Issue 03

SPIDeRR NEWSLETTER

Improving targeted healthcare and disease prevention for patients with rheumatic diseases.



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Project achievements

Video: Why would you want to be a Patient Research Partner?

Patient advisory group, Interview with Péter Mihajlik and Peter Böhm

SPIDeRR on tour: building a web of collaboration

SPIDeRR blog

In this Issue...

The SPIDeRR consortium ('Stratification of Patients using advanced Integrative modelling of data routinely acquired for diagnosing Rheumatic complaints') aims to revolutionize musculoskeletal health with innovative data-based tools to speed up diagnosis and correct treatment.

In this issue, we bring you the latest highlights from the Horizon Europe funded consortium. Below, you can discover the achievements from the SPIDeRR's Work Packages, hear from our Patient Advisory Group and watch a video why people with lived disease experience should join research projects!

And of course we have been out and about: bringing SPIDeRR people and findings out of the lab at conferences and meetings. View the images to see how that looked.

Want to stay up to date with the SPIDeRR consortium and our outcomes? Connect with us on LinkedIn

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Project Achievements

WP3: AI Tools & Modular SPIDeRR

Over the last six months, WP3 has continued working on tools that may help people with joint, muscle or other musculoskeletal symptoms reach the right care earlier. Recruitment is ongoing in several countries to test the Rheumatic? online questionnaire in different settings, including the general population, primary care and rheumatology clinics. We have also expanded dissemination activities to reach more people with musculoskeletal symptoms, including public campaigns such as advertisements in Madrid subway stations.

In parallel, we have continued preparing the basis for the Modular-SPIDeRR prediction models. These models aim to combine information from healthcare records and other tests to estimate which patients may benefit from referral to a rheumatology specialist. To support this work, we have developed a common structure for organising data from different countries and started implementing a shared analysis workflow that different partners can use and adapt when testing the prediction models in different countries. Regarding the Modular SPIDeRR, we expect to move towards a first prototype of the prediction model. This prototype will not yet be a final clinical tool, but it will allow the consortium to test how information from healthcare records and other available data can be combined to estimate which patients may benefit from specialist rheumatology assessment. In the next six months, WP3 will continue recruiting participants for the validation of the Rheumatic? questionnaire across SPIDeRR countries and care settings. We expect to have more complete recruitment figures and first validation results from some of the participating sites. So if you are interested, join us by completing the questionnaire

WP5: Genetics & Multi-Omics Integration

We study if genetic risk scores (PRS) can help doctors make a diagnosis. We used health data and genetic data from clinics in Europe. So far, PRS only adds a small benefit. We are still improving our methods. We will check again and then publish our results. In addition, we study if genetic and clinical data over time can help us understand inflammatory arthritis better. To do this, we are building a secure system to combine data from many European partners. This is almost ready.

While we wait, we used data from the BIO-FLARE study in Newcastle. In this study, patients with rheumatoid arthritis stopped their medicine. Half of them had a flare within 6 months. We studied blood samples over time and found 1,289 molecules linked to flare risk. We also found 13 key molecules that may cause flare. These are linked to immune system processes. We think Joint Modelling could be a suitable method to use as a tool for identifying new causal networks associated with favourable/unfavourable outcomes in early rheumatic disease, with possible implications for its treatment. And we will be investigating this in the coming months!

WP6: Implementation & Clinical Integration

In 2025, the WP6 team finalised the European patient journey maps and five "personas" representing diverse backgrounds to help researchers understand the emotional and practical barriers to diagnosis and appropriate management. This included the publication of a systematic review of patient journeys, a European survey highlighting how health systems and GP "gatekeeper" roles vary by country, and the paper on the development of the personas, which that was published in the latest issue of Eular Rheumatology Open. You can access our personas online on our website.

We also conducted usability testing on the "Rheumatic?" tool in Germany and began integrating it into Swedish primary care to support clinical referral decisions. In Spain, we secured nearly 250 participants for clinical validation through a high-impact metro advertising campaign and are about to start a large study in Primary Care (launched from WP3 but related to outcomes in WP6). During the consortium meeting in December, we started developing a roadmap for the certification of “Rheumatic?” and, potentially, “Modular SPIDeRR”, and made progress on the visualisation and actionability of the results, which we learned should differ depending on where we place the tools.

