMW): Bas gave an update on the [FAIR data project within the Covid-19 consortia funded by ZonMw](#). NWO and ZonMw have already committed themselves to Open Science, Open Access and FAIR data, but the SARS-CoV-2 outbreak demonstrated the urgency to accelerate its implementation.

Early on during the pandemic ZonMw funded [VODAN](#) and subsequently all projects granted funding by ZonMW on Covid-19 required the resulting data to be as FAIR as possible.

A good example of FAIR data implementation is the creation of machine-readable Covid-19 WHO report forms. These grant the user access to the data but at the same time leave the data at the site where it was collected. In this setup the user can run analysis on it without the need to download it (see Rob's introduction).

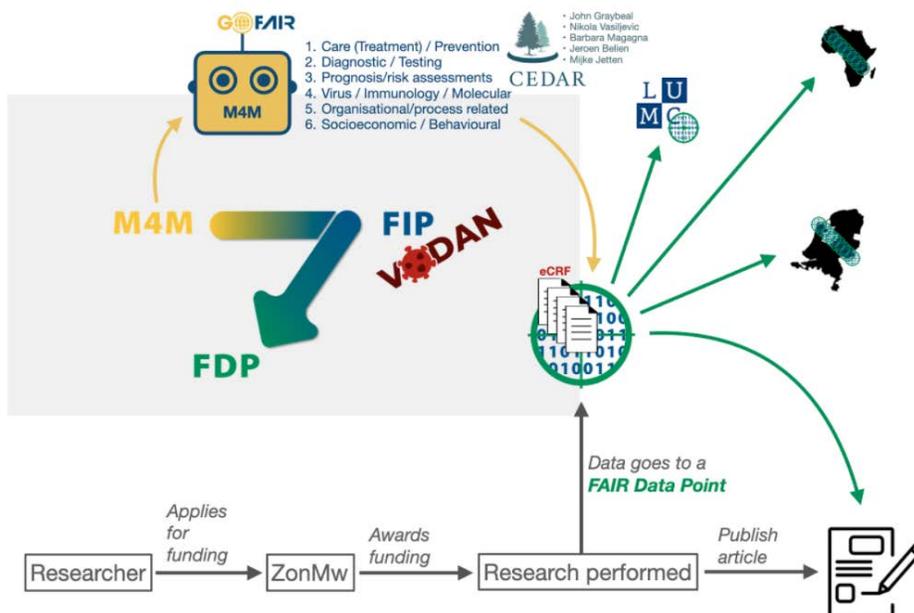
Furthermore, ZonMw's Covid-19 calls all required the researchers to include data stewards into the research projects and granted a devoted budget of 5% to data stewardship. This benefits the researchers who can now focus on their research and the data stewards can focus on FAIRification of the research data. Another advantage is the creation of experience with FAIRification of data sets amongst data stewards and the exchange of experiences amongst them. These calls therefore further support building a community of trained data stewards (see Mijke Jetten's presentation below) at universities, university medical centers and university of applied sciences.

It also supports the researchers and data stewards with checklists, webinars and training. It consequently also strengthens the collaboration of data stewards and researchers, leading to the development of specific metadata templates (depending on the community/discipline/topic). Increased FAIRness of research data via FAIR metadata improves computer readability (via FAIR data points) and readability for humans via a national data portal.

This approach also accelerates the availability of research outcomes and data, thus enabling advanced research to contribute to solving the current Covid-19 crisis.

Erik Schultes (GoFAIR, DTL): Erik Schultes spoke about the ‘[Three-Point FAIRification Framework](#)’ in the context of the ‘Virus Outbreak Data Network (VODAN)’. The ‘Three-Point FAIRification Framework’ provides practical “how to” guidance on how to do FAIR. Erik explained that the ‘Three Point FAIRification Framework’ consists of three core elements: 1.) FAIR metadata, formulated in domain-specific metadata 4 machines (M4M) workshops, 2.) a FAIR Implementation Profile (FIP) and 3.) FAIR Data Points (FDP). The FAIR metadata can then feed into a larger FAIR implementation profile, which guides FAIR data points.

