

D6.3 / First report on project visibility and educational material

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List of abbreviations

AI	Artificial Intelligence
DHU	Digital Health Uptake
DoA	Description of Action
EU	European Union
HCPs	Healthcare Professionals
HRB	Horizon Results Booster
ICT	Information and communication technologies
IT	Information technology
KPIs	Key performance indicators
NGO	Non-governmental organisation
PDF	Portable Document Format
PDPID	PsA digital phenotyping and inflammation drivers study
PsA	Psoriatic Arthritis
PsO	Psoriasis
R&I	Research and Innovation

Executive summary

This document is deliverable D6.3, “First report on project visibility and educational material.” It provides a detailed overview of project visibility through dissemination, communication, and networking activities, along with the impact indicators and educational content developed up to M18 of the project duration. The document highlights various strategies implemented to enhance visibility and stakeholder engagement over the course of the project. These strategies include creating a distinct project identity, leveraging various media platforms, engaging directly with the target audience through multiple channels, and developing educational content focused on PsA management.

A cohesive project identity has been established, ensuring a unified and recognisable presence across all dissemination and communication channels. Regular project updates and achievements have been promoted through media platforms and dissemination channels such as social media, newsletters, the project website, interviews, and conferences, keeping the community informed about the project's progress and results, and amplifying engagement. Targeted communication activities have made project outputs visible to various stakeholders, including researchers, healthcare professionals (HCPs), industry representatives, people with PsA, and the general public.

Networking and clustering activities have been initiated to foster collaboration, raise awareness, exchange knowledge, and communicate the project's vision and outcomes to key stakeholder groups.

In terms of educational content, the project has focused on developing materials to support non-specialist audiences, such as patients, their families and caregivers, to support better health outcomes and quality of life and increase engagement with the project. The educational content includes a comprehensive PsA handbook and infographics, which provide essential information on symptoms, management strategies, and available treatments for patients. Additionally, infographics present key information about PsA in an accessible and engaging manner.

The activities covered in this deliverable adhere to the guidelines set forth in deliverable D6.2, “Dissemination, exploitation and communication plan”, which outlines the communication and dissemination strategy, key objectives and targeted dissemination and communication KPIs for the iPROLEPSIS project.

As part of WP6 “Dissemination, communication and exploitation”, this deliverable is associated with T6.1, “Dissemination and communication planning, implementation and monitoring”, T6.2 “, Clustering and networking activities”, and T6.3 “, PsA educational content development”.

This deliverable serves as a periodic report. For future reporting, deliverable D6.5, “Midterm report on project visibility and educational material”, is scheduled for M32, and deliverable D6.6, “Final report on project visibility and educational material”, is planned for M48.

1 Introduction

Deliverable D6.3 is the first report on project visibility, networking, and educational material developed. It gives a detailed overview of the dissemination and communication strategy implementation, detailing the activities carried out and KPIs achieved during the M1-M18 period of the project.

1.1 Document scope

Deliverable D6.3 is the third deliverable of WP6, “Dissemination, communication, and exploitation”. It provides a comprehensive overview of the dissemination, communication, and networking efforts over the first M18 period of the project. The report details the actions and progress made towards increasing project visibility, raising awareness, and developing educational materials to improve the understanding and management of Psoriatic Arthritis (PsA). Moreover, deliverable D6.3 includes the performance evaluation based on key performance indicators (KPIs).

This deliverable is part of Task 6.1, “Dissemination and communication planning, implementation and monitoring, Task 6.2, “Clustering and networking activities”, and T6.3, “PsA educational content development”.

Task 6.1, led by SMARTSOL SIA, is dedicated to the development, implementation and oversight of the dissemination and communication activities. It also focuses on building an active iPROLEPSIS stakeholder community to increase awareness and visibility of project results. Task 6.1 is closely linked with Task 6.2, led by INTRA, which involves clustering and networking activities to raise awareness and share project vision and outcomes with key stakeholders. Task 6.3, led by SPR, aims at developing educational content about psoriatic arthritis (PsA) in close collaboration with clinical partners from WP5.

The overall objective of these tasks is to ensure the openness, visibility, and reuse of iPROLEPSIS outcomes through open science, effective dissemination and communication, and strategic networking activities.

This deliverable is closely related to deliverable D6.2, “Dissemination, exploitation, and communication plan,” which outlines the communication and dissemination strategy, approach, and KPIs. D6.3 provides a detailed account of the dissemination, communication and networking activities undertaken, showcasing the project's commitment to effective dissemination, impactful communication, and collaborative engagement.

1.2 Document structure

This document provides an overall view of dissemination, communication, networking activities, and educational material developed within the iPROLEPSIS project up to M18. The sections included are as follows:

- Executive Summary provides a summary of the whole document.
- Section 1 introduces the scope of the first report on project visibility and educational material.
- Section 2 encompasses various aspects, including dissemination and communication approaches, target audience, usage of project identity and branding, utilisation of different media platforms for project promotion, dissemination of project findings through scientific and business publications, participation in events, development and

distribution of communication materials, creation and distribution of educational content related to PsA, engagement in collaboration activities.

- Section 3 includes evaluation of performance based on key performance indicators.
- Section 4 provides a summary of the main findings and conclusions drawn from the report.
- Finally, the Annex section contains the PsA handbook and infographics developed.

2 Report on project visibility and educational material

2.1 Dissemination and communication approach

The dissemination and communication approach detailed in deliverable D6.2, the “Dissemination, Exploitation, and Communication Plan,” served as a background in planning and implementing the activities detailed in this deliverable. D6.2 defined a set of activities, tactics, and tools aimed at increasing the project’s impact. All dissemination and communication activities have the following objectives:

- Inform key stakeholders about project results and their clinical innovation potential;
- Make the outputs widely available for research and business purposes in the long term;
- Increase people with/at risk of PsA engagement for addressing their issues and concerns to increase their awareness and build trust in new technology;
- Reach similar/relevant R&I projects for promoting networking and joint activities;
- Establish a forum/community for healthcare professionals (HCPs) and authorities to develop new guidelines and standards.

The overall dissemination and communication approach is based on the following pathways:

1. **Publications** in peer-reviewed journals and business magazines;
2. **Dissemination events:** clinical, research and business conferences, workshops, special sessions, seminars and clinical focus groups with patients;
3. **Media presence:** newsletters, website, social media posts or local/national major media (TV and radio) presentations;
4. **PsA educational content development:** handbook and infographics for patients living with PsA and at PsA risk;
5. **Synergy and networking:** campaigns and organisation and participation in events;
6. **Formulation of diversified messages, languages, and content** for different target audiences;
7. **Conception and design of a coherent project branding** to achieve an effective visual identity, including logo, infographics, and banners. Acknowledgements of EU funding, to be included in all materials relevant to communication, dissemination, Intellectual property rights (IPR) and major results;
8. **Set up of different communication channels:** project website and social media accounts to be populated with project news and achievements, further contributing to the growth of its communities of interest and an open access publication archive within the Zenodo OpenAIRE public repository;
9. **Preparation of diversified communication materials:** print-based (e.g., brochures, posters) and multimedia (e.g., photos, teaser videos, interviews, demos) to be spread through the website, events, conferences and social media.

The iPROLEPSIS dissemination and communication approach is designed to be dynamic and flexible, allowing adjustments based on feedback from various information providers, including consortium members and stakeholders. This comprehensive and adaptive approach aims to

engage stakeholders, effectively convey project objectives, and ensure broad and impactful dissemination of the iPROLEPSIS project achievements while adhering to Open Science principles.

2.2 Target audience

iPROLEPSIS communication, dissemination, and outreach target audience covers a wide range of stakeholders, including citizens, patients, HCPs, relevant R&I projects, and policymakers at the EU and national levels. The dissemination and communication efforts target all involved, interested, and potential audiences to increase the impact of the project's different dimensions.

Based on the iPROLEPSIS project goals, the project's main target groups are:

- the relevant scientists and engineers;
- the relevant industries;
- the policy makers;
- the patients, their families and carers and their associations;
- citizens at large.

A matrix of the dissemination and communication channels associated with the respective objectives and targeted groups is presented in **Table 1**.

Using various dissemination and communication channels, such as scientific conferences, industry events, seminars, publications, the project website, social media platforms and more, we aim to effectively engage with our target audiences and disseminate key project findings. iPROLEPSIS partners leverage their extensive local, national, European, and international networks to maximise outreach.

Communication messages for different target groups must be carefully tailored to suit each group's needs and interests. By ensuring consistency in messaging across different channels, we aim to convey the project's objectives effectively and maximise engagement.

Table 1 Target groups

Main target groups	Target audience	Objectives	Dissemination & Communication channels
Academia and relevant scientists and engineers	This group targets all research communities interested in the project's developments, results and innovation, which can be beneficiary for their own research activities (research scientists, biologists, biochemists, pharmacists, clinicians and biomedical and AI engineers)	Communicate scientific findings and take feedback; Transfer of knowledge; Raise awareness; Building a community/forum; Get support from the scientific community; Boost the project sustainability through the development of new related research projects; Extend network	Scientific conferences; Events; Workshops; Mailing list; Special sessions; Seminars; Publications in peer-reviewed journals

Main target groups	Target audience	Objectives	Dissemination & Communication channels
Industry	Biomedical technology and pharmaceutical	Inform industry about the project's vision and exchange ideas; Extend network; Demonstrate the business potential; push towards adoption of iPROLEPSIS products and services; Collect feedback on expectations and requirement to adjust commercial exploitation plans; Convince about the technical feasibility and competitiveness of concept and tools developed;	Business/Industry events, and EXPOs stands/booths; mailing list; Publication in business magazines
Individuals and associations of people with/at risk of PsA, families and carers	The patients, their families and carers and their associations	Project involvement; General awareness; Increase engagement of the participants of the studies;	Clinical focus groups; Newsletters; Social media; Website; Major media presence
Policymakers	This is a wide group encompassing innovation driven local, regional, national authorities, representatives & associations, Ministries, parliaments and national & international Public Administrations, and regulatory bodies in healthcare and AI in personalised medicine	Project involvement; Attract the interest of relevant stakeholders	Website; Social media; Newsletters; Major media presence
General public	The general public consists of a general audience and other actors not identified as direct targeted groups by the project, though this group can have strong interest in the project: citizen Interest Groups, NGOs, Community Action Groups.	General awareness Project progress	Website; Social media; Newsletters; Major media presence

2.3 Project identity (visual and branding)

Visual identity encompasses graphic elements that distinguish a brand, business, or project. It includes visible components such as logos and brand colours that aid in brand recognition.

At the beginning of the iPROLEPSIS project, a unified branding identity was designed, including the project logo, colours, social media banners, templates and an animated logo video. These materials were distributed among partners and made available in the internal repository. Furthermore, the project logo and colour palette are easily accessible for dissemination and communication purposes on the project website within the “Knowledge base” subpage “Promo materials”¹.

The iPROLEPSIS logo (**Figure 34**) is an easily recognisable visual identity of the project. It features the project title combined with an attention-grabbing initial letter incorporating various colours. The overall image forms a solid logo with imagery representative of the healthcare theme, Arthritis’ purple ribbon, and smart innovations. These images combine the content of the iPROLEPSIS project.



Figure 1 iPROLEPSIS logo

The project's colour palette (**Figure 2**), aligned with the logo, is consistently used across iPROLEPSIS' templates and dissemination materials, ensuring a unified and recognisable visual identity for the project.

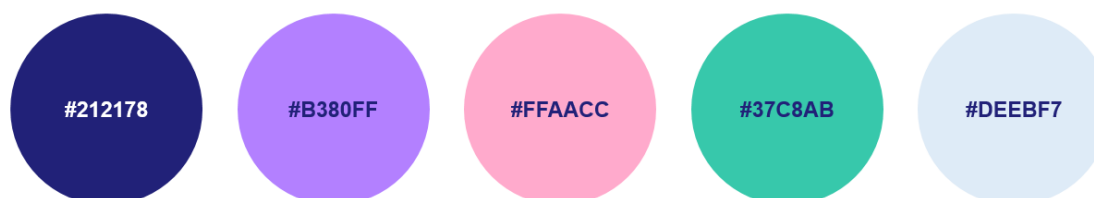


Figure 2 iPROLEPSIS colour palette

Moreover, an animated version of the project logo (**Figure 3**) was created to support social media and website communication efforts. This animated logo is also utilised as an introductory element in various video interviews, further reinforcing the project's visual identity.

¹ Promo materials, <https://www.iprolepsis.eu/promo-materials>



Figure 3 iPROLEPSIS logo animation

The animated logo video is accessible on the iPROLEPSIS YouTube channel².

Additionally, three essential templates for deliverables (Figure 4), meeting minutes (Figure 5) and presentations (Figure 6) were designed to ensure consistency in the consortium's project reporting and communication.

