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Incorporating the FAIR Principles in the Research Data Life Cycle

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Appendices

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Summary

Data are the foundation of modern medicine: they contribute to building evidence that is incorporated into the body of scientific knowledge and clinical practice. To gather new evidence, one sets up a research project in which data are collected, analyzed, and contextualized. Throughout such a project, proper management and stewardship of data are essential. The Research Data Life Cycle (Figure 1) guides researchers through the process of setting up and conducting research in line with these practices by describing all steps taken in a research project, as well as the associated data management tasks.

The FAIR Principles, similarly, are designed to guide the implementation of good data management and stewardship. They state that research data and metadata should be Findable, Accessible, Interoperable, and Reusable, both for humans and machines. Workflows have been developed over the years to make data and metadata FAIR step by step. However, present workflows are designed to be executed after research projects have been already conducted and data are collected, rather than throughout the life cycle of a research project. In this thesis we, therefore, aimed to incorporate the FAIRification steps (i.e., steps to make data and metadata more Findable, Accessible, Interoperable, and Reusable) into the Research Data Life Cycle, ensuring that data are FAIRified throughout the research process rather than after the project is completed. To investigate this, we distinguish three strands of research, which are addressed in the three parts of this thesis. These parts are summarized below.

Part I. State of FAIR

The FAIR Data Principles are rapidly being adopted by many research institutes and funders worldwide. However, little is known about the knowledge, perceptions, and efforts of individual clinical researchers and research support staff regarding data FAIRification.

In Chapter 2 we, therefore, assessed the awareness and attitudes of clinical researchers and research support staff regarding data FAIRification. We distributed a questionnaire to researchers and support staff in six Dutch University Medical Centers and Electronic Data Capture platform users. We found that 62.8% of the researchers and 81.0% of the support staff are currently undertaking at least some effort to achieve *any* aspect of FAIR (i.e., Findability, Accessibility, Interoperability, or Reusability). 11.0% and 23.8%, respectively, address all of the FAIR aspects. 94.7% of the researchers are aware that their data being FAIR might be useful for others and 89.3% are, given the right resources and support, willing to FAIRify their data.

In Chapter 3 we used the data of this questionnaire to gain insight into clinical researchers' understanding of the FAIR Principles and their experience with data FAIRification. We found that most researchers were unaware of the Principles' emphasis on both human and machine readability, as their FAIRification efforts were primarily focused on achieving human readability (93.9%), rather than machine readability (31.2%).

Part II. NLP and FAIR

Much of the data present in Electronic Health Records (EHRs) are stored as unstructured free text, as clinicians often resort to making free-text notes. These notes may be useful

for clinical research, but cannot be readily interpreted by a machine. Natural Language Processing (NLP) algorithms can make free text machine-interpretable by attaching it to ontology concepts, formal specifications of concepts and relations in a domain.

In Chapter 4 we reviewed the current methods used for developing and evaluating NLP algorithms that map clinical text fragments onto ontology concepts. We found many heterogeneous approaches to reporting on the development and evaluation of these algorithms. In order to standardize the evaluation of algorithms and reduce heterogeneity between studies, we developed a list of sixteen recommendations for future studies that can be used along with adherence to a generic reporting standard.

In Chapter 5 we developed and evaluated an NLP application with generic algorithms for the detection of (misspelled) concepts and of relationships between them. We evaluated the application by encoding free-text oncology charts. The evaluation results show that our application can detect oncology concepts and relationships with high precision. These concepts and relationships can be used to encode clinical narratives, and can thus substantially reduce manual chart abstraction efforts, saving time for clinicians and researchers.

Part III. FAIR by design

Existing FAIRification workflows are usually carried out *post hoc*: after the research project is conducted and data are collected, rather than throughout the life cycle of a research project. Researchers would benefit from a *de-novo* approach, where data are made FAIR automatically and in real-time, upon collection.

In Chapter 6 we present a workflow for *de-novo* FAIRification: a workflow where FAIRification steps are incorporated in the process of setting up and collecting data for a registry or research project. This facilitates automated, real-time FAIRification, without any intervention from data management and data entry personnel. The workflow is applied to a registry for vascular anomalies, and can, to a large extent, be reused by other research projects.

