Back to the kitchen table: an intimate brainstorming meeting about FAIR and "what needs to happen next?"

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Introduction

The meeting almost kept its original name. It was planned as a "kitchen table" gathering, a deliberate callback to the setting where so much of the Duchenne community's work has begun. But June 25th, 2026, turned out to be one of the hottest days of the year in Amsterdam, and the group gathered around a garden table instead. The name changed but the spirit behind it did not.

That spirit belongs, above all, to Elizabeth Vroom, Chair of World Duchenne Organization. It was Elizabeth who invited this small circle of FAIR and Duchenne experts to her home, and in her own words, for *"An intimate brainstorming session rather than a conference"*. Most of those at the table had been there in March 2019, at the very first meeting on data sharing for Duchenne, also in Amsterdam. Her invitation is worth quoting at length, because it sets the tone for everything that follows:

"As you may know, many successful Duchenne projects started around our kitchen table. Just to mention a few: the Duchenne Parent Project itself, the Emergency Program and the World Duchenne Awareness Day, now the only Awareness Day for rare diseases officially supported by the United Nations, the European Parliament and the late Pope. All with the principle of 'think big, start small'. Thanks to Barend Mons we started with the Duchenne FAIR Data Declaration which was the kickstart of many activities related to FAIR data.

Now is the moment to make sure that the outcomes of these activities are implemented. A moment to go back to the kitchen table with the same spirit and ask the most important question: what needs to happen next?"

Around the garden table was Barend Mons, the retired but very much active "godfather" of FAIR, fondly *summoned* for the occasion. Peter-Bram 't Hoen, professor of Bioinformatics at Radboudumc and a longtime Open Science and FAIR ambassador. Marco Roos, Biosemantics Group Lead at Leiden University Medical Center (LUMC), who led the original FAIRification workflow. Sander van Boom and Rick Overkleeft, guest researchers at LUMC and co-founders of 4MedBox, the latest hands-on, inventive FAIR enthusiasts. Anneliene Jonker, Director of the Duchenne Parent Project (DPP), representing FAIR's flagship success, the Duchenne Data Platform (DDP). Arjen Bergsma, DPP board member, representative of the Dutch Research Council (NWO), and Duchenne's most loyal FAIR stakeholder. Nawel Lalout, PhD candidate at Radboudumc and former DDP FAIR project manager, now researching the human barriers to FAIR adoption firsthand. Then, there was Justus Kuijer, an adult living with Duchenne muscular dystrophy, and co-host as Elizabeth's son. He sat right at the table in his wheelchair, being part of every discussion, a quiet reminder of exactly who this FAIR work is for. With Justus joining the group, the gap between FAIR's proof-of-concept and its real-world adoption stopped being an abstract, academic problem.

It was in that relaxed setting that the group set out to answer Elizabeth's question “What needs to happen next?” and the harder one underneath it: “If FAIR works, what's still holding the rare disease domain and in particular the Duchenne community back?”. To help ground that conversation, participants received beforehand a discussion guide, drawing on two sources: an interview with Barend Mons (CCC, December 2024)[1] and Lalout et al.[2] 2025 account of the DDP's own FAIR journey, published in the *Journal of Neuromuscular Diseases*. Together, these gave the group a shared starting point. What follows in this meeting report traces the gap between vision and real-world implementation, it lists some of the barriers that have kept FAIR adoption from scaling up. It also looks at who is still missing from the table, and what more might be possible if they joined. It closes with the themes that emerged on the day, and a shared vision for what FAIR adoption in the Duchenne community could look like by 2030.

Photo: *FAIR meeting around the ‘garden’ table due to exceptionally warm weather; clockwise starting with Justus, Rick, Anneliene, Elizabeth, Barend, Nawel, Arjen, Sander, Marco and Peter-Bram.*

Setting the scene: two perspectives on the same problem

The macro view: Barend Mons

Mons notes the FAIR article has been cited well over 20.000 times, spread over 400 disciples and it is endorsed in policy statements from the G7 (G7, 2017) and G20 (G20, 2016). He argues FAIR is now at that convergence point, propelled further by the rise of Large Language Models (LLMs), for which FAIR data is not just useful but essential. He reframes FAIR as data being 'Fully AI Ready.'

Mons was equally candid about FAIR's downside as a hype term: wide citation and political endorsement have not always translated into careful implementation, and too often organisations adopt FAIR's language without doing the underlying work, a pattern the Pistoia Alliance has termed 'FAIR theatre.' Even where FAIR is genuinely and rigorously applied, as the DDP's own experience shows, Reusability does not automatically produce actual reuse. In Mons' assessment, the missing ingredient has mainly been ready-to-use infrastructure for 'data visiting': the technical means by which others can actually query and reuse FAIR data without moving it. That infrastructure gap is why GO FAIR co-founded the LIFES Institute: as he put it, 'FAIR without infra is still lame.'