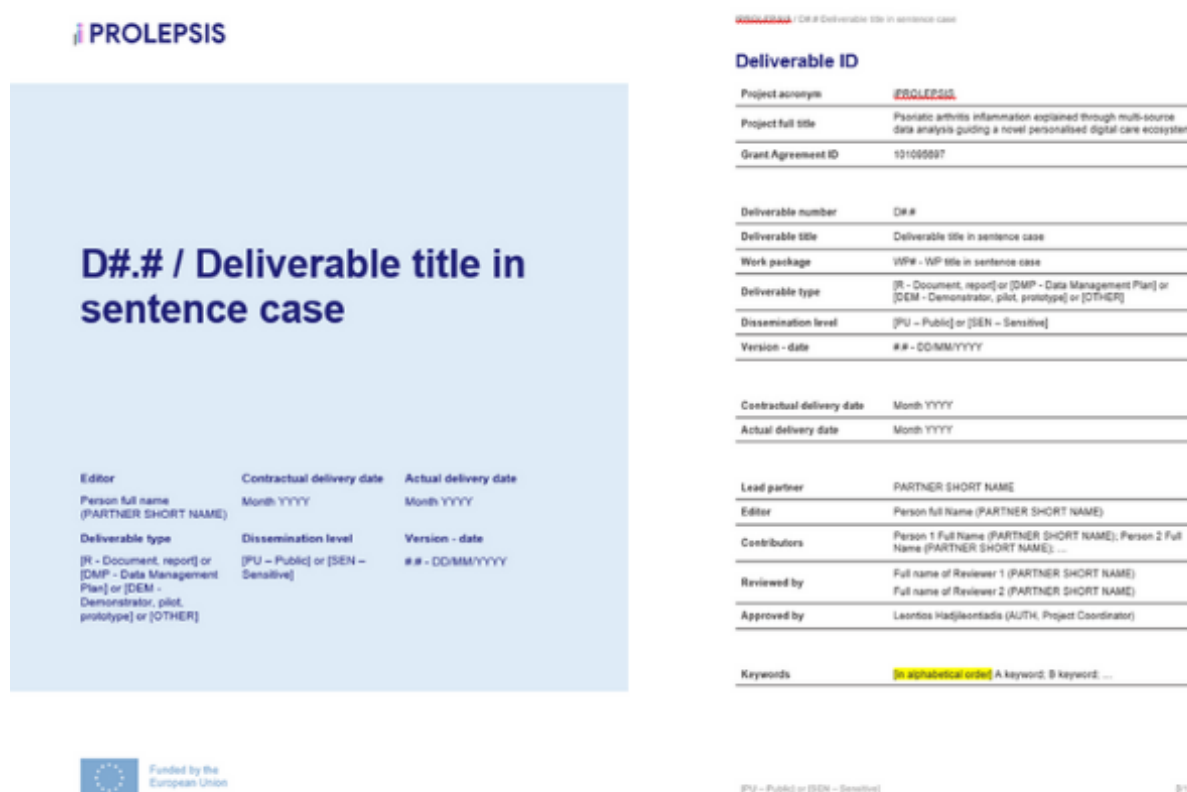


Figure 4 iPROLEPSIS deliverable template

² iPROLEPSIS animated logo video, <https://www.youtube.com/watch?v=Yp3GBZMO3CQ>

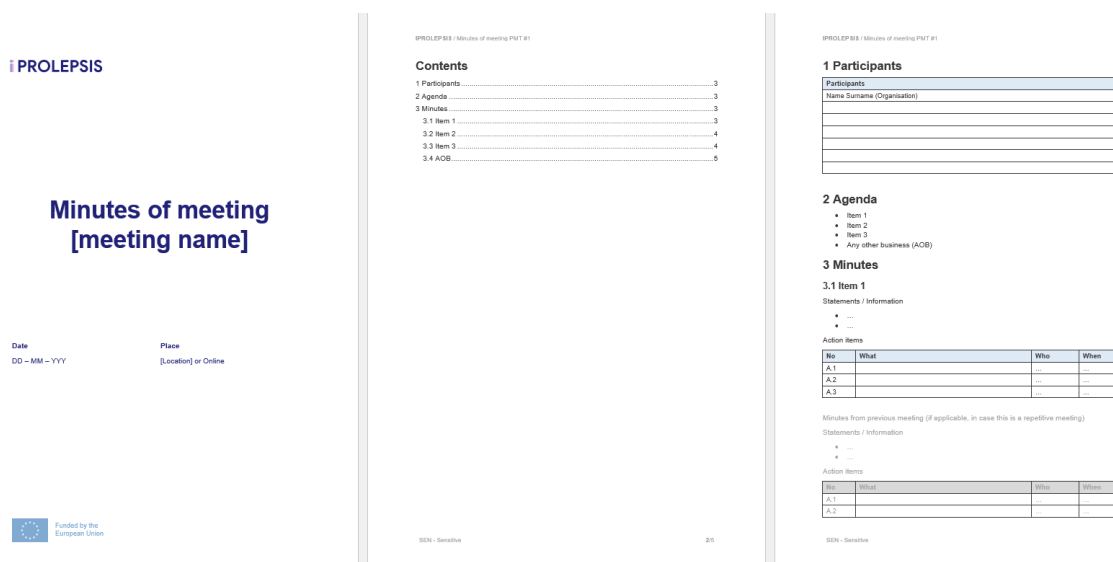


Figure 5 iPROLEPSIS Minutes of meeting template

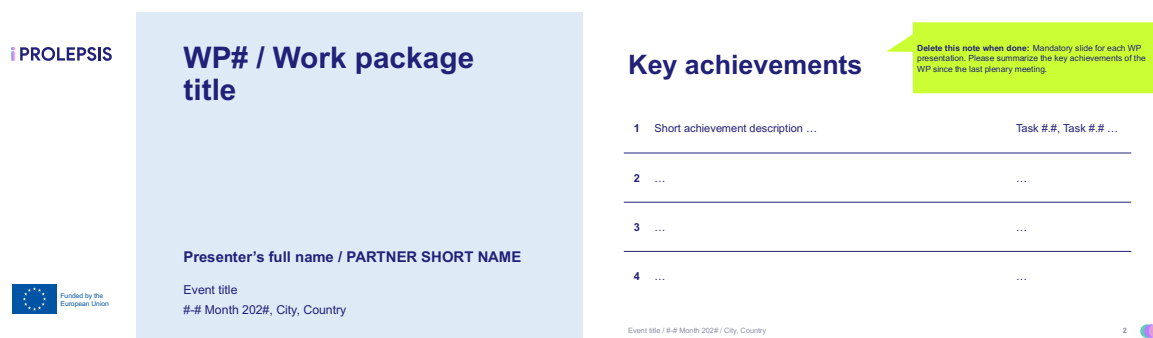


Figure 6 iPROLEPSIS presentation template

By maintaining a unified visual identity across all project materials and communication, we ensure that our message remains clear, coherent, and easily recognisable to our target audience.

2.4 Media

iPROLEPSIS utilises various media-based communication to increase project visibility, disseminate results, raise awareness and offer information to stakeholders. This communication is based on four different activities:

- Website posts;
- Social media posts;
- Newsletters;
- Major media (TV/radio).

Communication efforts through the project website and social media channels have been ongoing since the beginning of the project, ensuring continuous engagement and dissemination of project-related information.

2.4.1 Website

The iPROLEPSIS website³ is the main platform for presenting the project to external stakeholders, sharing its main objectives, and showcasing results and achievements. It was launched in M3, and its development rationale was thoroughly described in deliverable D6.1, “Project branding and communication channel”.

The iPROLEPSIS website (Figure 7) underwent a significant upgrade in M6 to improve the user experience and clarity in presenting project solutions. The upgraded website effectively communicates complex project information to diverse stakeholders using a picture-based visualisation strategy. Efforts were made to enhance the website's overall appeal, making it more attractive and user-friendly. Interactive features and dynamic content were incorporated to create a more engaging and captivating user experience.

The upgraded website is linked with social media platforms, providing seamless integration between the website and social media channels. This enhances the project's online presence and extends its reach to a wider audience. The website also features an event calendar, allowing visitors to stay informed about upcoming project events.



Figure 7 The iPROLEPSIS website

Furthermore, the website has been translated into two project languages: Greek⁴ and Portuguese⁵. At the time of the deliverable preparation, the Dutch language is undergoing translation review and will be included once finalised.

The website is flexibly built, i.e., sections may be added or removed as required. It is frequently updated (on average, 2 posts per month) with new input, e.g., project news, meetings, participation in events, developments, etc (Figure 8). Additionally, visitors can directly download dissemination materials from the website. Overall, the website upgrade represents

³ The iPROLEPSIS website, <https://www.iprolepsis.eu/>

⁴ The iPROLEPSIS website in Greek: <https://www.iprolepsis.eu/el>

⁵ The iPROLEPSIS website in Portuguese: <https://www.iprolepsis.eu/pt>

a significant improvement in accessibility, functionality, and visual appeal, enhancing its effectiveness as a communication and dissemination tool for stakeholders.

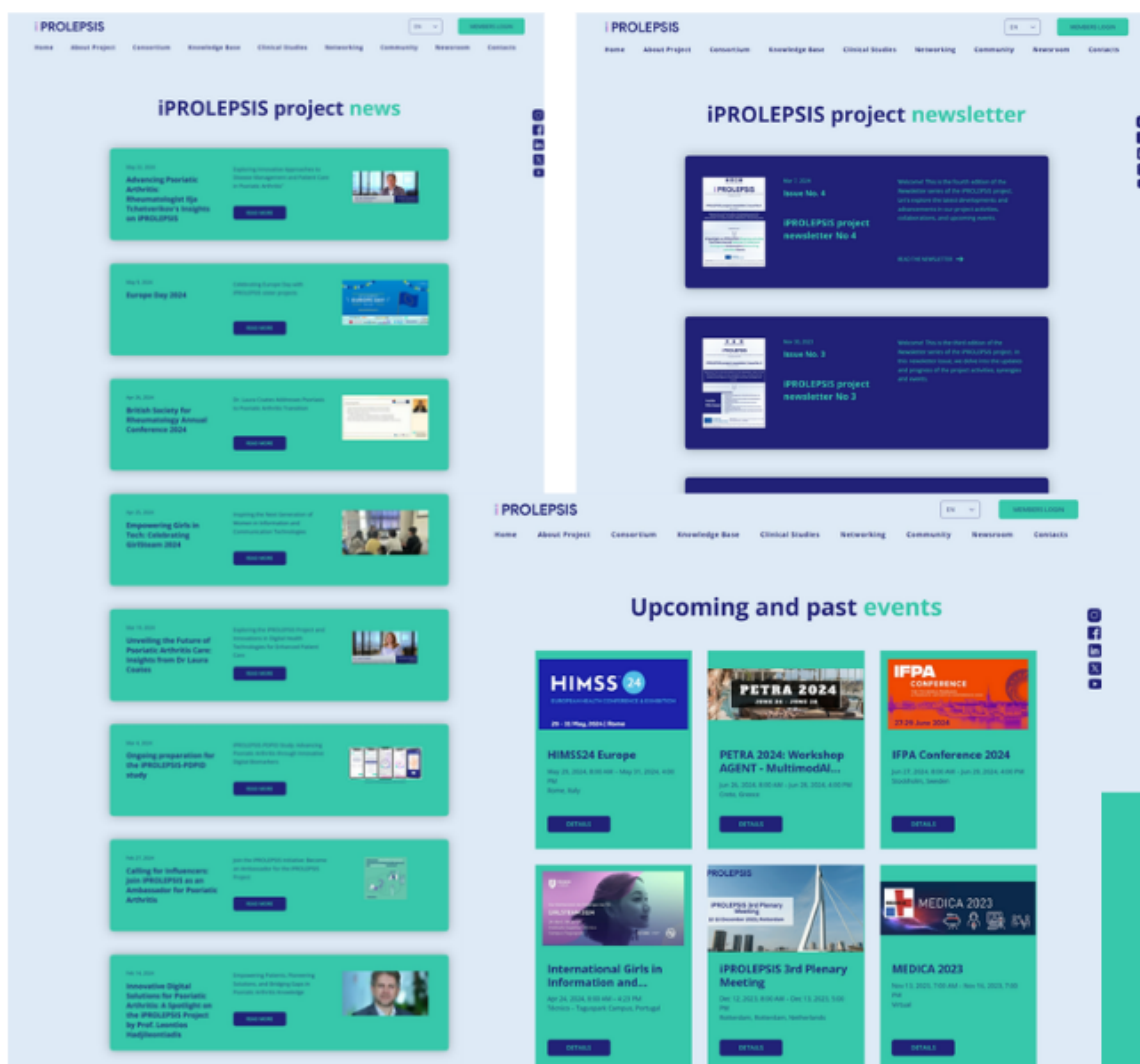


Figure 8 Newsroom section on the website

Website analytics became available from M6 once the upgrade was completed (**Figure 9**). On average, over the M6-M18 period, the website received 182 visitors per month, which is below the planned KPI of 1000 visitors per month. One contributing factor to this shortfall is the website-building platform Wix⁶. Traffic reports from Wix include only data from visitors who have accepted the cookie consent policy, limiting the availability of a full traffic report. Additionally, from M1 to M18, the project was primarily in the development phase, with limited significant scientific and tangible results available and clinical study applications still under development.