In Chapter 7 we describe the implementation and evaluation of Chapter 6's workflow in an Electronic Data Capture (EDC) system, the place where medical research data are often collected and stored via electronic Case Report Forms (eCRFs). Our implementation ensures that eCRF data entered into an EDC system can be transformed into machine-readable, FAIR data using a semantic data model (a canonical representation of the data, based on ontology concepts and semantic web standards) and mappings from the model to questions on the eCRF. Its application in the registry for vascular anomalies and the evaluation results show that the method can be used to make clinical research data FAIR when they are entered in an eCRF, without any intervention from data management and data entry personnel.

In Chapter 8 we describe the process of transforming the International Society for the Study of Vascular Anomalies (ISSVA) classification, a classification for vascular anomalies that enables specialists to unambiguously classify diagnoses, into an ontology. The classification was only available in a human-readable format, but is now made machine-readable and interoperable, and now includes mappings to existing ontologies. We be-

lieve that the ontology will increase the interoperability between clinical studies and registries and, therefore, will contribute to FAIRer vascular anomaly research.

Conclusion

Chapter 9 presents an overall discussion of the work in this thesis. The conclusions drawn in this thesis are summarized in Figure 1.

The FAIR Principles are gaining more and more traction. However, many researchers are currently unaware of the (meaning of the) FAIR Principles or how to apply them to their work. The work presented in this thesis quantifies the lack of FAIR awareness of clinical researchers and research support staff and provides a FAIRification workflow with tooling that is incorporated into the current way in which researchers work, i.e., the Research Data Life Cycle. Workflows and tools contribute to making data FAIRification more scalable. User-friendly tools that are integrated with the software used by researchers play a crucial role in this, since they facilitate automated data FAIRification throughout the course of a research project and take the majority of the work off researchers' shoulders. To accelerate FAIRification at scale, policy makers, funders and research institutes need to work together to provide standards, methods, support, tools, and funding to the research community, effectively making FAIRification of research data a joint mission. Ultimately, this paves the way for a future where collected data brings maximal value to patient care.

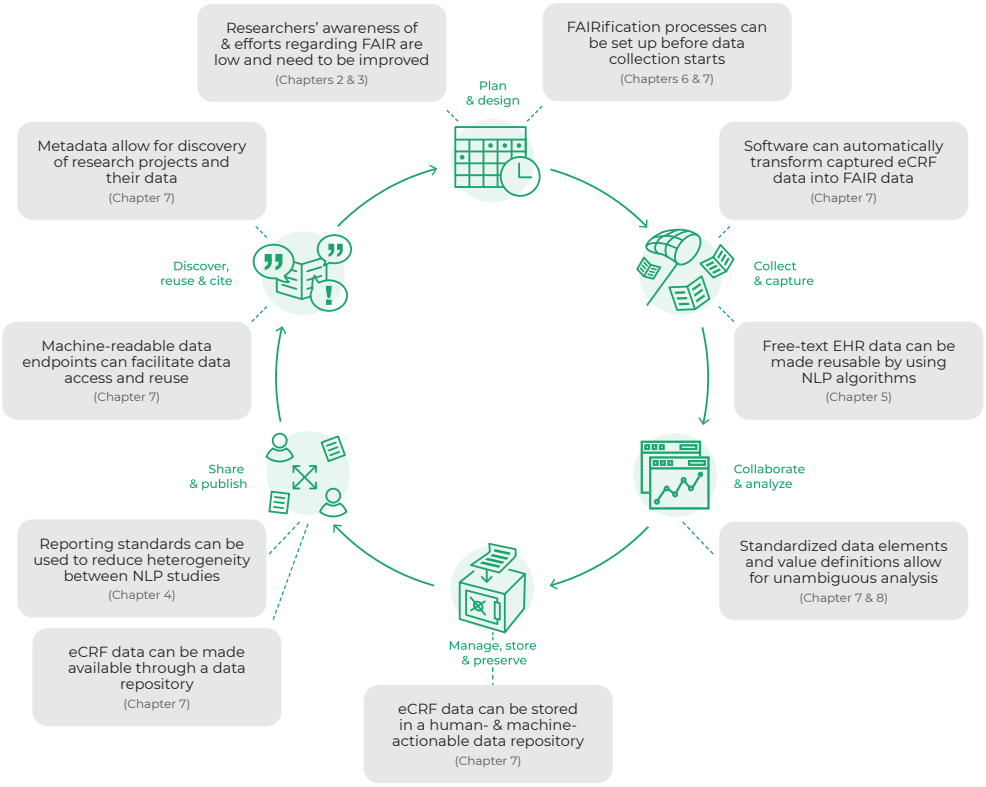


Figure 1: Summary of main findings and conclusions, mapped to the Research Data Life Cycle