WP7: Ethics, Legal & Data Governance

This workpackage might sound the most boring but actually is playing a pivotal role in the potential success of SPIDeRR. Data sharing in modern medicine is crucial for advancing research, improving patient care, and developing innovative solutions. But, despite good intentions, legal barriers, slow administrations and financial issues stand in the way. This also raises questions about the broader ethical and societal implications like the patient perspective. Patients who consent to the use of their data for research often do so with the expectation that their contribution will support tangible scientific progress. Thus, if excessive procedural constraints ultimately hinder research, we must ask whether the system designed to protect patients might, paradoxically, be failing them. Our workpackage has gained practical experience and is currently putting out a paper that shares insights and practical help in this area, contributing to improve data sharing, and future patient care.

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Why would you want to be a Patient Research Partner?

Over the last decades more and more researchers have realized that working in academic or clinical silos is not the way to go if you want your research to have an effect on the real world. So it is very common today that researchers from different disciplines and expertise team up within a project. But over the last few years it has become also clear that you also need other types of expertise to really be able to make a change in the way the world works. Think about people with business expertise, knowledge on healthcare system change and also people that have lived experience with a disease or condition, as they will be able to help prioritise what is needed in the real world and ask questions that can be just as difficult and relevant as fellow academics and doctors. But why should people with lived rheumatism experience join research projects and make available their time and expertise? Two of the Patient Research Partners that are helping SPIDeRR researchers give you some answers to that in **this video**

If becoming a full fledged Patient Research Partner feels like a bit too much, do not worry, there are also other, less intensive ways of helping to make research better! Within SPIDeRR one of the easiest ways is to complete an online questionnaire (Rheumatic?) that we are developing as a tool, that in the future might help doctors with quicker and better diagnosis.
If that sounds interesting, just click on the links below (questionnaire is available in different languages) and help make a difference already today!

Rheumatic? Links: Hungarian English Spanish Dutch German

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Patient Advisory Group

Time to learn more…

While in Madrid for SPIDeRR's Annual Meeting in March this year, we had the chance to talk with two of the SPIDeRR Patient Advisory Group members: Péter Mihajlik from Hungary and Peter Böhm from Germany.

Péter, can you tell us what motivated you to become a patient research partner?

Péter Mihajlik:



First of all, I was asked to become one, and I had never tried this before.

Of course, I have had rheumatoid arthritis since I was 15, so that is more than 35 years ago now. I have a lot of experience as a patient, and if I can share that experience—if I can contribute to any project related to the treatment or diagnosis of rheumatoid arthritis and similar diseases—then I am more than happy to do so.

And how about you, Peter?

Peter Böhm:

For me personally, it was also interesting to be involved in research. In 2014, there was a call in Germany for patients who were interested in contributing to research. They offered a special training, for which you had to apply.

I applied and was able to do the training, which was very nice and interesting for me. It was also valuable to meet other patients who were interested in contributing to research.

I had already been working in a patient organization and doing patient consultations. I am a psychologist, and for many years I had been interested in seeing the results of research. There had been a big lack of rheumatology research before the year 2000, but then it started to improve.

I was happy to become involved, and in 2015 I was the first patient at national level involved as a patient research partner. It was a very good experience.

What kind of education did you get for the first research project?

Peter B:

We learned how research is done in general and how research in rheumatology is conducted specifically. This included clinical research, as well as basic and translational research.

We also learned how to search literature databases such as PubMed and others to find research articles on specific topics.

In addition, we were introduced to research applications and learned how to assess whether they were okay or whether something was lacking. This gave us a good overview.

Of course, I already had some background knowledge, as I am an academic psychologist and completed an academic degree, so I already knew some of the basics of research. That was probably a good starting point.

And what does your role as a patient research partner involve in practice?

Peter B:

In practice, we were asked by researchers to contribute. In the beginning, this was also a new process for everyone, including the researchers.

The researchers involved us as PRPs—there were two of us in the project: a colleague of mine, Uther from Hamburg, and myself.

We also had to show in which topics we could contribute, because the researchers were not always aware of our capacities and abilities. But they were very open-minded. They accepted us and shared information with us.

It was not always clear that we would receive all information automatically, so sometimes we had to actively ask or confront the researchers. Still, it was a very good process.

We were able to bring in our ideas and opinions, and the project itself was very patient-centered, which made the collaboration easier.

And what does your role look like in SPIDeRR, Péter?