⁶ Wix, <https://www.wix.com/blog/what-is-wix>

Month	Page views	Site sessions	Unique visitors	
Jun, 2024		82	37	25
May, 2024		197	98	75
Apr, 2024		230	137	129
Mar, 2024		203	111	95
Feb, 2024		68	24	13
Jan, 2024		158	66	26
Dec, 2023		83	28	16
Nov, 2023		79	31	22
Oct, 2023		122	47	26
Sep, 2023		175	61	31
Aug, 2023		156	61	36
Jul, 2023		247	139	100
Jun, 2023		560	151	86

Figure 9 Website analytics, June 2023-June 2024

To increase website visibility and number of visitors, 5-day Google ads campaigns were launched in M15 and M16 (Figure 10). The campaign on 18-22 March 2024 resulted in 135 clicks and 5416 impressions⁷, and the campaign on 1-5 April 2024 resulted in 252 clicks and 1907 impressions. These campaigns generated a significant number of impressions and clicks over a short time period, indicating increased visibility and engagement with the website.

Campaign report 18 March 2024 - 22 March 2024				Campaign report 01 April 2024 - 05 April 2024			
Campaign	Clicks	Impr.	Bid strategy type	Campaign	Clicks	Impr.	Bid strategy type
iProleptis	135	5416	Maximise conversions	iProleptis	252	1907	Maximise conversions
	135	5416			252	1907	
	135	5416			252	1907	

Figure 10 Google ads campaign results, June 2023 - May 2024

As the project progresses and more tangible results are produced, starting from M19, we expect an increase in visitors. Furthermore, the integration of educational content in a more engaging manner on the website is anticipated to boost interest and the number of visitors.

2.4.2 Social media

Social and digital media are important in raising awareness about the iPROLEPSIS project and showcasing its progress. iPROLEPSIS is currently active on five social media platforms: LinkedIn, X (previously Twitter), Facebook, Instagram, and YouTube (Table 2).

Table 2 Social media channels

Social media channel	Handle in the channel	Reference
LinkedIn	@iProleptis	https://www.linkedin.com/company/iproleptis/
X	@iproleptis	iPROLEPSIS (@iproleptis) / X (twitter.com)
Facebook	@iPROLEPSIS	https://www.facebook.com/iPROLEPSIS
YouTube	@iPROLEPSIS	iPROLEPSIS - YouTube
Instagram	@iproleptis	https://www.instagram.com/iproleptis/

The presence on social media is a significant tool for disseminating iPROLEPSIS results, enabling the project to:

- To create awareness;
- Promote iPROLEPSIS identity and build a strong reputation;

⁷Impressions definition, <https://support.google.com/google-ads/answer/6320?hl=en>

- Engage and encourage stakeholders and the public in dialogue;
- Disseminate project news, results, actions and events.

The iPROLEPSIS LinkedIn, X and Facebook accounts were established from the beginning of the project and are the main project communication channels. YouTube and Instagram were introduced in M13 and M15, respectively, to support engagement with visual content and broader audience interaction.

Social media channels have been branded with the project look and feel following brand identity guidelines. To date, iPROLEPSIS has 649 followers across all social media accounts (**Figure 11**), and the number is constantly increasing. Since M12, the total number of followers has doubled.

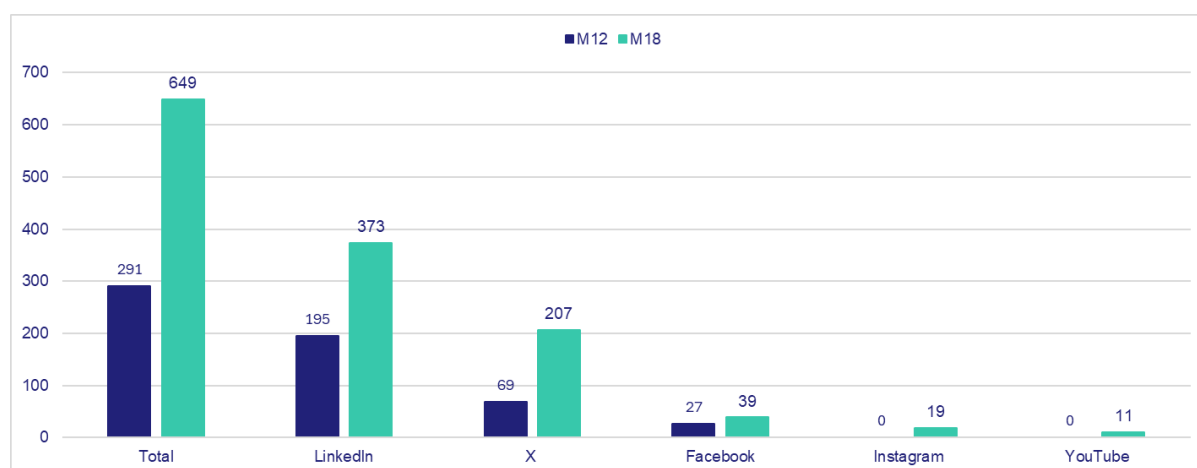


Figure 11 iPROLEPSIS number of followers on social media channels

To maintain engagement, at least 2 posts are made per month across the main project channels: LinkedIn, X and Facebook. Social media accounts are linked with the iPROLEPSIS website and accessible by clicking on the corresponding social media icons on the project's website.

2.4.2.1 LinkedIn

To date, the project's LinkedIn account has been the most active social media channel of iPROLEPSIS (**Figure 12**). The page currently has 373 followers from a wide variety of industries, including but not limited to:

- Research services;
- IT services and IT consulting;
- Government administration;
- Hospitals and healthcare;
- Biotechnology research;
- Non-profit organisations;
- Software development.

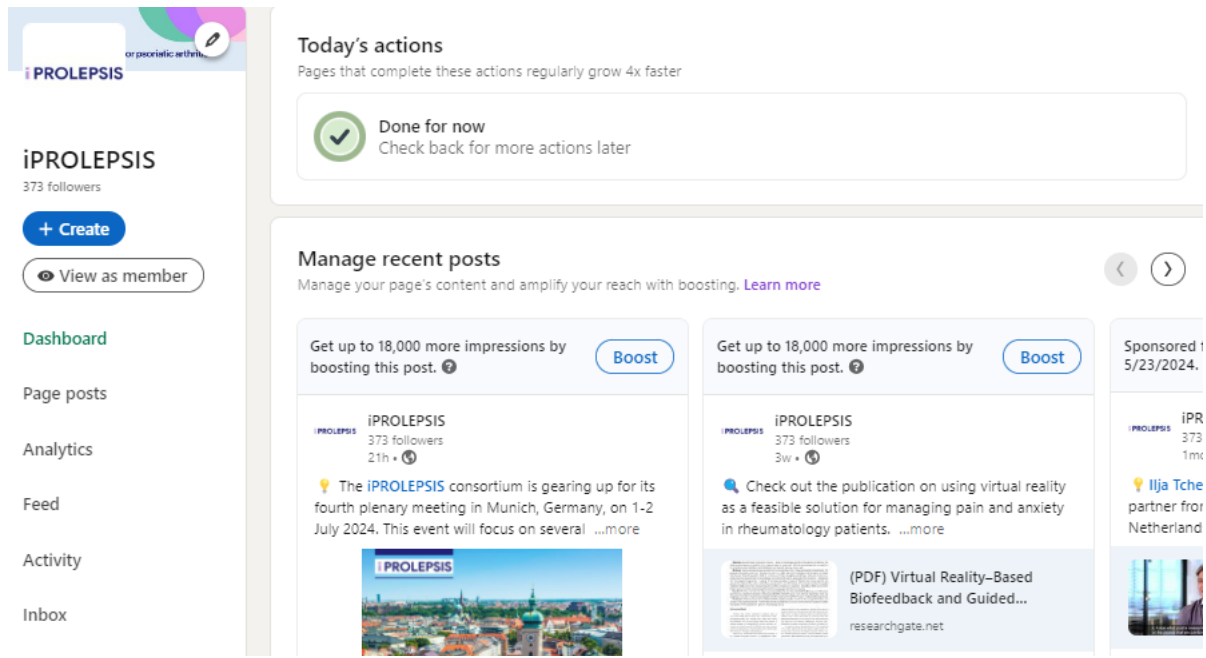


Figure 12 iPROLEPSIS LinkedIn profile

A total of 75 posts have been published on LinkedIn, not including reposts. To maintain engagement, at least 2 posts are made per month. Content includes project updates, event participation, interviews with project members, key achievements, partners' activities, communication on supported projects, and external content, such as various scientific and other publications relevant to the project topic (Figure 13).

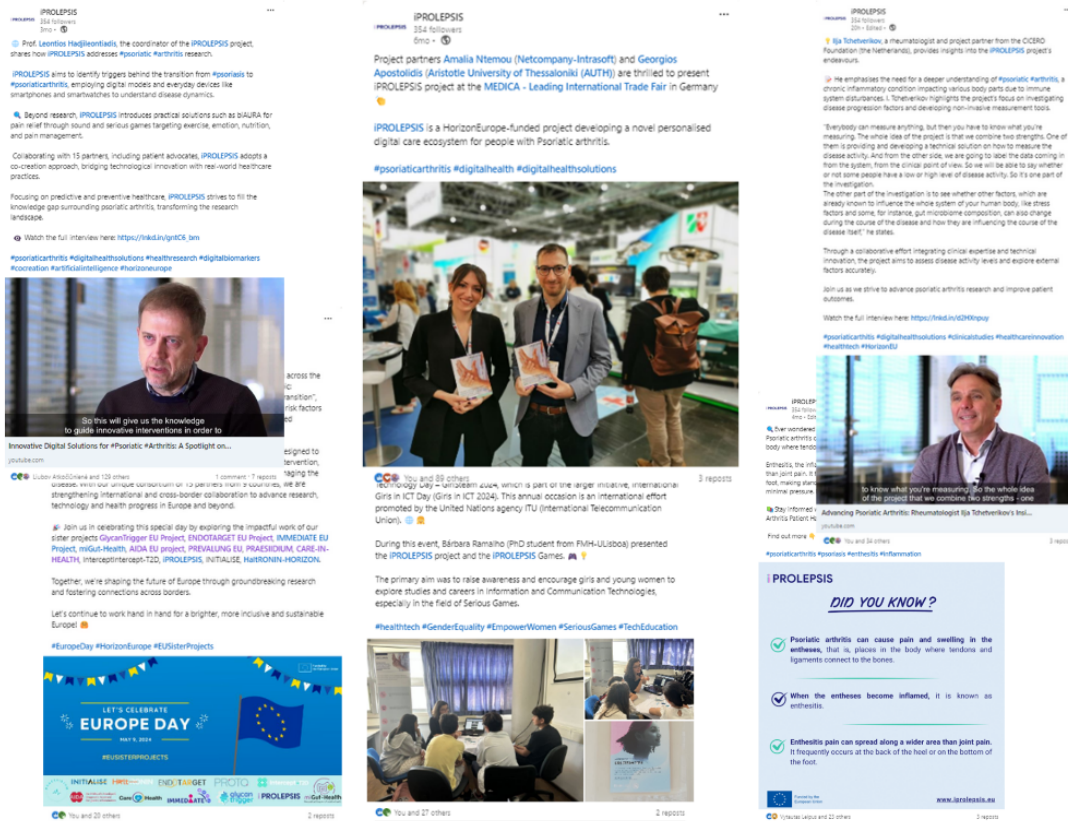


Figure 13 Presence of iPROLEPSIS on LinkedIn

LinkedIn's active engagement and diverse follower base make it a crucial platform for the iPROLEPSIS project, enhancing its visibility and impact within the professional community.

2.4.2.2 X (previously Twitter)

As a rapid and professional communication tool, X allows real-time interactions and has a very high potential for outreach to the iPROLEPSIS target audience using hashtags and thematic tweets.

The X account is used for promoting and disseminating the iPROLEPSIS developments, news, events, outcomes, etc. Additionally, relevant and interesting content from disparate sources is retweeted to broaden engagement and visibility. Through targeted following of other relevant users, iPROLEPSIS not only gets access to more relevant content and updates but also acquires more followers.

Since the iPROLEPSIS account launch in M1, the project's X activities have led to 207 followers (some of them being followed by thousands of followers) and 288 followed accounts. The total number of tweets is 75. To maximise engagement, strategic use of hashtags such as #PsoriaticArthritis, #DigitalHealth #HealthTech #ArtificialIntelligence, #HealthcareInnovation, HorizonEU ensures that tweets reach a wider audience interested in these topics (Figure 14).



Figure 14 Examples of tweets

Partners also participate in online communication efforts via their own or entity channels (Figure 15).



Figure 15 Examples of tweets by partners

iPROLEPSIS will continue its efforts to publish on a regular basis on X and to highlight the activities of the project. Consistent posting and engagement are key strategies to maintain and grow the project's online presence and influence.

2.4.2.3 Facebook

iPROLEPSIS maintains a Facebook page (Figure 16) to reach a broader and less specialised audience. The project's Facebook page includes news, photos and information about the iPROLEPSIS project, its developments and activities.

The page currently has 39 followers. It should be noted that Facebook's presence is low for most R&I EU projects, mainly due to the audience of this medium.