FAIR: Findable, Accessible, Interoperable and Reusable, NLP: Natural Language Processing, eCRF: electronic Case Report Form, EHR: Electronic Health Record

Samenvatting

Data liggen aan de basis van de hedendaagse geneeskunde: ze dragen bij aan het verkrijgen van bewijs dat vervolgens wordt opgenomen in de wetenschappelijke literatuur en de klinische praktijk. Om nieuw bewijs te verzamelen, voert men in het algemeen een onderzoeksproject uit waarin data worden verzameld, geanalyseerd en gecontextualiseerd. Tijdens een dergelijk project zijn *data management* en *data stewardship* essentieel. De Research Data Life Cycle (Figuur 2) leidt onderzoekers door het proces van het opzetten en uitvoeren van onderzoek. De Life Cycle beschrijft alle stappen die in een onderzoeksproject worden genomen met de bijbehorende data management-taken.

Ook de FAIR Principles zijn opgesteld ten behoeve van goed data management en data stewardship. Ze stellen dat onderzoeksdata Findable, Accessible, Interoperable en Reusable (vindbaar, toegankelijk, interoperabel en herbruikbaar) moeten zijn, zowel voor mensen als voor machines. Door de jaren heen zijn er workflows ontwikkeld om data en metadata stap voor stap FAIR te maken. De huidige workflows zijn echter ontworpen om te worden uitgevoerd nadat onderzoeksprojecten al zijn uitgevoerd en data zijn verzameld, in plaats van gedurende het verloop van een onderzoeksproject. Het in dit proefschrift beschreven onderzoek was erop gericht de FAIRificatie-stappen (de stappen om data en metadata meer Findable, Accessible, Interoperable, and Reusable te maken) op te kunnen nemen in de Research Data Life Cycle. Dit om ervoor te zorgen dat data FAIR worden gemaakt gedurende het onderzoeksproces, in plaats van na het voltooien van het project. We onderscheiden hierbij drie onderzoekslijnen, die in de drie delen van dit proefschrift aan de orde komen. Deze delen zijn hieronder samengevat.

Deel I. De huidige staat van FAIR

De FAIR Data Principles zijn snel overgenomen door veel onderzoeksinstituten en subsidieverstrekkers over de hele wereld. Er is echter weinig bekend over de kennis, percepties en inspanningen van individuele klinische onderzoekers en onderzoeksondersteuners (zoals data managers en data stewards) met betrekking tot data FAIRificatie.

In Hoofdstuk 2 hebben we daarom het bewustzijn en de houding van klinische onderzoekers en onderzoeksondersteuners ten aanzien van data FAIRificatie beoordeeld. We hebben hiertoe een vragenlijst verspreid onder onderzoekers en ondersteunend personeel in zes Nederlandse Universitair Medische Centra en gebruikers van een Electronic Data Capture-platform. We ontdekten dat 62,8% van de onderzoekers en 81,0% van het ondersteunend personeel momenteel op zijn minst enige moeite doen om *enig* aspect van FAIR te bereiken (d.w.z. Findability, Accessibility, Interoperability of Reusability). Respectievelijk 11,0% en 23,8% behandelen alle FAIR-aspecten. 94,7% van de onderzoekers is zich ervan bewust dat het FAIR zijn van onderzoeksdata nuttig kan zijn voor anderen en 89,3% is, met de juiste middelen en ondersteuning, bereid om onderzoeksdata FAIR te maken.

In Hoofdstuk 3 hebben we de data van de vragenlijst gebruikt om inzicht te krijgen in het begrip dat klinische onderzoekers hebben van de FAIR Principles en hun ervaring met data FAIRificatie. De meeste onderzoekers bleken zich niet bewust te zijn van de nadruk die de Principles leggen op leesbaarheid van metadata en data voor zowel mensen als machines, aangezien hun FAIRificatie-inspanningen voornamelijk gericht waren

op het realiseren van leesbaarheid voor mensen (93,9%), in plaats van leesbaarheid voor machines (31,2%).

