Agenda and minutes Data Stewards Interest Group - Meeting 41

Date: 2 July 2024 **Time:** 13:15 (coffee) - 13:30

(start) - 15:00 CEST

Location: virtual **Chair**: Mijke Jetten

Virtual via Zoom:

https://us02web.zoom.us/j/8573783868?pwd=bWU2ZWdTY2ZjR1hBY0FOeDVLQSt4dz0

9 Meeting ID: 857 378 3868 Passcode: 949224

Attendees: See page 2

Register here

Agenda and minutes of previous DSIG meeting

Time	Topic	Comments/results	Owner
13:15	Informal start: joint coffee		All
13:30	Formal start and introduction round		Mijke, All
13:40	2. New and Newsworthy	Share your successes with the group; Share insights from workshops and seminars you have visited	Mijke, All
13:55	3. ICYMI	RDM news-bits, in case you missed it	Mijke
14:05	4. Presentation	RDM at Sport Data Valley, the national data infrastructure for sport, exercise and health, in research, education and practice. Its mission is to contribute to a more vital Netherlands with sports and exercise data, and improved top sports performance. The Sport Data Valley DataHub is the place to find and analyse all sports and exercise data in the Netherlands, openly accessible to Dutch sports scientists.	Dennis van Kooij
14:55	5. Closure/any		Mijke



	other business	
15:00	6. IG meeting end/feedback	All

MINUTES

1a. Welcome

- Zoom; try the gallery view
- These notes are for you! Please add comments, +1s, gifs
- Don't forget to provide feedback (see below, Feedback)

1b. Community Participation Guidelines reminder

- Be respectful, honest, inclusive, accommodating, appreciative, and open to learning from everyone else.
- Do not attack, demean, disrupt, harass, or threaten others or encourage such behavior.
- Issues: report them to Mijke.

1c. Roll call

Add your name to the roll call below

Name / affiliation / social media / email

- Fieke Schoots, Health-RI, fieke.schoots@health-ri.nl
- Bert Huizing/University of Groningen-DCC/b.huizing@rug.nl
- Maryam Shabestari/UvA (FNWI) / m.hashemishabestari@uva.nl
- Esther Plomp (TUD) / toothfairy / e.plomp@tudelft.nl
- Joeri van der Velde (UMCG) / k.j.van.der.velde@umcg.nl
- Kristina Hettne / Leiden University Library / k.m.hettne@library.leidenuniv.nl
- Emily Barbas (VU Faculty of Social Science) / e.k.barabas@vu.nl
- Mijke Jetten (Health-RI), mijke.jetten@health-ri.nl
- Anne de Jong
- Jessica Hrudey
- Dennis van Kooij, Sport Data Valley
- Fieke Schoots, fieke.schoots@health-ri.nl

2. New and Newsworthy

Choose a question to answer: Share your successes with the group? Share insights from workshops and seminars you have visited? What do you need from this call? Nice upcoming event to share?



- Esther: as part of the AREN training programme I worked on some presentations/workshops on Open Data:
 - Open Data: Principles and Tools
 - Open Data: Benefits and Challenges
 - o Reusing Open Data
 - o Sharing Open Data
- https://taxila.nl if you want to share your materials, events etc.

materials since we use an internal Teams site for them.

- Health-RI organised an introductory 3 day course for datastewards in the health domain in June. Programme (and soon also the materials) to be found here:
 10.5281/zenodo.11566784 Contact fieke.schoots@health-ri.nl if you want to know more
- At the Centre for Digital Scholarship we recently organised the "CDS Summer Training Week" for Leiden researchers/staff:
 https://www.digitalscholarshipleiden.nl/articles/cds-summer-training-week-2024 Let me (Kristina Hettne, k.m.hettne@library.leidenuniv.nl) know if you are interested in the

3. ICYMI

RDM news-bits, in case you missed it

- <u>Slides</u>
- Join the <u>Slack channel</u> to stay up to date! Suggestion: download the desktop app, which has a notifications option and is much more user friendly than the browser version

4. Presentation & discussion

Links:

- https://info.sportdatavalley.nl/over-sport-data-valley/
- https://info.sportdatavalley.nl/cohort-manager/
- Presentation: 240702_41 SportDataValley.pdf

Notes presentation

- Dennis van Kooij presents Sport Data Valley.
- Building an infrastructure/platform for multi dimensional analysis, mainly elite sports, but broadening quickly to other sports as well
- Collaborating with Movement Alliance (government), to make more impact on society and research level
- Dennis is responsible for developing the platform and the project
- Small team: responsible for infrastructure. We need to do it together, SDV acts as neutral broker
- Collaboration with VU, Delft, Leiden, HvA, RIVM, Kenniscentrum Sport and Movement
- Funding from government to stay neutral, foundation
- Users: research (cohort data), coaches (talented and elites physical and mental well