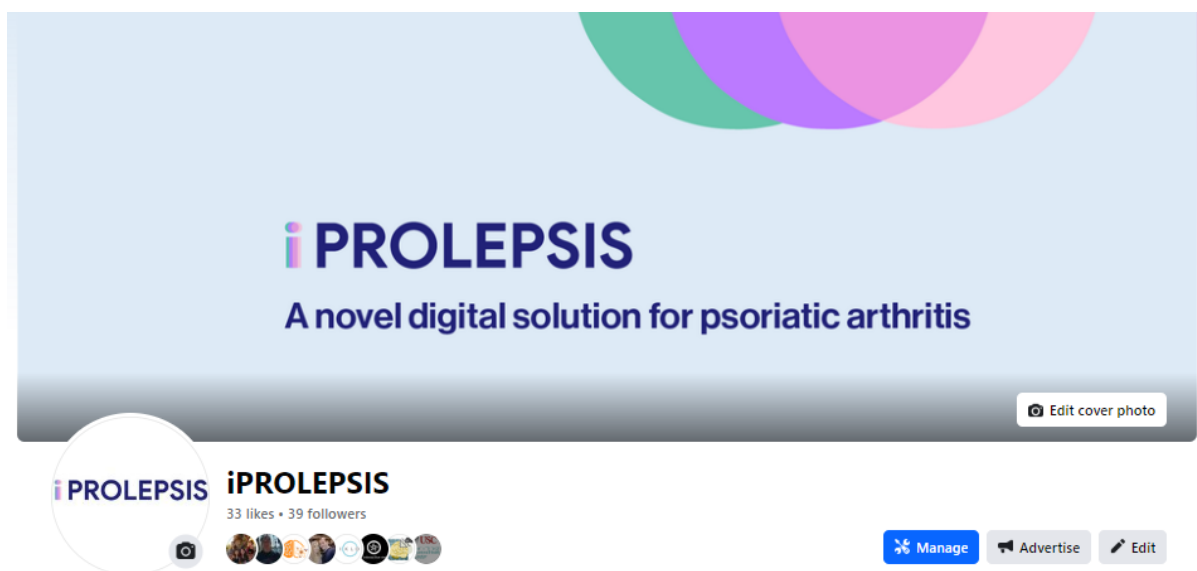


Figure 16 iPROLEPSIS Facebook profile

To increase visibility and engagement, iPROLEPSIS has joined a Psoriatic Arthritis support group⁸ that has 31.3K members. Educational content, including a PsA handbook and

⁸ Psoriatic Arthritis Support Group on Facebook, <https://www.facebook.com/groups/PsoriaticArthritis>

infographics, is currently under development. Once developed, this content will be shared within this group, which is expected to boost the number of followers and overall engagement.

2.4.2.4 Instagram

iPROLEPSIS Instagram account (Figure 17) was created in M15 to support engagement with visual content and broader audience interaction. The project's page includes mainly video interviews and information about the iPROLEPSIS project. The page currently has 19 followers.

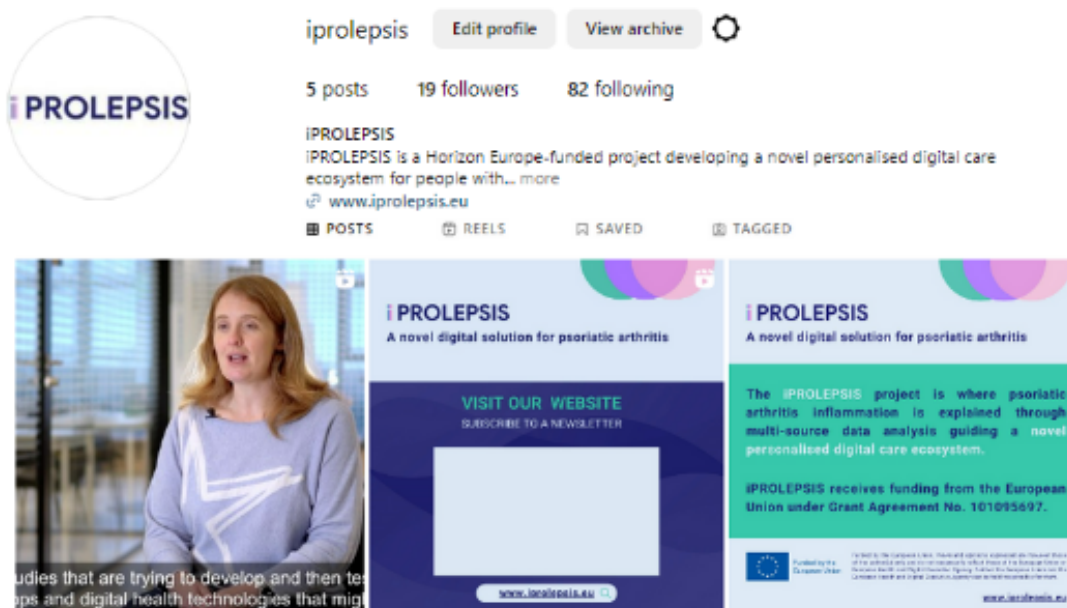


Figure 17 iPROLEPSIS Instagram profile

Educational content, adapted from the PsA handbook into visually engaging posts suitable for Instagram, will be shared on this platform, which is expected to boost the number of followers and overall engagement.

2.4.2.5 YouTube

YouTube is used to post and promote dynamic media content (videos) developed over the course of the project. The iPROLEPSIS YouTube channel (Figure 18) was created in M13 to showcase iPROLEPSIS in an audiovisual setting. Currently, the channel has 11 subscribers and features 5 uploaded videos. Among these, one of the first videos was related to Psoriatic Arthritis Awareness Day, while the other 3 were interviews with the project coordinator and clinical partners. In addition, material gathered at the third plenary will complement future videos.

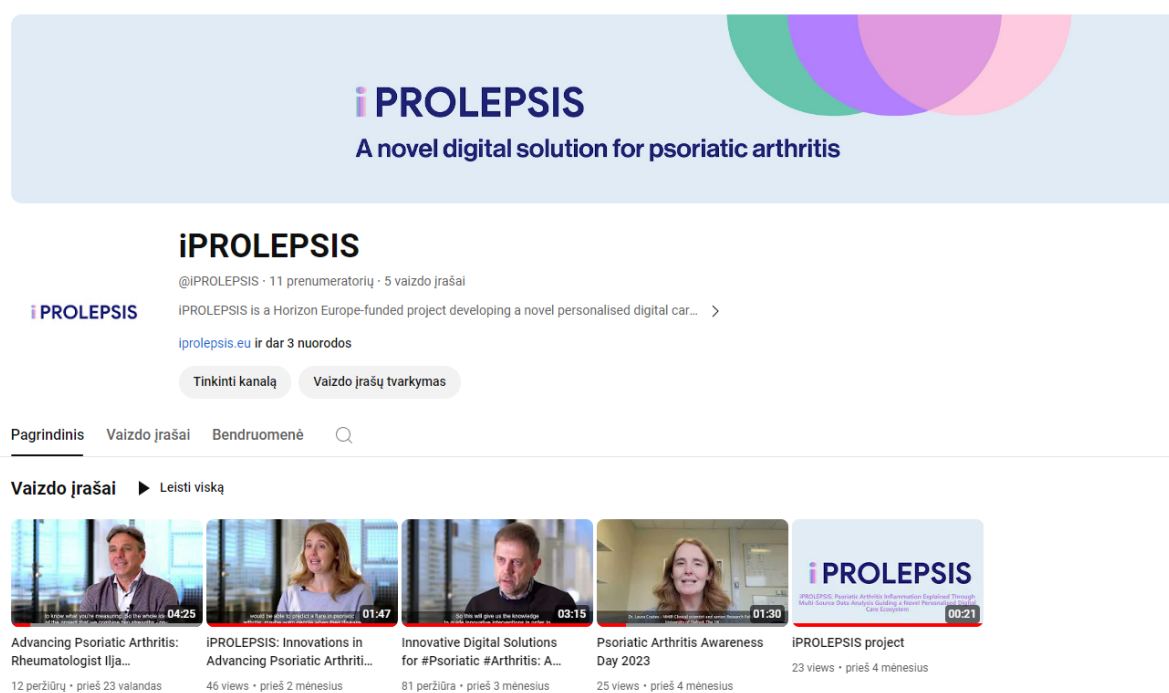


Figure 18 iPROLEPSIS YouTube channel

We have cross-promoted our content and used social media sharing to drive traffic between our channels and website.

2.4.3 Partners involvement in online visibility

Aligned with the iPROLEPSIS dissemination and communication strategy, consortium members share information about the iPROLEPSIS project through their respective websites, social media accounts, articles, and other initiatives. This effort ensures that information about iPROLEPSIS reaches a broader audience.

In addition to the social media activities highlighted in the previous section of this deliverable (X (previously Twitter) **2.4.2.2**), further examples of partners' engagement are provided below. Partners have introduced the iPROLEPSIS project on their respective websites or social media accounts (**Figure 19**) providing a short project description, main goals and objectives. Moreover, partners have disseminated the project through various interviews, in newsletters and mentioned the project in their personal profile descriptions (**Figure 20**).



Figure 19 Examples of iPROLEPSIS project dissemination on partners' websites and social media



Figure 20 Examples of partner's dissemination activities

The list of partners' public iPROLEPSIS dissemination and communication activities and links to the websites and social media is presented below in **Table 3**.

Table 3 List of partners' dissemination and communication activities

Partner	Type	Link
CICERO	Interview	Ilja Tchetverikov: 'Het DEPAR-register is echt van ons allemaal' (zomnw.nl)
AUTH	Website	https://imedphys.med.auth.gr/project/iprolepsis
Signal Processing & Biomedical Technology Unit - AUTH	Social media	https://www.linkedin.com/posts/signal-processing-and-biomedical-technology-unit-auth_psoriaticarthritis-psoriasis-digitalhealth-activity-7121047000929742849-Au31?utm_source=share&utm_medium=member_desktop
Signal Processing & Biomedical Technology Unit - AUTH	Social media	https://www.linkedin.com/posts/signal-processing-and-biomedical-technology-unit-auth_patient-representatives-cocreation-activity-7140621780234285056-hJiT?utm_source=share&utm_medium=member_desktop
CERTH	Website	https://vcl.itl.gr/projects/psoriatic-arthritis-inflammation-explained-through-multi-source-data-analysis-guiding-a-novel-personalised-digital-care-ecosystem/
CICERO	Website	https://ciceroreumatologie.nl/iprolepsis
UOXF	Website	https://www.ndorms.ox.ac.uk/team/laura-coates
AIN	Website	https://ainigma.tech/projects/
DBC	Website	https://www.diadikasia.gr/en/health/
AUTH	Social media	Facebook
FMH	Social media	https://www.instagram.com/fmh_ulisboa/p/CpvEgb9qSVC/?img_index=1
SMARTSOL SIA	LinkedIn newsletter	https://www.linkedin.com/pulse/may-newsletter-smartsol-sia-tfeve/ https://www.linkedin.com/pulse/april-newsletter-smartsol-sia-6zrte/ https://www.linkedin.com/pulse/march-newsletter-smartsol-sia-tpfef/ https://www.linkedin.com/pulse/february-newsletter-smartsol-sia-dguse/ https://www.linkedin.com/pulse/january-newsletter-smartsol-sia-9bcbe/
PLUX	LinkedIn	https://www.linkedin.com/posts/pluxbiosignals_inflammatory-psoriasis-research-activity-7113126622647451649-VbAb?utm_source=share&utm_medium=member_desktop
INTRA	Website	https://www.netcompany-intrasoft.com/news/netcompany-group-showcase-innovative-healthcare-it-solutions-medica-2023-dusseldorf

2.4.4 Newsletter

The iPROLEPSIS newsletter (**Figure 21**) has been issued quarterly, starting from M3. Up to date, four (4) have been issued. The content is presented in accessible language and designed for the general public and contains a summary of the latest news about the project, past and upcoming project events, interviews with the project partners, and other interesting activities and new initiatives related to the project.

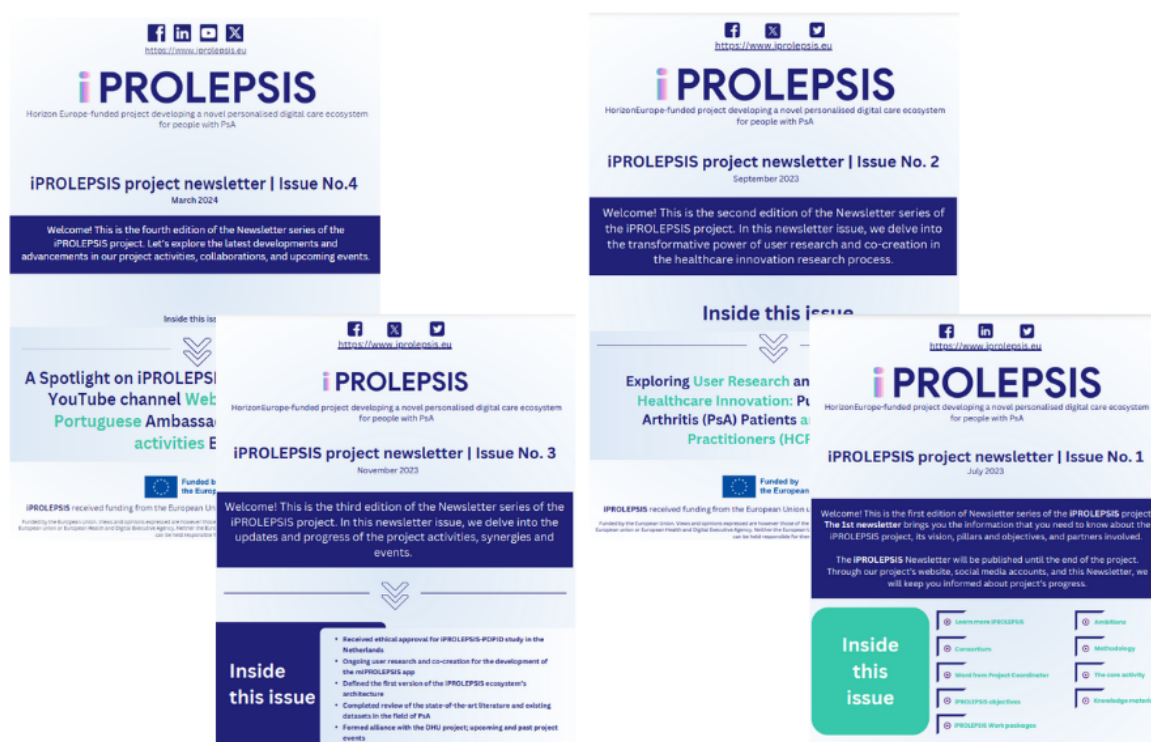


Figure 21 iPROLEPSIS Newsletters

A sign-up form for the newsletter is on the project website. To date, 60 subscriptions have been made (**Figure 22**).