Deel II. NLP en FAIR

Veel van de data in Elektronisch Patiënten Dossiers (EPDs) worden opgeslagen als ongestructureerde vrije tekst, omdat clinici vaak hun bevindingen noteren in notities. Deze notities kunnen nuttig zijn voor klinisch onderzoek, maar kunnen niet gemakkelijk worden geïnterpreteerd door een machine. Natural Language Processing (NLP) algoritmen kunnen vrije tekst interpreteerbaar maken voor machines door tekstfragmenten te koppelen aan concepten in een ontologie, dat wil zeggen formele specificaties van concepten en relaties in een domein.

In Hoofdstuk 4 hebben we de huidige methoden besproken die worden gebruikt voor het ontwikkelen en evalueren van NLP-algoritmen die klinische tekstfragmenten koppelen aan ontologieconcepten. We hebben een hoge heterogeniteit geconstateerd in de wijze van rapportage van de ontwikkeling en evaluatie van deze algoritmen. Om de evaluatie van algoritmen te standaardiseren en de heterogeniteit tussen onderzoeken te verminderen, hebben we een lijst met zestien aanbevelingen voor toekomstige onderzoeken ontwikkeld die kunnen worden gebruikt in combinatie met het gebruik van een generieke rapportagestandaard.

In Hoofdstuk 5 hebben we een NLP-toepassing ontwikkeld en geëvalueerd met generieke algoritmen voor de detectie van concepten en hun onderlinge relaties in vrije tekst met mogelijk spelfouten. We hebben de toepassing geëvalueerd door voortgangsnotities van oncologiepatiënten te annoteren. De evaluatieresultaten laten zien dat onze applicatie oncologische concepten en relaties met hoge precisie kan detecteren. Deze concepten en relaties kunnen gebruikt worden voor het annoteren van klinische notities, en kunnen dus de noodzaak voor handmatige screening van dossiers aanzienlijk verminderen, wat tijd bespaart voor clinici en onderzoekers.

Deel III. “FAIR by design”

Bestaande FAIRificatie-workflows worden meestal *post hoc* uitgevoerd: nadat het onderzoeksproject is uitgevoerd en de data zijn verzameld, in plaats van gedurende het verloop van een onderzoeksproject. Onderzoekers hebben baat bij een *de-novo*-aanpak, waarbij data automatisch en in realtime FAIR worden gemaakt wanneer deze verzameld worden.

In Hoofdstuk 6 presenteren we een workflow voor *de-novo* FAIRificatie: een workflow waarbij FAIRificatie-stappen opgenomen zijn in het proces van het opzetten en verzamelen van data voor een registratie of onderzoeksproject. Dit maakt geautomatiseerde, realtime FAIRificatie mogelijk, zonder tussenkomst van data management of data entry personeel. De workflow is toegepast op een registratie voor vasculaire anomalieën en kan voor een groot deel worden hergebruikt door andere onderzoeksprojecten.

In Hoofdstuk 7 beschrijven we de implementatie en evaluatie van de workflow van Hoofdstuk 6 in een Electronic Data Capture (EDC) systeem, de plaats waar medische on-