The ground view: Lalout et al. (2025), Duchenne Data Platform (DDP)

Since 2020, DDP has undergone full FAIRification, achieving a score of 20/22 on the FAIR Evaluator and demonstrating federated, privacy-preserving analyses across five independent neuromuscular disease registries with mock data. The 10-step process addressed legal, ethical, technical, financial, and governance dimensions. Yet despite this proof of concept, the FAIR team's invitation to other Duchenne and Becker muscular dystrophy (DMD/BMD) registries worldwide to join the FAIR effort has not resulted in a single new participating project. Hesitancy, the authors conclude, is driven not by technical obstacles but by human-related barriers: conceptual, implementation-related, and benefit-related.

Where the two perspectives diverge: Identified gaps

Mons' interview and the paper by Lalout et al. reveal six critical gaps between the vision for FAIR and the reality of its implementation.

Gap	What is missing and what the DDP experience adds
1. Awareness vs action	Mons notes the FAIR article has been cited well over 20.000 times, spread over 400 disciples and it is endorsed in policy statements from the G7 (G7, 2017) and G20 (G20, 2016). Yet Lalout et al. report that not a single DMD/BMD registry has joined the DDP's FAIR network despite active invitation. The gap between knowing and doing is the defining problem.
2. No forcing function	Mons draws on TCP/IP and GSM to argue convergence requires a catalyst. But in rare disease research, there is (in Mons' opinion) no equivalent of the telecoms industry. The DDP's multidisciplinary team, coordinated by a FAIR project manager, acted as a local forcing function but this model has not spread.
3. Misconceptions as the primary barrier	Lalout et al. document three classes of barriers that block adoption: conceptual (e.g. machine-actionability is optional), implementation-related (e.g. FAIRification costs too much), and benefit-related (e.g. FAIR only benefits others). Mons has identified a lot of misconceptions in the past that overlap with those identified in practice.

4. The guidance vacuum	At project inception, the DDP team found 'very little guidance for how to undertake a FAIR initiative.' Their 10-step plan addressing legal, ethical, privacy, technical, and maintenance dimensions, had to be invented.
5. Privacy as a perceived barrier	A dominant misconception is that FAIR means open data. The DDP's 'data visiting' model, where data never leaves its registry and only pre-approved, ethics-reviewed queries are executed directly addresses this. Although federated analysis offers many benefits with respect to privacy, it comes with its own caveats and challenges. Governance and ethics review built into each query can introduce additional layers of processing and paperwork that communities don't always anticipate. Yet this solution remains unknown to most communities.
6. AI-readiness in practice	Mons reframes FAIR as being 'Fully AI Ready', a powerful concept. Lalout et al. confirm this in practice: FAIRification forces semantic clarification that improves data quality and makes it usable for both logic-based and statistical AI. But what does this mean for a registry with no data engineer or ontologist?

If FAIR could work, why isn't everyone implementing it?

This is where the mood in the garden shifted from celebration to reckoning.

Seven years after the Duchenne FAIR Declaration, and five years into a working FAIRification project, adoption beyond the DDP itself remains essentially flat. The challenge, participants agreed, is no longer *whether* FAIR is possible as it was demonstrated but *why* it hasn't spread.

Several threads emerged as to why:

- **Simply put, "It takes a village":** This progress was described almost affectionately as a decade of frustration that nonetheless kept moving: "we're getting there," "keep on moving," "the journey continues" were phrases used more than once, alongside a shared acknowledgment that persistence, not a single breakthrough, is what has carried FAIR this far. One participant went further and named the operating principle directly: *it takes a village.* Give up, and the community simply won't get there.
- **A word problem, not just a technology problem:** More than one participant flagged that "FAIR" itself may now be a liability as a term. A hype word that invites eyerolling rather than curiosity, and that the strongest counter to this may simply be a long-form, human narrative of what FAIR has actually delivered over ten years, told through the people who built it.
- **Open-data misconception:** By far the most repeated barrier was the belief that FAIR equals open data. It doesn't. The DDP's "data visiting" model, where data never leaves its home registry and only pre-approved, ethics-reviewed queries are executed, was described as "the Holy Grail" for data sharing yet, remains poorly understood outside a small circle.
- **Impatience with culture change:** One participant admitted the field is "probably too impatient to change the culture", expecting behavioural and institutional change to move at the speed of a technical pilot, when it doesn't.
- **Academic incentive problem:** Another participant was candid that his own greatest disappointment has been with academia itself: funded projects create time pressure, and when the funding ends, so does the project. Momentum gets built and then deliberately switched off.
- **Fear dressed up as caution:** Several participants converged on the idea that what looks like institutional caution is often plain fear of new technology and loss of control. As one participant memorably put it, people would rather the river stay the same even once it has dried up, because moving the whole village elsewhere takes a genuinely radical mindset.

- **Doctors, hierarchy, and access:** More than one participant pointed to clinical hierarchy as a quiet but powerful bottleneck: access to data still depends heavily on *who* you are, not on a consistent policy. It was noted that unfortunately “Access conditions are not the same for everyone”.
- **Scientists are not natural marketers:** A recurring, half-joking, half-serious observation was that scientists are simply bad at selling their own success: "the worst marketeers," in one participant's words. It means a working proof of concept can sit quietly unnoticed by exactly the people who should be adopting it.

Who is missing from the FAIR discussions?