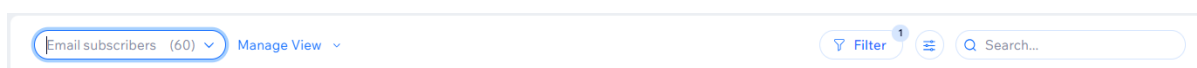


Figure 22 Number of newsletter subscribers through the website

The newsletter is available in PDF format, which is suitable for both online and offline communication and dissemination activities. It is distributed via Wix Email marketing. Additionally, the newsletter is promoted on the project’s social media channels and the project website⁹ ensuring broad accessibility and dissemination. The delivery statistics for the fourth project newsletter (**Figure 23**) show a high open rate of 57%, indicating strong interest in our updates. A click rate of 24% shows that a significant portion of our audience interacts with the links provided.

⁹ iPROLEPSIS project newsletters, <https://www.iprolepsis.eu/newsletter>

Delivery statistics

This email was sent to **43 contacts**. Check how they interact with it. [How to read this data](#)

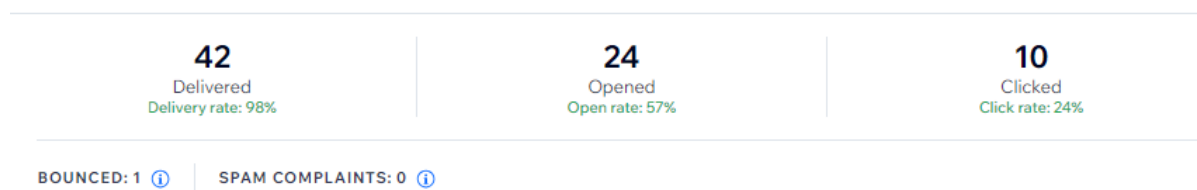


Figure 23 Delivery statistics of the 4th newsletter

With the fourth newsletter edition, a LinkedIn newsletter (**Figure 24**) was introduced in M15 to increase the number of subscribers. To date, 191 subscriptions have been made on this platform, bringing the total number of newsletter subscribers, including website subscriptions, to 251.

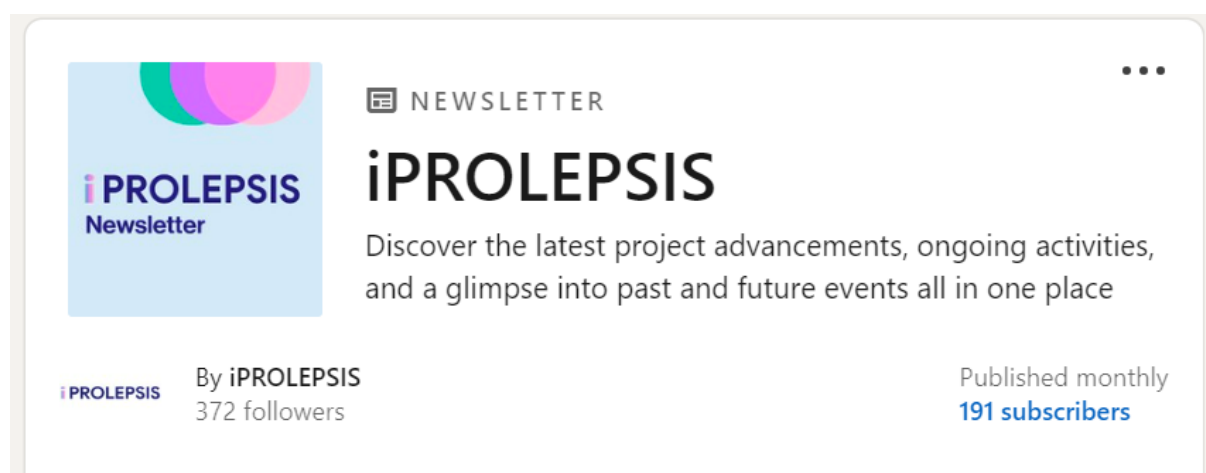


Figure 24 iPROLEPSIS LinkedIn newsletter

Furthermore, the newsletter is also made available through the Zenodo OPENAIRE public repository¹⁰, ensuring access to a wider audience, including researchers, stakeholders and the general public, thus enhancing the dissemination and impact of the project's results (**Figure 25**).

¹⁰ Zenodo OPENAIRE public repository, <https://zenodo.org/me/uploads?q=&l=list&p=1&s=10&sort=newest>

The screenshot displays the Zenodo interface for the iPROLEPSIS project. It features a search bar at the top left and a navigation menu. The main content area shows a list of four newsletter entries, each with a 'View' button and a 'Download' icon. The entries are:

- iPROLEPSIS Newsletter No 4** (March 7, 2024): Welcome to the fourth edition of the Newsletter series of the iPROLEPSIS project. In this issue, we present the latest updates and progress of the project activities, collaborations, and upcoming and past events. Follow us at our social media accounts and visit our website for more information: <https://www.irolepsis.eu/>.
- iPROLEPSIS Newsletter No 3** (November 30, 2023): Welcome to the third edition of the iPROLEPSIS project newsletter series. In this issue, we present the latest updates and progress of the project activities, collaborations, and upcoming and past events. Follow us at our social media accounts and visit our website for more information: <https://www.irolepsis.eu/>.
- iPROLEPSIS Newsletter No 2** (September 5, 2023): We welcome you to the second iPROLEPSIS Newsletter edition. In this issue, we're diving into healthcare innovation research and the incredible impact of user research and co-creation. Follow us at our social media accounts and visit our website for more information: <https://www.irolepsis.eu/>.
- iPROLEPSIS Newsletter No.1** (July 4, 2023): We kindly welcome you to get acquainted with iPROLEPSIS - Horizon Europe Research & Innovation project. This is four-year effort that will conduct research to explain the transition from health to Psoriatic Arthritis (PsA), and innovate towards an AI-driven toolkit for disease screening, progression monitoring, and treatment optimisation, to em...

A file viewer for 'iPROLEPSIS project newsletter_issue No. 1.pdf' is also visible, showing the cover of the first newsletter issue.

Figure 25 iPROLEPSIS Newsletter on Zenodo

These efforts ensure that the iPROLEPSIS project remains transparent and engaging to a broad audience, promoting its activities and results effectively. Going forward, we will continue to refine our newsletter content and distribution strategies to maximise outreach and impact, ensuring that all stakeholders are kept informed of our progress and achievements.

2.4.5 Major media

No major media (TV/radio) presence was achieved up to M18. Major media engagement is planned to commence from M36 once tangible results have been produced and can be showcased.

2.5 Publications

2.5.1 Scientific publications

The project aims to publish at least twenty (20) scientific publications targeting Q1 journals to communicate scientific findings. The project will ensure open access, with free-of-charge online access for any user to all peer-reviewed scientific publications relating to its results. Scientific publications are planned to start from M18 once solid scientific results are available.

To date, one conference paper titled “Federated Learning Aggregation based on Weight Distribution Analysis” was published in ResearchGate¹¹ and IEEE Explore¹² in October 2023.

Additionally, several publications have been prepared for submission:

- **DSAI 2024¹³ - Software Development and Technologies for Enhancing Accessibility and Fighting Info-exclusion.** Title: Developing Sensorimotor Art Games for Psoriatic Arthritis using Agile Storyboarding and Game Co-design Processes;

¹¹ ResearchGate,

https://www.researchgate.net/publication/374440973_Federated_Learning_Aggregation_based_on_Weight_Distribution_Analysis

¹² IEEE Xplore, <https://ieeexplore.ieee.org/document/10355708>

¹³ DSAI 2024 – 11th International Conference on Software Development and Technologies for Enhancing Accessibility and Fighting Info-exclusion

- **Annals of the Rheumatic Diseases** journal. Title: Determinants of Patient's Intention to Use Serious Games in Psoriatic Arthritis: A Partial Least Squares Structural Equation Modelling Approach;
- **Nature Reviews Rheumatology**. Title: Digital Phenotyping: Opportunities and Challenges in Psoriatic Arthritis;
- **RMD Open**. Title: Digital Biomarkers for Psoriatic Arthritis: A Qualitative Focus Group Study on Patient-Perceived Opportunities and Barriers;
- Title: iPROLEPSIS: New Insights in Psoriatic Arthritis via Explainable Artificial Intelligence.

These prepared manuscripts, prepared for submission, mark significant progress towards meeting the project's publication objectives and aim to disseminate its research findings widely. However, their acceptance is contingent upon peer review and editorial decisions.

2.5.2 Publications in business magazines

No publications in business magazines were considered up to M18 of the project. Publication in these outlets is foreseen from M18, when solid scientific results will be available. It is expected to publish at least four (4) publications in business magazines.

2.6 Events

Events are one of the most important parts of the dissemination and communication strategy. They allow the project to connect with stakeholders and the general public, encourage networking and show advances and results of the project. Events also feed the content of the communication channels and tools (website, social media, newsletters), generating great impacts on different audiences.

The strategy of participation in events is set up at four different levels: scientific conferences, business/industry events, workshops/seminars/special sessions and clinical focus groups. It is expected project partners to participate in at least:

- **20 (twenty) scientific conferences;**
- **3 (three) business/industry events/EXPOSs stands;**
- **8 (eight) workshops/sessions/seminars;**
- **6 (six) clinical focus groups with patients.**

Project partners involvement in the activities during the reporting period:

- **Scientific conferences:** Participated in 3 conferences, including the IEEE International Conference on Imaging Systems and Techniques, XXV Congresso Português de Reumatologia, and the British Society for Rheumatology Annual Conference 2024. Upcoming participation is scheduled for the IFPA Conference 2024 and Petra 2024 by the end of M18;
- **Business/Industry Events:** Participated in 2 events, such as the 2024 HIMSS European Health Conference and Exhibition and Medica 2023. Presented a project to representatives from Eli Lyli company;
- **Workshops/Seminars/Special Sessions:** Presented the project during the International Girls in ICT Day – GirlSteam 2024. Scheduled is the "AGENT" workshop at PETRA 2024 by the end of M18;

- **Clinical focus groups with patients:** Conducted 9 focus groups and 1 one-on-one interview to gather insights from patients and HCPs to guide the creation of digital health tools.

Detailed descriptions of these events are presented below in subsections **2.6.1-2.6.4**.

2.6.1 Scientific conferences

During the reporting period, the project has participated in 3 (three) scientific conferences:

- **2023 IEEE International Conference on Imaging Systems and Techniques¹⁴;**
- **XXV Congresso Português de Reumatologia¹⁵** (The 15th Portuguese Rheumatology Congress) and
- **British Society for Rheumatology Annual Conference 2024¹⁶.**

The IEEE International Conference on Imaging Systems and Techniques took place in October 2023 in Copenhagen, Denmark. Project partners from AUTH and CERTH presented a conference paper titled “Federated Learning Aggregation based on Weight Distribution Analysis”.

XXV Congresso Português de Reumatologia was held on 25-28 October 2023 in Albufeira, Portugal (**Figure 26**). This scientific conference attracted approximately 700 participants from academia and clinicians. Cátia Gonçalves, Reuma.pt Study Coordinator, and Ana M. Rodrigues, Reuma.pt National Coordinator and Assistant Professor at NOVA Medical School, presented the iPROLEPSIS project, its goals, and clinical studies. Portuguese Rheumatology centres were invited to participate in the iPROLEPSIS-PDPID study, marking a significant step in advancing the project research.



Figure 26 XXV Congresso Português de Reumatologia

British Society for Rheumatology Annual Conference, the UK’s leading rheumatology event, bringing together over 2,000 rheumatology professionals, took place on 24-26 April 2024 (**Figure 27**). Dr Laura Coates from the University of Oxford discussed preventing the transition of psoriasis to psoriatic arthritis, including the evidence so far and studies underway with iPROLEPSIS and HIPPOCRATES IMI.