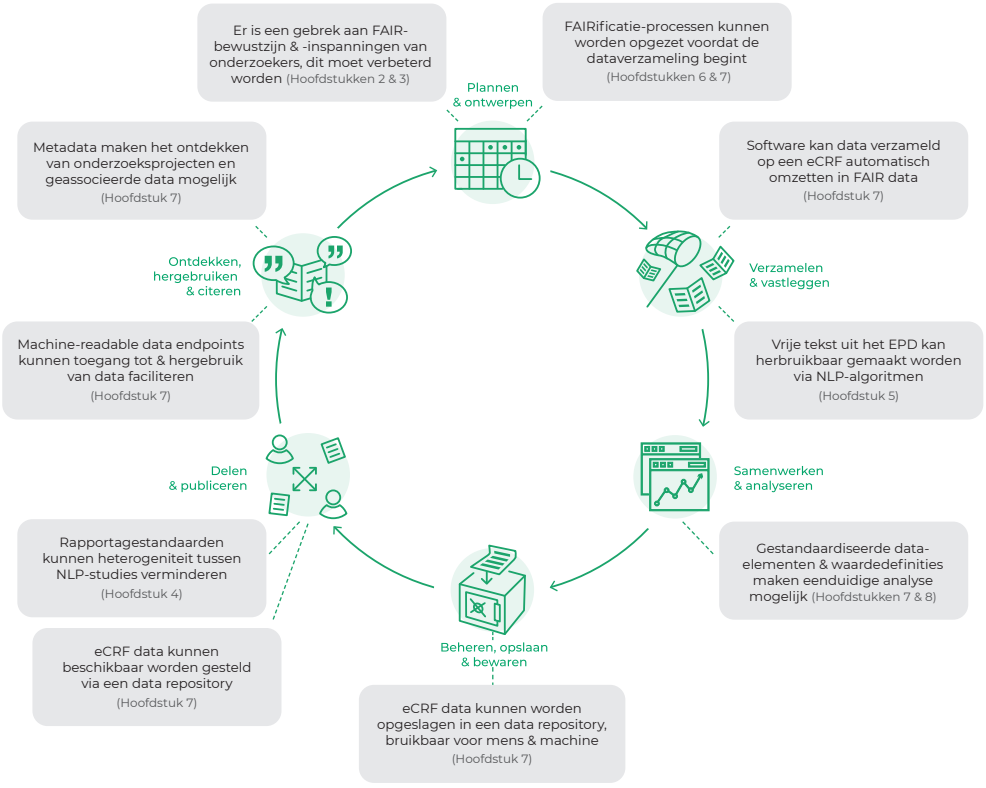
derzoeksdata vaak worden verzameld en opgeslagen via electronic Case Report Forms (eCRF's). Onze implementatie zorgt ervoor dat eCRF-data die in een EDC-systeem zijn ingevoerd, kunnen worden omgezet in machineleesbare, FAIR-data met behulp van een semantisch datamodel (een canonieke representatie van de data, gebaseerd op ontologieconcepten en semantisch-webstandaarden) en mappings van het model naar vragen op het eCRF. De toepassing ervan in de registratie voor vasculaire anomalieën en de evaluatieresultaten laten zien dat de methode kan worden gebruikt om klinische onderzoeksdata FAIR te maken wanneer ze worden ingevoerd in een eCRF, zonder tussenkomst van data management en data entry personeel.

In Hoofdstuk 8 beschrijven we het proces van het omzetten van de International Society for the Study of Vascular Anomalies (ISSVA) classificatie, een classificatie voor vasculaire anomalieën die specialisten in staat stelt diagnoses eenduidig te classificeren, in een ontologie. De classificatie was alleen beschikbaar in een formaat dat door mensen te lezen was, maar is nu machineleesbaar en interoperabel gemaakt en bevat nu verwijzingen naar bestaande ontologieën. Wij verwachten dat de ontologie door het gebruik van persistent identifiers en eenduidige definities de interoperabiliteit tussen klinische studies en registraties zal vergroten en daarom zal bijdragen aan "FAIRer" onderzoek naar vasculaire anomalieën.

Conclusie

Hoofdstuk 9 bevat de algemene discussie van het werk beschreven in dit proefschrift. De conclusies die in dit proefschrift worden getrokken, zijn samengevat in Figuur 2.

De FAIR Principles krijgen steeds meer tractie. Veel onderzoekers zijn momenteel echter niet op de hoogte van de (betekenis van de) FAIR Principles of hoe ze deze in hun werk kunnen toepassen. Het werk beschreven in dit proefschrift kwantificeert het gebrek aan FAIR-bewustzijn van klinisch onderzoekers en onderzoeksondersteunend personeel en biedt een FAIRificatie-workflow met tooling die is opgenomen in de huidige manier van werken van onderzoekers, de Research Data Life Cycle. Workflows en tools dragen bij aan het schaalbaar maken van data FAIRificatie. Gebruiksvriendelijke tools die zijn geïntegreerd in de software die door onderzoekers wordt gebruikt zijn hierin cruciaal, omdat ze geautomatiseerde FAIRificatie van data gedurende het verloop van een onderzoeksproject vergemakkelijken en het grootste deel van het werk van onderzoekers uit handen nemen. Om verdere schaalbaarheid mogelijk te maken moeten beleidsmakers, subsidieverstrekkers en onderzoeksinstituten samenwerken om standaarden, methoden, ondersteuning, tools en financiering te bieden aan de onderzoeksgemeenschap, waardoor FAIRificatie van onderzoeksdata een gezamenlijke missie wordt. Uiteindelijk baant dit de weg voor een toekomst waarin verzamelde data zoveel mogelijk waarde toevoegen aan de patiëntenzorg.