Péter M:

Sometimes we have specific tasks, for example creating a lay-language version of the SPIDeRR homepage,

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which was an interesting task.
Before that, I participated in surveys. At this meeting, my role is mainly to observe the presentations from a patient perspective and to give feedback to the researchers—such as pointing out where things might need more explanation or could be seen differently by patients.

Does that match the expectations you had?
Péter M:
Yes.
And Peter Boehm, how is that for you?
Peter B:
My involvement began with Rheumatic, where I participated in focus group discussions. I was asked by a German partner who was also working with Rheumatic, and he contacted my patient organization to provide patient partners for the project.
Through Rheumatic, I became aware that there were other tools within the consortium and some coordination of PRP activities. Together, we built a PRP group and discussed what PRPs could contribute—not only to Rheumatic, but also to other aspects of the project.
One proposal from the PRP group was to help with lay, easily understandable language for the homepage, and we were able to contribute to that. Overall, it was a very good experience.
This is now my first on-site meeting, here in Madrid, and I am eager to see how Rheumatic is progressing. We are also involved in the Patient Advisory Board, where I have the honor of representing the patient perspective. So there have been good developments from the beginning until now.

Péter, can you tell us something about the status of patient involvement in your country?
Péter M:
Actually, I do not really have a broad overview. I became involved in SPIDeRR because my rheumatologist asked me if I would like to participate, as they needed patient research partners.
Probably also because I am a researcher myself—although in a different professional field—she believed it would not be too difficult for me, and that turned out to be true.
In the first year, it was difficult to get used to all the abbreviations, but now it is much easier.

And how is it in Germany?
Peter B:
In Germany, we had the first patient partner training at the end of 2014, and the first national-level involvement followed in 2015. This was a project funded by our patient organization, and one of the conditions was to involve patients as PRPs.
The project was very patient-focused, and the researchers were very willing to integrate patients. Since then, it has continued to develop.
We now have a national network of patient research partners in Germany. Since 2015, there have been more than 70 or 80 projects with patient involvement.
Some of us also work at international level, for example in consortia like SPIDeRR. Together with the European patient organization, there is also a European patient partner network connected to the German one. So we now have long-standing experience.

Taking a step back, at which stages of the research process are you involved as a PRP?
Peter B:
I have been retired for two years now, so I have more time to spend on these activities. I am involved in many projects, both national and international.
This involvement spans different stages of research. It can be academic research, work during implementation, or a combination. In consortia such as SPIDeRR, it often covers several phases.
I am also involved in committee work. For example, I am a member of the EULAR European Research Committee, where patient representatives contribute the patient perspective.
I have also been involved in the development of guidelines, both nationally and internationally. At the European level, there are major recommendations for patient involvement in research, and there is now a project focused on implementing these recommendations, where I am also involved to some extent.
In addition, I contribute to the organization of congresses, such as the patient program for the EULAR congress.
Overall, it is a very broad and varied range of voluntary work.

Well, that sounds like very worthwhile and valuable contributions you are making. I would like to keep talking with you both a bit more, there are more topics we can discuss, I am sure….. Keep an eye on the SPIDeRR website for further interviews with these gentlemen!

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SPIDeRR on tour

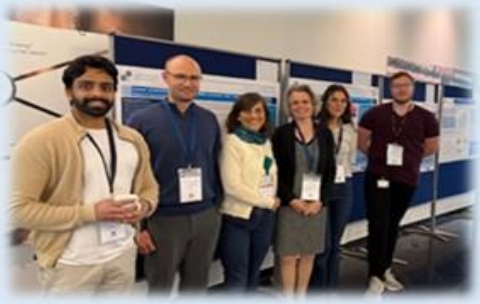












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SPIDeRR Blog

Bridging Borders, Connecting Minds

Behind every innovation is a team — or in this case, a European network. Through SPIDeRR, rheumatologists, data scientists, and bioinformaticians combine forces to turn patient stories into smarter diagnostics. Today: what happens when Spanish and Dutch collaboration becomes inspiration.



When Inés, a passionate rheumatologist from Spain, embarked on a six-month research stay in Leiden, she had no idea how transformative the experience would be. Her journey was part of the European funded SPIDeRR project. SPIDeRR strives to contribute to new digital diagnostic tools for earlier and better diagnosis of people with muscle and joint complaints. What started as a research contract soon evolved into a deeply personal and professional adventure.
To read her blog, continue on to the SPIDeRR website

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