¹⁴ IEEE International Conference, <https://ieeexplore.ieee.org/document/10355708>

¹⁵ Congresso - Sociedade Portuguesa de Reumatologia (spreumatologia.pt)

¹⁶ British Society for Rheumatology Annual Conference
<https://www.rheumatology.org.uk/eventslearning/conferences/annualconference>

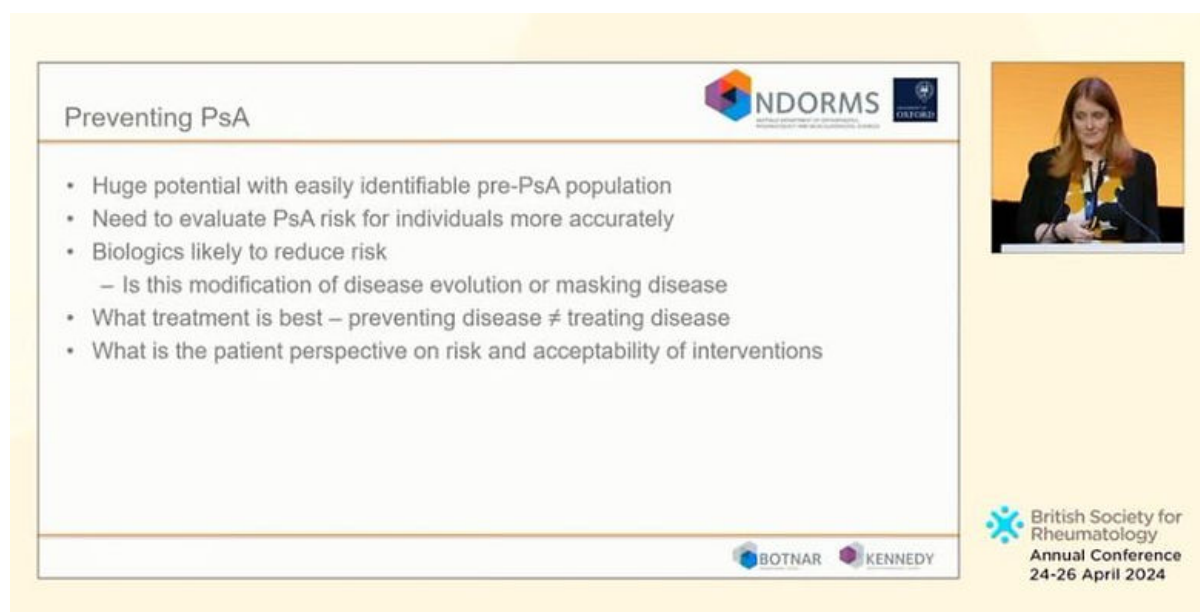


Figure 27 British Society for Rheumatology Annual Conference 2024

The upcoming conferences by the end of M18 include:

- **IFPA Conference 2024**¹⁷ and
- **Petra 2024 conference**¹⁸.

IFPA Conference, the 7th World Psoriasis & Psoriatic Arthritis Conference, will be held on 27-29 June 2024 in Stockholm, Sweden. As a key platform for clinical and research professionals, the conference fosters dialogue and collaboration on advancements in the prevention, diagnosis, and treatment of psoriatic diseases, including related comorbidities. Participants will discuss current achievements and future directions in basic, translational, and clinical research, focusing on patient-centric approaches and global collaboration to improve care worldwide.

The Pervasive Technologies Related to Assistive Environments (PETRA) will take place on 26-28 June 2024 in Crete, Greece. The conference is a highly interdisciplinary conference that focuses on computational and engineering approaches to improve the quality of life and enhance human performance in a wide range of settings: in the workplace, at home, in public spaces, in urban environments, and others. The outcomes of this conference have a broad impact in application areas that include manufacturing, transportation, healthcare, energy systems, security and safety, robotics, biomedicine, environment and conservation, and many others.

2.6.2 Business and industry events

Business, industry and EXPO events are important for informing the industry about the project's vision and exchanging ideas. During the reporting period, the project had one presentation to business representatives and was also showcased at two EXPOs: the 2024 HIMSS European Health Conference and Exhibition and Medica 2023.

In November 2023, project partner Ilja Tchetverikov from the CICERO Foundation presented the results and prospects of the DEPAR¹⁹ cohort and introduced iPROLEPSIS clinical studies

¹⁷ IFPA Conference, <https://conference.ifpa-pso.com/>

¹⁸ PETRA conference, <https://www.petrae.org/index.html>

¹⁹ DEPAR, <https://ciceroreumatologie.nl/depar>

to the representatives of Eli Lilly company in the Netherlands. DEPAR, with the participation of over 900 patients, supports rheumatologists in gaining insight into the treatment and course of psoriatic arthritis. The presentation highlighted iPROLEPSIS as a logical next step in the further development of DEPAR, emphasising the project's vision and its aim to explain psoriatic arthritis inflammation through multi-source data analysis, guiding to a novel personalised digital care ecosystem (**Figure 28**).

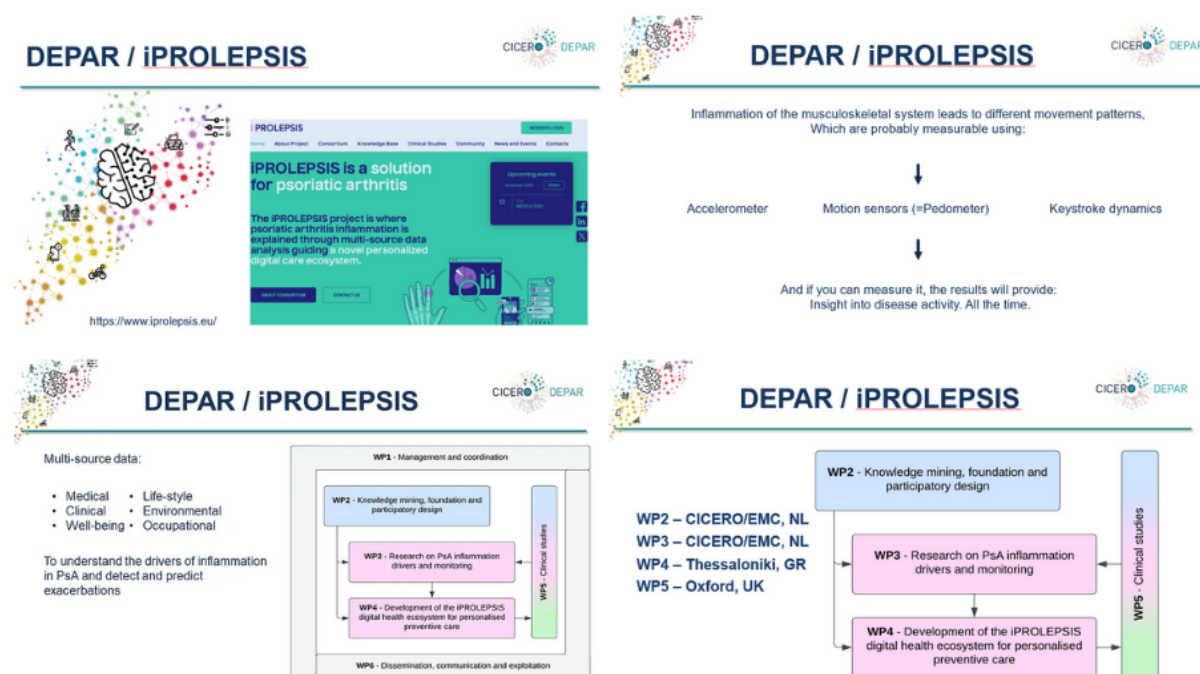


Figure 28 iPROLEPSIS presentation to Elli Lilly company

Project partners from PLUX Biosignals participated in the 2024 HIMSS European Health Conference and Exhibition²⁰, where they showcased the innovative work of the iPROLEPSIS project (**Figure 29**).

The 2024 HIMSS European Health Conference and Exhibition was a major event for the European digital health community, bringing together approximately 2,500 healthcare executives, practitioners and professionals from 84 different countries to Rome. Held from May 29 to 31, the conference showcased the latest advancements in healthcare technology and provided a platform for critical discussions on the future of digital health in Europe and worldwide. HIMSS24 Europe addressed the region's strategic initiatives in digital health, including the AI Act and the European Health Data Space, which aim to position Europe as a leader in digital health.

²⁰ HIMSS Europe, <https://www.himss.org/event-himss-europe>

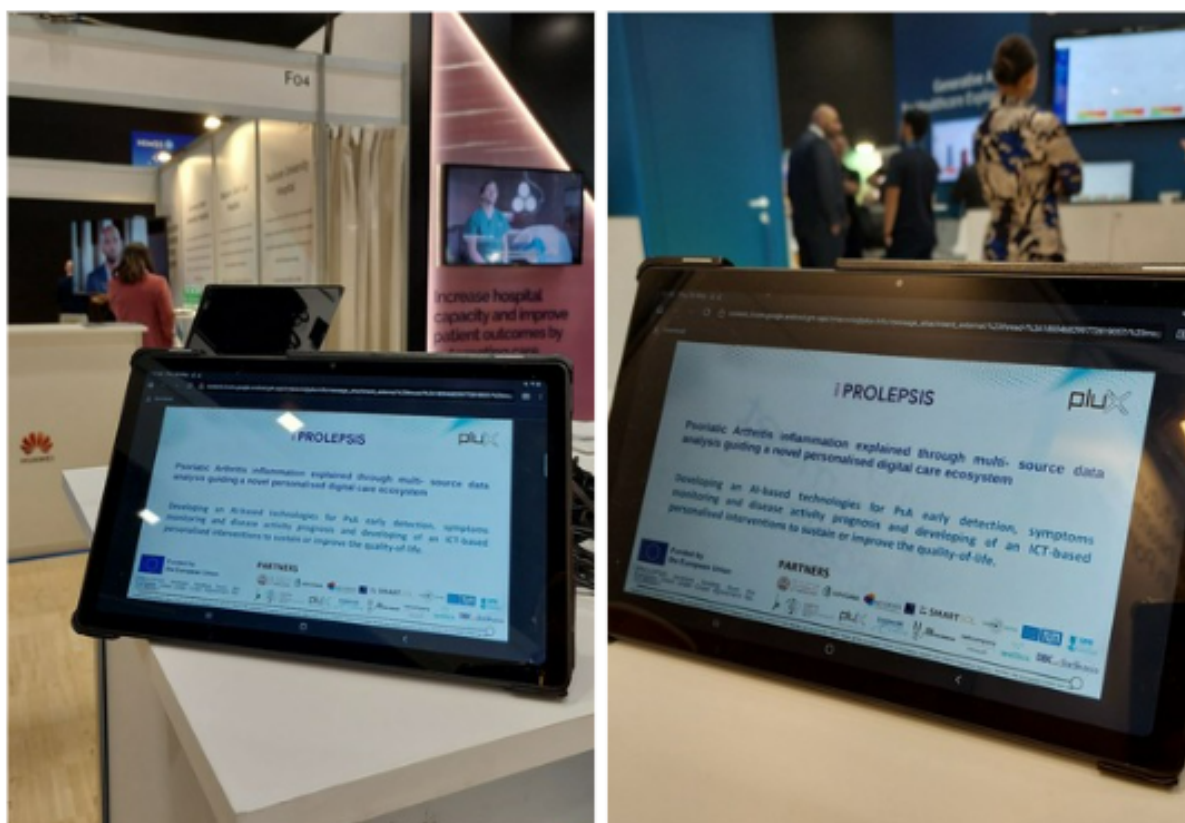


Figure 29 2024 HIMSS European Health Conference and Exhibition

Project partners Amalia Ntemou (INTRA) and Georgios Apostolidis (AUTH) presented the iPROLEPSIS project at the MEDICA²¹ 2023, the leading International Trade Fair in Germany and the world's largest event for the medical sector. In 2023, it brought together more than 81,000 attendees and 4,500 exhibitors from across the globe. Furthermore, each year, leading individuals from business, research, and politics grace this top-class event with their presence. MEDICA 2023 took place from 13 to 16 November 2023 in Düsseldorf, Germany.

²¹ MEDICA Trade fair, <https://www.medica-tradefair.com/>



Figure 30 Medica 2023

2.6.3 Workshops, seminars and special sessions

To date, the project has been presented at International Girls in Information and Communication Technology Day – GirlSteam 2024²² (Figure 31).

This event, organised on 24 April 2024, is part of the larger initiative, International Girls in ICT Day (Girls in ICT 2024), promoted by the United Nations agency ITU (International Telecommunication Union). During the event, Bárbara Ramalho (PhD student from FMH-ULisboa) presented the iPROLEPSIS project and the iPROLEPSIS Games.

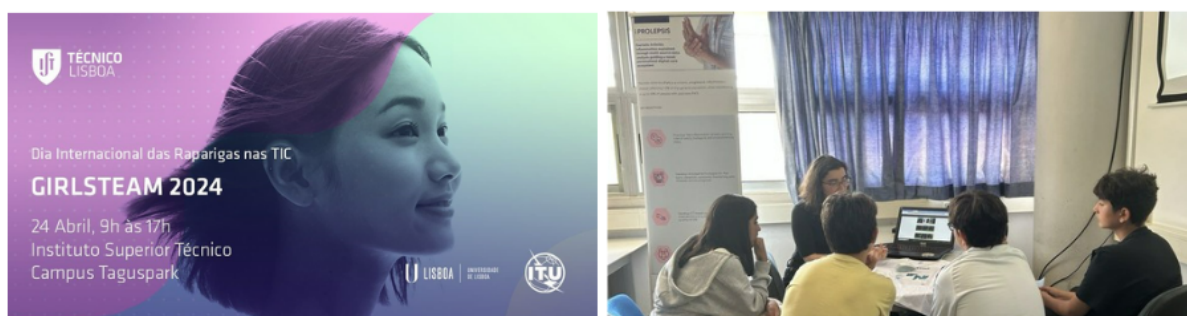


Figure 31 International Girls in Information and Communication Technology Day – GirlSteam 2024

Furthermore, the workshop "AGENT - Multimodal siGnal sensing/analysis, innovative interactive Environments, and persoNalized behavioral modeling for improving qualiTY-of-life"

²² International Girls in Information and Communication Technology Day – GirlSteam 2024 – Técnico Lisboa (ulisboa.pt)

has been accepted in PETRA 2024²³ and will take place by the end of M18. The workshop will be organised by the CERTH, AUTH and FMH-ULisboa in cooperation with the iPROLEPSIS and AI-PROGNOSIS projects.