Figuur 2: Samenvatting van de belangrijkste bevindingen en conclusies, gelinkt aan de Research Data Life Cycle

FAIR: Findable, Accessible, Interoperable en Reusable, NLP: Natural Language Processing, eCRF: electronic Case Report Form, EPD: Electronisch Patiënten Dossier

Curriculum vitae

Martijn Gerard Kersloot was born in Amsterdam, the Netherlands, in 1996 at the VU University Medical Center (VUmc, now part of Amsterdam UMC). He grew up with his parents in Rijsenhout. After completing his pre-university education at the Kaj Munk College in Hoofddorp (2014), he started studying Medical Information Sciences at the University of Amsterdam and moved to Amsterdam.

During the first year of his bachelor's studies (2015) he started working at Castor, a health-tech startup that accelerates the medical research process with user-friendly technology. In the last year of his bachelor's studies, Martijn visited the University of Victoria in Victoria, BC, Canada as a co-op student and wrote his thesis under the supervision of dr. Francis Lau. After obtaining his bachelor's degree in 2017, he started a pre-PhD trajectory, a combination of the Medical Informatics Master's program and a PhD program, at the Department of Medical Informatics at the Academic Medical Center (AMC, now part of Amsterdam UMC) in collaboration with Castor. Between 2017 and 2021 he performed the research described in this thesis under the supervision of prof. dr. Ameen Abu-Hanna, dr. ir. Ronald Cornet, and dr. Derk Arts. After graduating cum laude in 2019, Martijn started working full-time on his PhD. As part of his PhD research, he spent three months abroad at The Stanford Center for Biomedical Informatics Research (BMIR), Stanford, CA, United States, and performed research under the supervision of prof. dr. Mark Musen. Next to his PhD, Martijn was a board member of Jong Amsterdam UMC – a platform connecting over 3000 young Amsterdam UMC colleagues through social and educational events.

Martijn is currently living in Aalsmeer and combines 'the best of both worlds' (business and academia) as a Product Owner at Castor and postdoctoral researcher at the Department of Medical Informatics in Amsterdam UMC.

Portfolio

PhD candidate:	Martijn G. Kersloot
Period:	September 2017 to December 2021
Supervisors:	Prof. dr. Ameen Abu-Hanna
	Dr. ir. Ronald Cornet
Co-supervisor:	Dr. Derk L. Arts

PhD training	Year	ECTS
General courses		
The AMC World of Science – AMC, Amsterdam	2017	0.7
Project Management – AMC, Amsterdam	2019	0.6
Specific courses		
Introduction to Systematic Review and Meta-Analysis – Johns Hopkins University, Coursera	2017	1.3
SNOMED CT Implementation Course – IHTSDO (online)	2017 - 2018	3.6
Clinical Epidemiology: Systematic Reviews – AMC, Amsterdam	2018	0.7
Clinical Epidemiology: Evaluation of Medical Tests – AMC, Amsterdam	2018	0.9
Clinical Epidemiology: Observational Epidemiology – AMC, Amsterdam	2018	0.6
Clinical Epidemiology: Randomized Clinical Trials – AMC, Amsterdam	2019	0.6
Modeling Biomedical Systems: Ontology, Terminology, Problem Solving – Stanford University, US	2020	0.6
ODM Implementation – CDISC (online)	2021	1.4
CDASH Implementation – CDISC (online)	2021	1.4
Seminars, workshops and master classes		
GO-FAIR Metadata4Machines Workshop – Leiden	2018	0.5
GO-FAIR FAIR Funders meeting – Leiden	2019	0.3
BMI Tuesday Talks – Stanford, US	2020	0.5
BMIR Research Colloquium – Stanford, US	2020	0.3
ELIXIR Interoperability Platform Meeting – online	2020	0.6
EJP CDE Semantic Model Hackathon – online	2020	0.4
How to work and write from home for early career researchers – online	2020	0.1