Two funded projects were tasked with setting up FAIR data points: 1.) the Phillips foundation in Africa (VODAN Africa) and 2.) the ZonMw funded project of setting up a FAIR data point at the LUMC which evolved into the current ZonMw Covid-19 program. Data created in the ZonMw funded research program should be as FAIR as possible. How does this work?



In contrast to the classical research track (depicted on the bottom), where data is generally not FAIR, this time data should be funneled into a FAIR Data Point. Erik explained that the start is the FAIR Implementation Profile, which is provided by the projects. For this FAIR Implementation Profiles and electronic Case Report Forms (eCRF) are used. It also includes FAIR metadata for all of the funded projects. These will be created in a series of *Metadata-4-Machines* workshops which will be launched in November. In these workshops, data stewards and principal investigators from all funded projects will be defining domain-relevant variables, measurements, data types and vocabularies. By doing so, it is made sure that the local FAIR Data Points contain

suitable content for later search queries. The ultimate goal of this process is a national observational data portal for Covid-19 data at Health-RI.

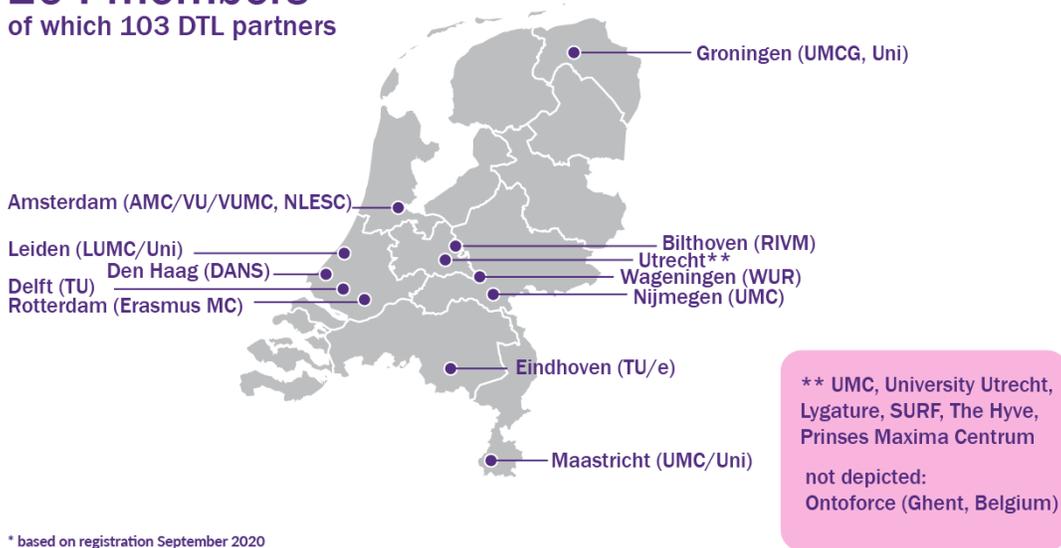
Mijke Jetten (DTL, HealthRI): Mijke Jetten is the data stewards community manager at DTL and Health-RI. In her presentation she emphasized the importance of data stewards and the roles of multiple organizations to advance the role of data stewards such as ELIXIR, LCRDM, ZonMw, GoFAIR, NPOS, FAIRsFAIR, Health-RI and the establishment of local Digital Competence Centers (DCCs).

ZonMw explicitly acknowledges the importance of a strong data steward community by requiring grantees of Covid-19 research grants to embed data stewards into the research and to refer them to DTL's Data Stewards Interest Group (DSIG). This is done to prevent the creation of yet another community. Within the 'Data Stewards Interest Group' (DS-IG) a 'Special Interest Group' (SIG) was set up in which participants can align their work on data management issues of Covid-19 research. This subgroup now focuses on Covid-19 related work but could lay the foundation for a general FAIR implementation group in the future. For data stewards involved in Covid-19 research, multiple [webinars](#) and [workshops](#) are available, which are based on ZonMw's FAIR data and Open Science [requirements and recommendations](#). If you want to join the 'Data Stewardship Interest Group', [join the mailing list](#), [check out when it meets again](#) and/or join the [Slack channel](#).