This question produced one of the liveliest exchanges of the day. Suggested additions to the table included:

- **Patients and patient organisations**, not as subjects of research but as informed partners and executers.
- **Social scientists,** to explain what people actually want before technologists build for them.
- **Private and angel investors,** to understand these efforts and their real-world impact.
- **Pharmaceutical partners,** ahead on FAIR implementation in some cases.
- **Commercial organisations such** as the big IT companies with expertise and bandwidth to move from professorware to commercial- and regulatory-grade solutions.
- **Policy makers,** who need to be actively trained, not just briefed.
- **Legal advisors,** who do not understand the concepts and overinterpret GDPR.
- **Hospital IT personnel,** who are concerned about security and do not trust open-source solutions
- **Journalists,** to translate the story for a wider public.

One participant offered an honest observation, “we don't know who we're missing, and that not-knowing is itself the missed opportunity”. Barend added a personal, almost self-deprecating illustration that even the "godfather of FAIR" once tried to explain the value of vaccines to his own grandson in the simplest terms he could manage and still lost the attention of a whole school-class full of five-year-olds. If FAIR's own architect can't always land the message with a five-year-old, the group agreed, simplifying the pitch for very different audiences is harder than it looks and worth taking seriously.

What emerged from the ‘garden’ table?

Five themes emerged throughout the day.

On **awareness versus action**, the group kept circling back to incentives as the real game-changer: technology should come last, not first. The real question is what people actually need, and social scientists may understand that better than technologists do. One sharper point was made: funders should simply refuse to fund anything that doesn't publish FAIR data. No exceptions and no excuses.

On the **human barriers** such as misconceptions, leadership gaps, organisational culture, fear of losing control, the group agreed these are the same barriers visible back in 2019, just far better understood now. The DDP's own experience proves the point: what its FAIR team ran into wasn't technical, it was conceptual ("machine-actionability is optional"), implementation-related ("FAIRification costs too much"), and benefit-related ("FAIR only benefits others").

On **what is still missing** for example better guidance, funding, dedicated FAIR project managers, training and education, hands-on support, participants questioned how much of the original vacuum

has actually been filled, versus simply shifted from "no guidance exists" to "guidance exists, but nobody outside the DDP knows it." Concrete signs of that gap closing are starting to appear.
Barend Mons points to Senscience's FAIR² approach as an example of easy-to-use FAIRification infrastructure, and to a striking demonstration of it: a large batch of raw CSV files together with Max van Boom's Master's thesis were processed by an AI agent named Clara, resulting in a peer reviewed publication in Frontiers in Bioinformatics alongside an accompanying Data Portal that was entirely LLM-generated and then peer-reviewed by the authors.

On **scaling**, from five FAIR registries to fifty-five, ideas ranged from the practical (a "hospital starter kit," mandatory data-publishing descriptions, services built around the data) to the structural: bringing to pharmaceutical companies, who several participants noted have already done FAIR well, and building real public–private partnerships because public centres alone, as one participant put it, "can't get it done." It was added that training novice users and ready-made starter kits can also break through scepticism on their own, which could help by proposing the 'coalition of willing' Duchenne players and repositories as a GO FAIR Recognised Expert Community — one that would develop its own recommended FAIR Implementation Profile (FIP) and starter kit.

It was Justus who introduced a new theme that felt like a 'lightbulb moment': **speculative research**. His suggestion was simple: try running *"what if"* scenarios. What if we did this, and then that? Treat FAIR adoption less like a policy rollout and more like gamification, or even a war game: give people a scenario, let them play it out, and see where the pressure points actually are before committing real resources or real patient data. It's an approach borrowed more from design and strategy than from academic research, but that may be exactly its value. It lets registries, funders and clinicians rehearse the hard conversations about data visiting, governance and trust in a low-stakes setting, long before they have to make binding decisions in a high-stakes one. Coming from the one person around the table whose stake in all this is anything but hypothetical, the idea carried particular weight: sometimes the most serious way to solve a problem is to first play it out.

Conclusion

To the question what success could look like for Duchenne by 2030, the group produced a shared answer: federated, privacy-preserving analyses of real patient data across all fifty-five DMD/BMD registries worldwide, not just five. Getting there will take regulation that pulls with adoption rather than against it. What could help is firstly, the incoming European Health Data Space that was named more than once as exactly that kind of push. Secondly, it will take evidence shown back to the patients who gave their data in the first place, so trust is earned rather than assumed. Thirdly, a stick alongside the carrot will be needed, since obligation, not persuasion alone, is what finally moves institutions. Lastly, it will take patience matched with urgency as the drive to keep asking better questions, informed by everything a decade of hard-won progress has already taught this Duchenne community.

The group concluded that none of the above is out of reach. If anything, Elizabeth, Justus and their guests were more convinced than at the start of the meeting that the vision from 2019 was right, the proof now exists, and what remains is simply the work of finishing what was started in Amsterdam seven years ago. The next meeting, participants agreed, shouldn't open by revisiting whether FAIR works as that question is closed. It should open with a simpler one: *what else needs to happen for FAIR data to translate into a faster diagnosis, a new trial, or a treatment for someone living with a rare disease?*

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