PhD training (continued)	Year	ECTS
Presentations		
Poster: "Real-time FAIRification of rare disease patient registry data" – DTL Communities @ Work conference (Utrecht)	2018	0.5
Software demo: "Real-time FAIRification of rare disease patient registry data" – SWAT4(HC)LS (Antwerp, Belgium)	2018	0.5
Oral: "The future of data standardization in medical research: FHIR & FAIR" – Webinar (online)	2019	0.5
Poster: "Real-time FAIRification of rare disease patient registry data" – HIMSS19 AMDIS/HIMSS Physicians Executive Symposium (Orlando, US)	2019	0.5
Oral: "FAIRification at the source: Transforming 'raw' eCRF data into machine-readable data" – EJP-RD CDE Semantic Model Hackathon (online)	2020	0.5
Oral: "A FAIRer Registry: Example of the Registry of Vascular Anomalies" – EJP RD General Assembly (online)	2020	0.5
Oral: "Applying the FAIR Data principles to a Rare Disease registry: a case study of the VASCA registry" – BioSB (online)	2020	0.5
Oral: "Castor's aanpak voor het FAIR maken van onderzoeksdata 'aan de bron'" – Webinar (online)	2021	0.5
Oral: "FAIRification efforts of clinical researchers: the current state of affairs" – EFMI STC (online)	2021	0.5
Oral: Promovendidag – Breukelen; Amsterdam; online	2018 - 2021	1.5
Conferences		
Medisch Informatica Congres (MIC) – Veldhoven	2017	0.5
Open Science Conference – Berlin, Germany	2018	0.5
DTL Communities @ Work – Utrecht	2018	0.25
SWAT4(HC)LS – Antwerp, Belgium	2018	0.75
HIMSS19 & Physicians' Executive Symposium – Orlando, US	2019	1.0
HL7 FHIR Dev Days – Amsterdam	2017-2019	2.25
Bioinformatics & Systems Biology conference (BioSB) 2020 – Online	2020	0.5
EFMI - Special Topic Conference (STC) – Online	2021	0.75

PhD training (continued)	Year	ECTS
Other		
Organisation Promovendidag: "KIK's Choice Awards"	2020 - 2021	1.0
Board member Jong Amsterdam UMC	2020 - 2021	1.0
Developing and updating Amsterdam Public Health Quality Handbook	2020 - 2021	0.5

Teaching	Year	ECTS
Tutoring, mentoring		
Project supervision: Uitwisseling van gezondheidsgegevens en -kennis – Bachelor Medische Informatiekunde	2021	0.5
Supervising		
1-month master Medical Informatics internship – Inez: "The use of HL7 FHIR to semantically model clinical research data"	2019	0.5
2-month master Medical Informatics internship – Sander: "Determining the variation in the modeling of electronic Case Report Form variables"	2020	1.0
5-month bachelor Medische Informatiekunde internship – Fauve: "Adoptie en kwaliteit van Common Data Elements in Nederland"	2021	2.0
Other		
Workshop: "Preparing data for machines: make data linkable & host FAIR data" – International Summer School on Rare Disease Registries and FAIRification of Data (online)	2020	0.5
Course: "Finding and capturing data" – Helis FAIR data stewardship course (online)	2021	0.5
Workshop: "Making Data Machine-readable & Hosting FAIR data: an example of a registry becoming FAIR" – International Summer School on Rare Disease Registries and FAIRification of Data (online)	2021	0.5
Workshop: "FAIR Game" – International Summer School on Rare Disease Registries and FAIRification of Data (online)	2021	0.5

List of publications

Publications in this thesis

1 FAIRification efforts of clinical researchers: the current state of affairs 2021
Kersloot MG, van Damme P, Abu-Hanna A, Cornet R, Arts DL
Studies in Health Technology and Informatics 287, 35-39. doi: 10.3233/SHTI210807

2 Data FAIRification in clinical research: perceptions and behavior of researchers and research support staff 2021
Kersloot MG, Abu-Hanna A, Cornet R, Arts DL
Submitted

3 The International Society for the Study of Vascular Anomalies (ISSVA) Ontology 2021
van Damme P *, **Kersloot MG***, dos Santos Vieira B, Schultze Kool L, Cornet R
Submitted