## Data Stewardship Interest Group

A professional community for Data Stewards and alike in "Life Sciences"

**204 members\***  
of which 103 DTL partners



Martijn van Rooijen (RIVM) mentioned that data stewardship is relatively new at the RIVM. To fulfill the societal demand for transparency on data and to safeguard the re-usability and reproducibility of science, it is important to the RIVM that it publishes open metadata. The metadata (DCAT) is published via [data.rivm.nl](http://data.rivm.nl) and [data.overheid.nl](http://data.overheid.nl). In the beginning of the pandemic pdf files with the most up to date Covid-19 data were published.

After legal issues were solved this was soon optimized by publishing this data as open data in the form of csv and json files. However, publishing data, metadata, scripts and code is new to RIVM and an improved workflow had to be set up. This workflow has recently been approved by the RIVM board.

Martijn further presented two studies that are currently conducted at the institute. The first one investigates how people behave during the Covid-19 crisis (the Covid-19 behavioral study). Due to legal issues not all data from this project can be published. However, they consulted DTL, GOFAIR and the company FAIRsolutions to publish as much of it as FAIR data.

The second project he described is 'SARSLIVA' (together with Spaarne gasthuis & UMCU). This project aims at stimulating researchers to think about data management and FAIR data early on in the grant application process.

He concluded that researchers today are more willing to share data and are more knowledgeable in FAIR and Open Science practices. However, there are still multiple legal issues to be tackled.

The Covid19 pandemic has demonstrated the urgent need to bring FAIR into practice.

**Questions/remarks/ answers raised during the presentation:**

- Erik Schultes (GOFAIR, DTL) remarked that a draft summary of the ZonMw COVID Program FAIR Data Stewardship Support can be found [here](#).

## 5. PAC Exchange: Reflection on presented approach. How could DTL partners contribute in realising a Dutch FAIR data ecosystem?

### Summary of the discussions in room 1:

The team exchanged on the levels of experience regarding FAIR data stewardship, which varies a lot (several organisations are considering appointing a data steward). All agree on the importance, although industries such as the agro breeding companies seem to understand FAIR as synonym to open data, which is a no-go for these companies. The team concludes that training is essential, investing in training (incl. train-the-trainer) in FAIR-based data stewardship must be high on everyone's (and DTL's) agenda.

Moderator: Ruben Kok

### Summary of the discussions in room 2:

The discussions in room 3 concluded that many companies are a bit behind with regards to the state of FAIR in comparison to academic groups. However, the companies who participated in the discussion saw a role for themselves. They acknowledged that they can benefit from FAIR data and existing standards, and they can also help and facilitate others to achieve it and co-build standards. The participants further concluded that the misunderstanding that FAIR is only applicable to public/open data must be eradicated.

Moderator: Rob Hooft

### Summary of the discussions in room 3:

There is not yet much knowledge about FAIR. FAIR is better known by PhD's than the PI's. Data stewards are still scattered throughout organisations, some organisations want to bundle the expertise, training is not yet sufficient. The learning process is step by step: first research data management, then data stewardship. It takes time to convince the management of organisations to invest and improve reusing of data. Specialists are needed: DCCs will help to bundle knowledge in organisations.

Moderator: Mijke Jetten

Summary of the discussions in room 4: Participants first discussed the role of RIVM in the current COVID-19 crisis. All hospitals need to provide data on the number of cases and deaths to RIVM, who in turn hands this information (anonymised, pseudonymised) over to the Royal Library for official record keeping. Within UMCs and at other places including RIVM now FAIR data points are being installed. These FAIR Data points mostly publish metadata of COVID-19 patients, thereby ensuring information security. Currently discussions are ongoing between hospitals, to ensure that these metadata follow

(inter)national standards (WHO case report forms), and making these metadata interoperable. Important for DTL to work with GOFAIR on specifications for FDP's to ensure interoperability of FDP's.