2.6.4 Clinical focus groups with patients

Clinical focus groups play an important role in the iPROLEPSIS project's development of Digital Health Tools (DHTs) aimed at the early detection and management of psoriatic arthritis (PsA) in psoriasis (PsO) patients. These groups gather valuable insights from patients and healthcare professionals (HCPs) to guide the creation of tools such as the miPROLEPSIS patient app, healthcare practitioner dashboard, biAURA binaural sounds app, Personalised recommendation system, and the Personalised Gaming Suite (PGS).

In total, 6 (six) focus groups with patients have been planned to start from M14, when the study applications will be available to increase the engagement of the study's participants.

The current status of user research and co-creation involved a dedicated focus on advancing the development of the PDPID app. Two methods, focus groups and a survey, were applied to elicit PsA patients' views on their disease and digital biomarkers. All were performed in the four participating countries: The Netherlands (NL), the United Kingdom (UK), Greece (GR), and Portugal (PT). The focus group and survey findings were used to create a Patient Experience Map and five different Personas.

In the PsA focus groups, participants discussed disease activity and symptom fluctuations. They mentioned experiencing a range of symptoms with varying severity and never being completely symptom-free.

In total, 9 focus groups and 1 one-on-one interview involving 39 participants were conducted in 4 different countries. The demographics are described in **Table 4**.

Table 4 Demographics Focus Groups

	UK	NL	PT	GR	Overall
Focus groups (N)	2	4	2 1 Interview 1- 1	2	10 1 interview 1- 1
Participants (N)	5	22	5	7	39

A survey was conducted to identify user requirements for the DHTs of iPROLEPSIS among a broader sample of PsA patients in the participating countries. A total of 299 participants provided responses, with a median age of 56 years (IQR 49-63 years), a balanced gender distribution and a range of educational levels, with a tendency towards medium to higher levels of education.

The initial focus groups and survey have provided valuable insights guiding the early development of DHTs. The planned focus groups from M14 onwards will continue to ensure user engagement and iterative improvement of the tools, enhancing project visibility and supporting the dissemination of project advancements.

2.7 Communication material

At the beginning of the project, in M1-M3, a communication kit was developed, which includes a project poster, flyer, and roll-up poster. These materials reflect the project's brand and

²³ PETRA 2024, <http://www.petrae.org/workshops/AGENT.html>

present a summary of key information about the project. In **Figure 32** the iPROLEPSIS flyer and poster are presented, respectively.

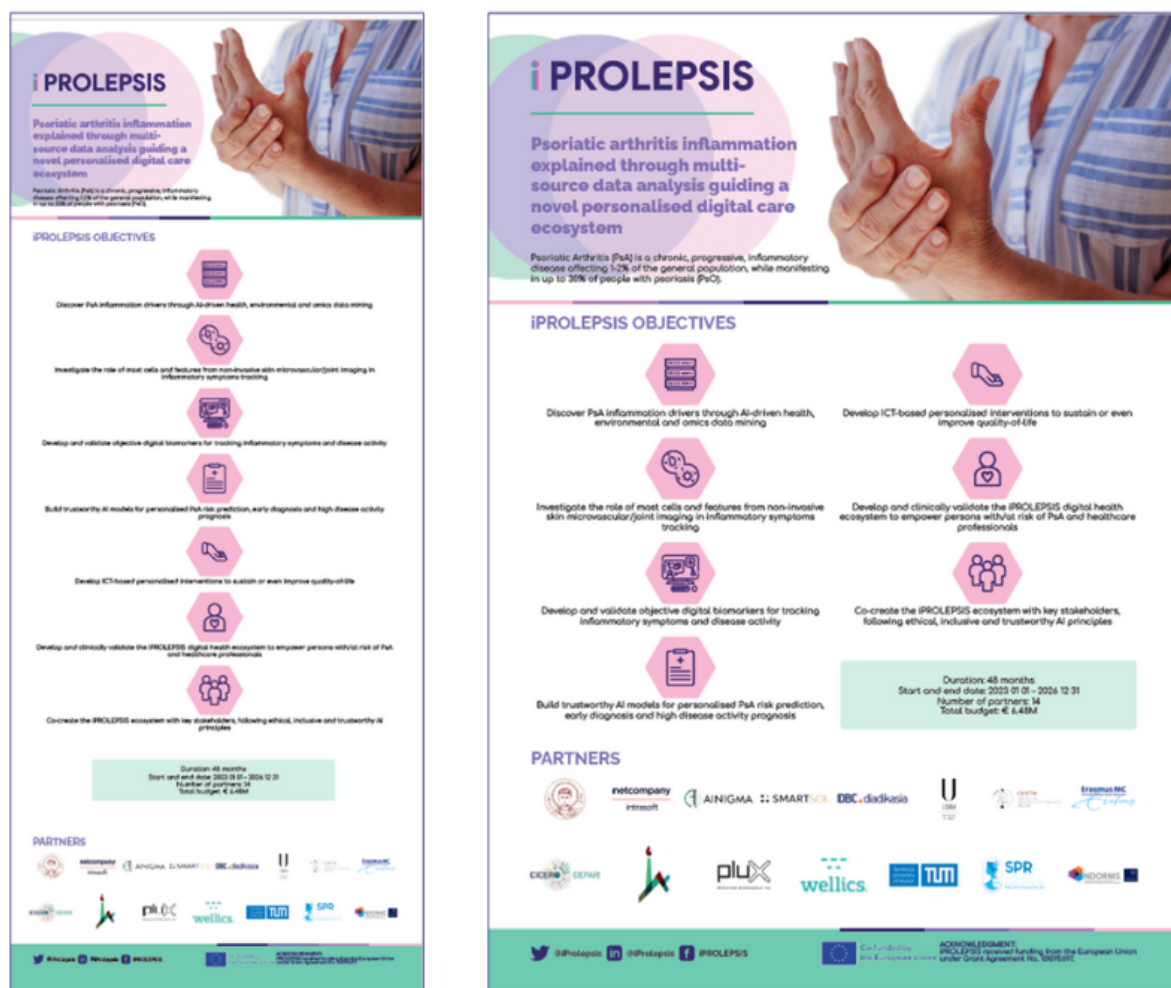


Figure 32 iPROLEPSIS poster and flyer

The materials are accessible for dissemination on the project website under the section Knowledge Base “Promo materials”²⁴.

The project flyer/poster is intended to be used in various contexts to promote and raise awareness about the iPROLEPSIS project, including conferences, workshops, various events and presentations. A roll-up banner is intended to be used as a promotional and informative tool at events, conferences, exhibitions, workshops, and other public events.

To date, the roll-up banner and flyer have been used in the plenary meeting, International Girls in Information and Communication Technology Day – GirlSteam 2024, and Medica 2023 (**Figure 33**). Furthermore, because of events, more than 80 leaflets have been handed out by iPROLEPSIS partners.

²⁴ Communication material, <https://www.iprolepsis.eu/promo-materials>



Figure 33 iPROLEPSIS flyer and roll-up displayed at events

2.8 PsA educational material

In close collaboration with project partners and patient organisations, it was determined that the educational resources developed within the iPROLEPSIS project should aim to empower people with PsA, provide information to support better health outcomes and quality of life and increase engagement with the project.

To fulfil these aims, a handbook for people living with PsA and a set of 18 infographics were developed. A draft version of the handbook was finalised in M7 and was subsequently reviewed by project partners and patient-research partners. A section on nutrition and physical exercise was authored by FMH-ULisboa. All clinical partners contributed with relevant information about their national legislation on reasonable workplace accommodations for workers with disabilities and local mental health resources available.

The handbook and infographics target non-specialist audiences, such as patients, their families and caregivers; and provide important information on PsA causes, symptoms, diagnosis and drug treatments. They also explore non-pharmacological interventions, such as diet, physical and occupational therapy, that can help reduce inflammation and positively impact quality of life. Lastly, the impact of PsA on the multiple domains of a person's life (e.g., sleep and fatigue, emotional wellbeing, relationships and sex, fertility, pregnancy and breastfeeding) is discussed, and information is provided on how to tackle or minimise some of the challenges that PsA may pose.

A graphic designer was hired to create visual representations of key information from the handbook and to craft a visually appealing handbook. A finalised version of the infographics is attached to this document (**Annex 1 Infographics**), as well as a preliminary version of the handbook (**Annex 2 PsA handbook**).

The handbook and infographics will be available in the four project languages: English, Dutch, Greek and Portuguese. Translation of the educational materials from English to the other project languages were finalised in M16. Finalised versions of the infographics and handbook in the four project languages should be available in the coming months (M19-M21).

Educational content is planned to be disseminated through various channels, including printed materials, dedicated newsletters, disease-specific webinars, and personalised interfaces within the digital health ecosystem's mobile applications. Additionally, the project website and social media accounts serve as platforms for distribution and engagement.

2.9 Clustering and networking activities

Clustering and networking activities (which is the subject of T6.2) involve establishing networks and connections with stakeholders associated with the project, other similar projects, and initiatives. The goal is to raise awareness, exchange knowledge, and communicate the project vision and outcomes. A preliminary list of R&I projects, initiatives for clustering and networking is already included in D6.2, "Dissemination, exploitation and communication plan" (submitted in M5).

Throughout the M1-M18 period, iPROLEPSIS conducted clustering and networking activities, which encompassed: a) establishment of a partnership with the Digital Health Uptake project, b) collaboration with sister projects, and c) application for Horizon Result Booster services. The said activities are described in detail in the following sections 2.9.1-2.9.3.

2.9.1 Establishment of a partnership with the Digital Health Uptake project

The Digital Health Uptake (DHU) project²⁵, funded through the Digital Europe Programme, is dedicated to aligning policies, strategies, instruments, and activities to promote the adoption of digital health solutions and services across Europe. DHU's efforts are categorised into three key aspects: RADAR, KNOWLEDGE COMMUNITY, and ACCELERATOR.

In the context of building a digital health ecosystem, which is a shared goal of both iPROLEPSIS and DHU, the projects commenced their interaction as of M8. Collaboration possibilities and synergies between the DHU project and iPROLEPSIS were discussed and agreed upon by the project coordinator of the iPROLEPSIS project (Prof. Leontios Hadjileontiadis), and the representative of empirica, the coordinating organisation of the DHU project (Ms. Anett Ruszanov). Mutual promotion of relevant news and events through websites, newsletters, and social media, as well as potential co-organisation of events, were among the identified areas of collaboration.

The iPROLEPSIS project was announced on the DHU website²⁶ (Figure 34). News about the iPROLEPSIS-PDPID study was featured in the DHU newsletter's December 2023 edition (Figure 35).

²⁵ <https://digitalhealthuptake.eu/>

²⁶ Digital Health Uptake project website, <https://digitalhealthuptake.eu/synergies/iprolepsis/>

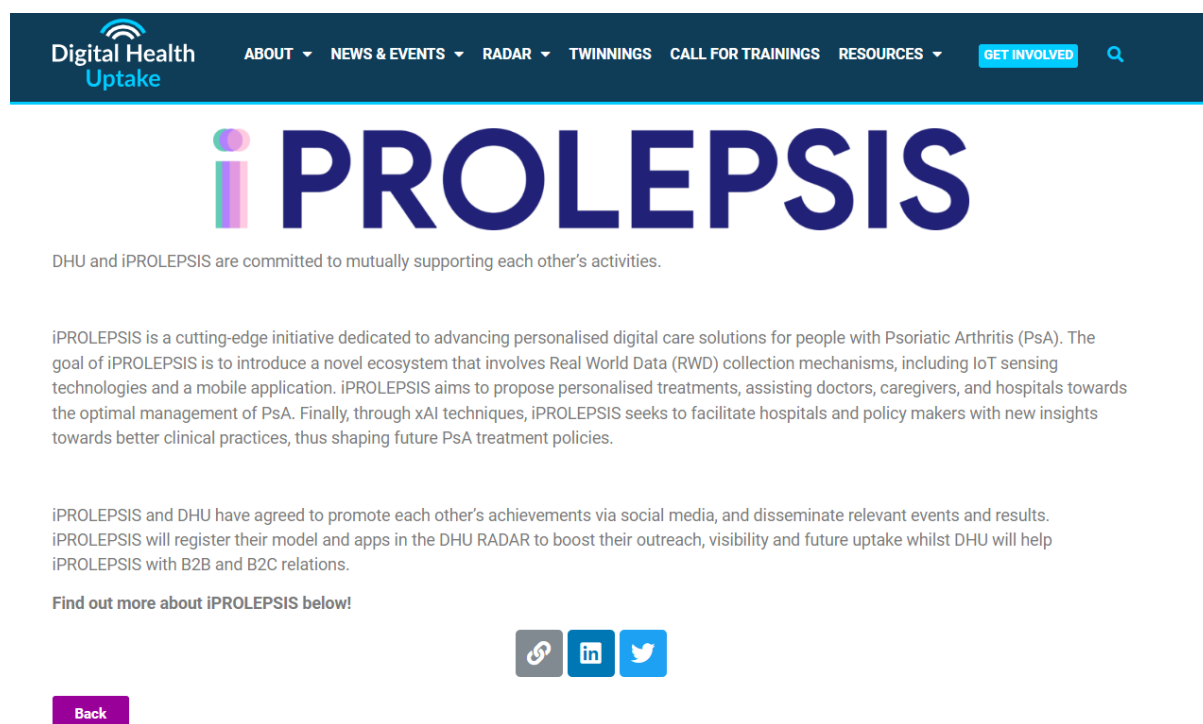


Figure 34 iPROLEPSIS on the DHU website



Figure 35 iPROLEPSIS in the DHU newsletter

Similarly, the DHU project was announced on the iPROLEPSIS website (Figure 36).