- being), teachers and students, policymakers in municipalities (help them to make better decisions, as they often lack data) E.g. in which neighborhoods do we need to take extra actions, compare with neighborhoods in other cities / regions?
- In 2023 ... SportGPT to compare cities and neighborhoods with demographic background, as with more data we can make more impact together. Government is pushing the data sharing to have more impact
- SDV builds the infrastructure, a platform to store, collect and analyzing data
- Everyone can create an account, it's a safe space to store data. You decide with whom and when you share your data
- Upload datasets, connections with API and wearables, phones, questionnaires (evidence based, well being, psychological items)
- Analysis, Atlas.ti
- Integration with JupyterHub
- Dashboard functionality
- Data stored in the Netherlands working towards a DATA Hub
- Benefits:
 - One infrastructure
 - Legally and privacy proof
 - Multidisciplinary analysis
 - Unlocking existing data sources
 - Time and cost saving
 - Informed consent via platform
 - Growing collection
 - IA ready
- Examples:
 - Research: People in the Netherlands move and sport too little.
 - Big data research need to use open data but challenging as this is often not possible due to ethical and legal issues
 - Citizen science Rheumatic patients
 - ALO Amsterdam study on complaints and injuries first year students with wearables
 - Sensor on wheel chairs
 - Fitbit AI model to inform user about their health (resting heart rate)
 - Different levels of open data from Deventer
- SDV in education
- SDV is the backbone for sport and movement data in NI, created as a service if you want to use it yourself with your organisation. Front-end can be adjusted, and back-end (plus storage) is what we at SDV take care of together with you.

Questions & discussion points

- **Jessica**: For us as FGB in the VU to be ok with storing data on SDV we'll need to sign a processing agreement with you guys. Is that possible?
 - **Dennis**: Yes, we did that with many partners already, with a single sign on.
- **Jessica**: What kind of metadata standards for documenting at the project and data level are used in sports sciences? I've never had any luck finding that info. Thanks!
- Dennis: park it for later to have a discussion about
 Dennis: discussion about ethical issues block research
- **Dennis**: aimed at creating this data hub, combining data that is available. Issues with



sharing data between commercial partners and professional organisations Question is: do we have a standard? Not yet, any one a suggestion? We want to make sure that the data is stored together (standard metadata) but also involving data from citizens.

Mijke: Currently in Health-RI we are starting the process. We have different types of data and different domains. The challenge isn't at the core of the metadata. DCAT AP NL is basic metadata, mandatory. At European level, there is an extension for the health and other domains. Within Health-RI we are trying to give the domains the mandate to decide upon a first version of standard(s). You need technical people to model that. How do we make the oncology community responsible for deciding upon the standards? We are doing this with EZK, VWS and OCW. Who could be the authoritative body?
DCAT-AP NL:

https://www.geonovum.nl/over-geonovum/actueel/consultatie-nederlands-profiel-op-dcat-ap-30

Health DCAT: https://healthdcat-ap.github.io/

GeoDCAT: https://semiceu.github.io/GeoDCAT-AP/drafts/latest/

(And there are some other ... DCATs)

- o **Dennis**: parties leave it to us, but we can not decide for all the others.
- o In movement data science there are no standards yet. In cohort studies such as Lifelines there is no movement data.
- Kristina: suggest to start with the core and then extend. GO FAIR metadata 4
 machines workshops. Get community together to find common standards. If there
 is funding, you could see if this is a way to go for you. You can contact the GO
 FAIR Foundation via learn@gofair.foundation
- Jessica: For the questionnaires there's DDI, but I'm not sure for wearables and kinematic data. https://ddialliance.org/learn/why-use-ddi
 Mijke: There is BioPortal as well, not sure if there is sport data in it: Welcome to

the NCBO BioPortal | NCBO BioPortalNCBO BioPortal Mijke: And FAIRsharing: https://fairsharing.org/

- Joeri: a lot of people like to create standards (or rather specifications) but people tend to forget why they create new data model. It is important that a model has a purpose. Can be simple, to discover data, harmonising within a research study, but also very detailed. Like a pyramid. "All models are wrong but some are useful"
- Dennis: who is setting it up and who is the owner?
- Besides user dashboard there is a researchers' space
- Connection with Health-RI:
 - We can take you along with the metadata standards (Health DCAT) and how to make the domains responsible

5. Closure/AOB

- Upcoming meetings:
 - Link to agenda & registration form will be shared via the DSIG and TDCC websites and usual channels (LinkedIn, Slack, Twitter, mailing lists etc.)
- Do you also want to chair one of the DSIG meetings? Have ideas about a topic? Contact



Mijke Jetten (mijke.jetten@health-ri.nl)

• Don't forget to provide feedback (below)

6. Feedback

KEEP: What worked well?

•

ADD: What new ideas do you have?

•

LESS: What didn't work?

•

MORE: What worked well and should we do even more?

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