4 De-novo FAIRification via an Electronic Data Capture system by automated transformation of filled electronic Case Report Forms into machine-readable data 2021
Kersloot MG, Annika Jacobsen A, Groenen KHJ, dos Santos Vieira B, Kaliyaperumal R, Abu-Hanna A, Cornet R, 't Hoen PAC, Roos M, Schultze Kool L, Arts DL
Journal of Biomedical Semantics 122, 103897 (2021). doi: 10.1016/j.jbi.2021.103897

5 The de novo FAIRification process of a registry for vascular anomalies 2021
Groenen KHJ *, Jacobsen A *, **Kersloot MG**, dos Santos Vieira B, van Enckevort E, Kaliyaperumal R, Arts DL, 't Hoen PAC, Cornet R, Roos M, Schultze Kool L
Orphanet Journal of Rare Diseases 16, 376 (2021). doi: 10.1186/s13023-021-02004-y

6 Natural language processing algorithms for mapping clinical text fragments onto ontology concepts: a systematic review and recommendations for future studies 2020
Kersloot MG, Van Putten FJP, Abu-Hanna A, Cornet R, Arts DL
Journal of Biomedical Semantics 11, 14 (2020). doi: 10.1186/s13326-020-00231-z

7 Automated SNOMED CT concept and attribute relationship detection through a web-based implementation of cTAKES 2019
Kersloot MG, Lau F, Abu-Hanna A, Arts DL, Cornet R
Journal of Biomedical Semantics 10, 14 (2019). doi: 10.1186/s13326-019-0207-3

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Other publications

8 Applying the FAIR Data Principles to the Registry of Vascular Anomalies (VASCA) 2020
Dos Santos Vieira B, Groenen K, 't Hoen PAC, Jacobsen A, Roos M, Kaliyaperumal R, **Kersloot MG**, Cornet R, Schultze Kool L
Studies in Health Technology and Informatics 271, 115-116 (2020). doi: 10.3233/SHTI200085

9 The Need of Industry to Go FAIR 2020
van Vlijmen H, Mons A, Waalkens A, Franke W, Baak A, Ruiter G, Kirkpatrick C, Bonino da Silva Santos LO, Meerman V, Jellema R, Arts DL, **Kersloot MG**, Knijnenburg SL, Lusher S, Verbeeck R, Neefs J
Data Intelligence 2 (1-2), 276-284 (2020). doi: 10.1162/dint_a_00050

10 FAIR Principles: Interpretations and Implementation Considerations 2020
Jacobsen A, de Miranda Azevedo R, Juty N, Batista D, Coles S, Cornet R, Courtot M, Crosas M, Dumontier M, Evelo CT, Goble C, Guizzardi G, Hansen KK, Hasnain A, Hettne K, Heringa K, Hooft RWW, Imming M, Jeffery KG, Kaliyaperumal R, **Kersloot MG**, Kirkpatrick CR, Kuhn T, Labastida I, Magagna B, McQuilton P, Meyers N, Montesanti A, van Reisen M, Rocca-Serra P, Pergl R, Sansone S, Bonino da Silva Santos LO, Schneider J, Strawn G, Thompson M, Waagmeester A, Weigel T, Wilkinson MD, Willighagen EL, Wittenburg P, Roos M, Mons B, Schultes E
Data Intelligence 2 (1-2), 10-29 (2020). doi: 10.1162/dint_r_00024

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The FAIR Principles, stating that research data and metadata should be Findable, Accessible, Interoperable, and Reusable for both humans and machines, are experiencing a vast uptake in acceptance and implementation by researchers, research institutes, funders, and government bodies. However, many researchers are currently unaware of the FAIR Principles, their implications, or how they can be applied to their research. Furthermore, existing workflows to make data FAIR are designed to be executed after research projects have been conducted and data have been collected, rather than throughout the life cycle of research projects.

The work presented in this thesis provides insight into researchers' and research support staff's knowledge and perspectives on the implementation of the FAIR Principles in practice (Part I), determines the role of Natural Language Processing in making data more FAIR (Part II), and develops a process for making data FAIR from the beginning of a research project and at the source (Part III). The presented work contributes to a future in which FAIR research data are the default, and the process of making data FAIR is optimized, to add maximum value to patient care with minimal cost, effort, and delay.