Moderator: Merlijn van Rijswijk

#### Summary of the discussions in room 5:

In this breakout room it was discussed that it differs a lot on how advanced research groups and institutes are with FAIR and data stewardship standards. There seems to be a lot of fragmentation. For example at one institute data stewards can be strong in the areas of policy and IT but less so when working with researchers. At other institutes this picture is completely different. To close this gap, each department should have at least one data steward and all data stewards should be well connected. Often researchers have no idea on how to start with data management, what to do and what not. For this reason an expert (data steward) should be consulted and she/he should be closely involved with the researcher's work. However, often it seems difficult to convince PI's of the value of hiring a data steward and there seems to be a lack of funding to do so. Even when institutes hire data stewards it is essential to also train the researchers on certain topics (to be knowledgeable in the basic data management tasks). The discussion should not concern data stewards as a 'cost factor' but rather a 'value factor', focusing on the return in investment when hiring one.

It is a challenge to convince people in charge about the added value in a typical research project when the data is collected, published and then the project moves on (data-publish-done). Also it is challenging to store data beyond the classical time frame of about 4 years of funded research projects. The question then is, who should pay for storing the data for a longer timeframe? To break this circle and demonstrate the value of data stewardship, lots of showcases and good examples should be communicated. Furthermore, there needs to be an awareness of data management before submitting a grant application. As well as a mindset that instead of spending millions of Euros on a machine, to invest more money into data stewardship. Also the issue of trust was discussed, as researchers generally use one's data when they trust the researcher or research group. Agreements on standards could solve this trust issue. What's more, it is important that researchers know, have access and use the right tools while they are collecting data: this is often a bottleneck. There could be a bigger role for tools/models from companies. Often, tools that are available today target more advanced users and there is a lack of simpler tools.

Moderator: Frederike Schmitz

**What could/should be DTL's role? (a summary)**

- **Advocacy of data stewardship:** DTL should show good examples of data stewardship and help build the 'business case for FAIR data and data stewardship'. It should advocate FAIR to the broad life science research community (close collaboration with GoFAIR). Also it should show that FAIR data is not equivalent to open data.
- **Creating an Overview:** DTL should be collecting tools and showcasing them on a central platform. DTL should not only help to generate FAIR data, but also tools to analyse FAIR data.
- **Being involved in policy discussions:** Handling data should be well connected to the strategy of an organisation. (Senior) management should be made aware of the value of data stewardship. The lack of funding for infrastructure should be addressed and it must be clarified who needs to take responsibility for long term storage of data (the institute or the funders).
- **Build a strong FAIR data stewardship Training programme.** Investing in training (incl. train-the-trainer) must be high on everyone's (and DTL's) agenda.
- **Connecting Experts:** DTL as a knowledge hub connects life scientists, data stewards and data scientists/bioinformaticians.

Participants per Breakout room:

<b>Breakout Room 1:</b>
Bas de Waard (ZonMw)
Eva van Ingen (Elevate Health)
Eric Kuijt (GenNovation)
Louis Ter Meer
Hans Niendieker (Ivido en HINQ)
Cees Hof (DANS-KNAW)
<b>Breakout Room 2:</b>
Henk-Jan van den Ham (ENPICOM)
Filip Pattyn/ONTOFORCE
Rob Hooft (DTL)
Rita Azevedo (Lygature and Health-RI)
Barend Mons (LUMC/GO FAIR)
Han Bakker (Lab Servant)
<b>Breakout Room 3:</b>
Jildau Bouwman (TNO)
Jantine Dirksen (Quaero Systems)
Jet Zoon (Prinses Máxima Centrum)
Jeroen Belien/Amsterdam UMC
Ronald van Schijndel (Amsterdam UMC)
Mijke Jetten (DTL, Health-RI)
<b>Breakout Room 4:</b>
Merlijn van Rijswijk (DTL / ELIXIR-NL)

Jaap Heringa (VU / ELIXIR-NL)
Martijn van Rooijen (RIVM)
Lars Ridder (eScience Center)
<b>Breakout Room 5:</b>
Frits van Merode
Rick van Nuland/Lygateure
Renger Jellema / DSM
Peter Hilbers
Patrick Kemmeren
Solon Pissis (CWI)
Frederike Schmitz (DTL)