Figure 36 DHU on the iPROLEPSIS website

In addition to the website, social media posts were created on different iPROLEPSIS social media platforms (LinkedIn, X and Facebook) to promote this collaboration with DHU (Figure 37).

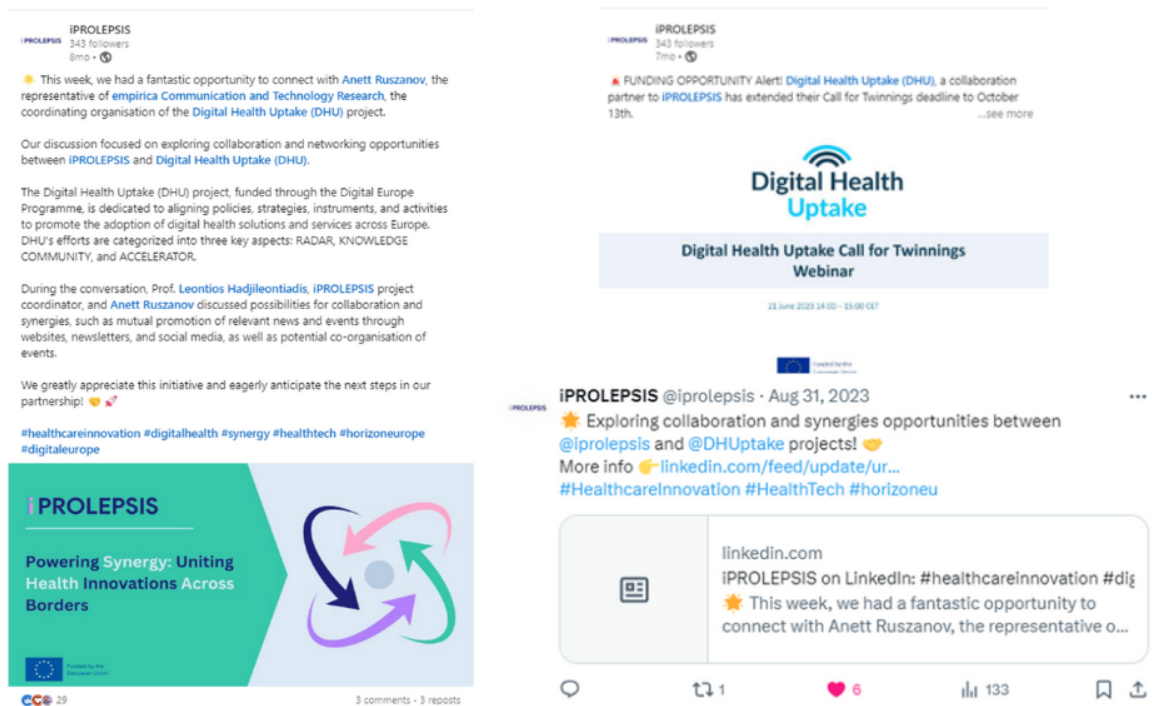


Figure 37 DHU on iPROLEPSIS social media

Information about the DHU project was also included in the iPROLEPSIS newsletter's November 2023 issue²⁷ (Figure 38).



Synergies and collaboration

In September 2023, iPROLEPSIS formed alliance with the Digital Health Uptake (DHU) project, marking a significant step forward in our commitment to advancing digital health solutions.

The Digital Health Uptake (DHU) project, funded through the Digital Europe Programme, is dedicated to aligning policies, strategies, instruments, and activities to promote the adoption of digital health solutions and services across Europe. The work of DHU is grouped under three key aspects: RADAR, KNOWLEDGE COMMUNITY and ACCELERATOR.

The partnership between iPROLEPSIS and Digital Health Uptake (DHU) will span various channels, encompassing websites, newsletters, and social media platforms. As our collaboration strengthens, we anticipate co-organizing events aligned with our shared mission.

Figure 38 DHU in the iPROLEPSIS newsletter

2.9.2 Collaboration with sister projects

In M13, the establishment of an ecosystem of initiatives began, consisting of projects funded under the call HORIZON-HLTH-2022-STAYHLTH-02-01. These projects are the following: iPROLEPSIS, CARE-IN-HEALTH, GlycanTrigger, IMMEDIATE, miGut-Health, INITIALISE, ENDOTARGET, PROTO, halt-RONIN, PRAESIIDIUM, PREVALUNG EU, INTERCEPT-T2D, and AIDA.

iPROLEPSIS led the initiative to contact the sister project and exchange communication materials with the aim of uploading to each project's website, thus raising awareness of the cluster vision. Subsequently, a "Networking"²⁸ subsection was created on the iPROLEPSIS website (Figure 39), featuring information about sister projects.

²⁷ The iPROLEPSIS newsletter issue No 3, November 2023, https://www.iprolepsis.eu/_files/ugd/981fae_07af6f85a4e940cea725c49061f324c0.pdf

²⁸ Networking subsection, iPROLEPSIS website, <https://www.iprolepsis.eu/networking>



Figure 39 The iPROLEPSIS Networking subsection

In M17 (9 May 2024), in celebration of Europe Day, a joint social media campaign was organised with all sister projects (Figure 40). The campaign aimed to highlight our connection and internationality, as well as our collective contribution to the common goals of understanding risk factors, providing personalised prevention measures, and reducing the burden of chronic diseases.

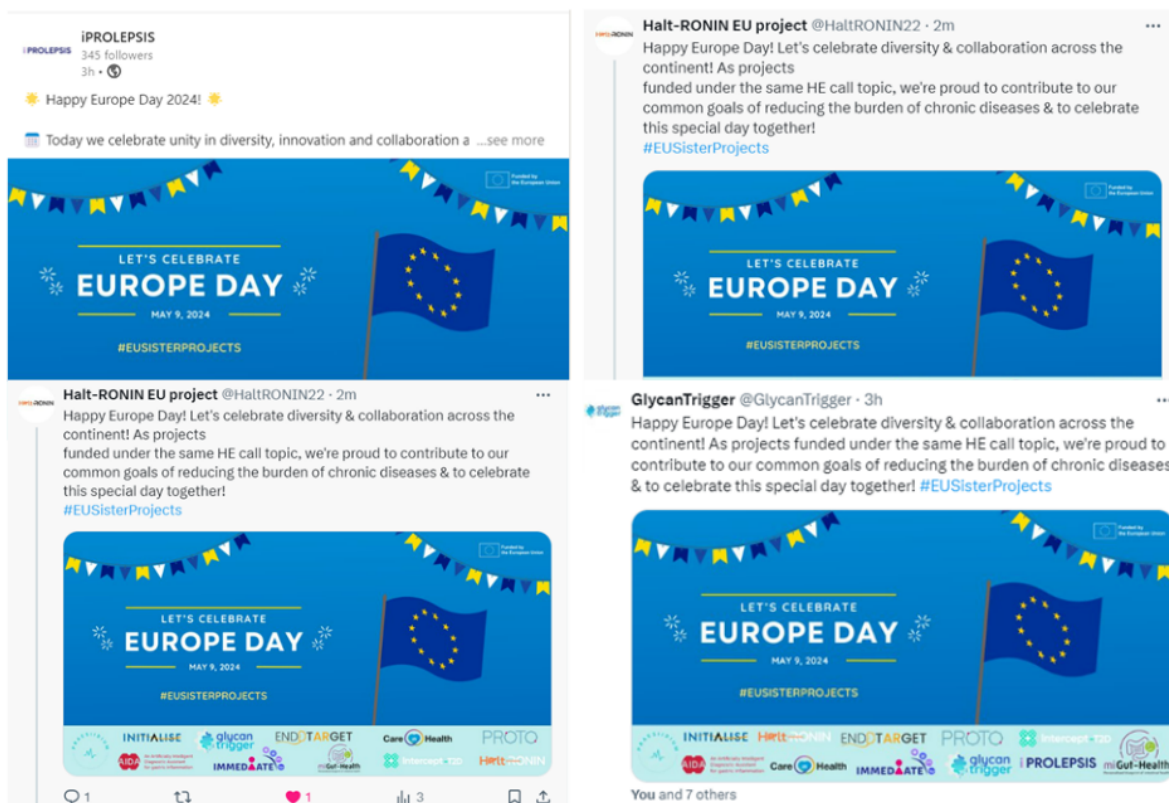


Figure 40 Joint social media campaign with sister projects for Europe Day

In M16, the iPROLEPSIS project shared some interesting ideas with the cluster about networking drivers among sister projects that the cluster can draw inspiration from. These drivers were: identifying common problems, sharing solutions, undertaking common dissemination activities, increasing the impact via collaboration, and providing collective feedback to EC, which will potentially be considered in the future.

2.9.3 Horizon Result Booster services

In M16, iPROLEPSIS applied for the Horizon Results Booster (HRB)²⁹ services Module A and Module C. HRB is an initiative of the European Commission which aims to maximise the impact of publicly funded research within the EU. With our application for Module A, we aim to identify and create a portfolio of R&I project results, while for Module C, we aim to get assistance in improving the project's exploitation strategy.

By leveraging HRB Services, iPROLEPSIS aims to create an R&I portfolio which enables us to showcase the tangible outcomes and advancements achieved through iPROLEPSIS, thereby increasing our project's visibility and impact. In addition, by utilising HRB services, we aim to identify and connect with similar ongoing projects funded by EU, national, and regional initiatives. This collaborative effort will facilitate knowledge exchange, foster synergies, and potentially lead to partnerships amplifying the impact of collective efforts in advancing healthcare.

As of the deliverable preparation, the application has been successfully approved. As a next step, we are working on creating a cluster of projects to start joint dissemination activities.

3 Communication and dissemination KPIs

Monitoring the impact of the different dissemination and communication activities involves a systematic collection of data and reporting of information from all partners. This information is needed to assess the success of the dissemination and communication strategy outlined in deliverable D6.2.

As set in D6.2, the communication and dissemination objectives are to be achieved through the activities of all partners: individually, through each partner's entity activities, and collectively, through the partner's contribution to the global strategy. The goal is to reach the project's stakeholders and build the iPROLEPSIS community.

Key Performance Indicators (KPIs) have been defined in the DoA to measure the impact of each dissemination and communication activity. Section 2 of this deliverable provides an overview and presentation of all performed activities in the period M1 – M18. The current section provides the cumulative results of these activities, which are summarised in **Table 5**.

Table 5 Target and reached KPIs for M1-M18

Dissemination and communication actions	What	When	Target KPIs	Reached KPIs M1-M18
Publications	Peer-reviewed journals	From M18, when solid scientific results are available	20 publications	1
	Business Magazines		4 publications	0

²⁹ Horizon Result Booster, <https://www.horizonresultsbooster.eu/>

Dissemination and communication actions	What	When	Target KPIs	Reached KPIs M1-M18
Event participation	Scientific conference presentations/posters	From M12, when initial scientific results are available	20 presentations/posters	5
	Business/Industry events and EXPOs stands/booths		3 events	3
	Workshops/Special sessions/Seminars	From M18, when solid scientific results are available	8 events 50 expected attendees	2
	Clinical focus groups with patients	From M14, when the study applications are available	6 focus groups	9 focus groups, 1 one-on-one interview
Media presence	Newsletters	From M3 every three months	1000 subscribers	4 newsletters; 251 subscribers
	Website/blog posts	From M1	2 posts/month 1000 visitors/month	Av. 2 posts per month; Av. 182 visitors/month
	Social media posts	From M1	2 posts/month 2000 followers	Av. 2 post/month 649 followers
	Major media (TV/radio) presence	From M36, when tangible results are produced	5 presences in national media 2 presences in EU-level media	0 0
Networking and clustering events			≥4 networking/joint initiatives	1 joint social media campaign with sister projects

The data indicate a mixed level of achievement regarding the dissemination and communication KPIs. There is steady progress in social media presence and newsletter subscriptions, although final targets have not yet been met. The phased nature of the project's activities accounts for the current progress levels. Moving forward, efforts will be intensified in generating and submitting publications as solid scientific results become available. Significant progress has been made in clinical focus groups, providing valuable insights for the development of digital health tools. As study applications are finalised, future efforts will

prioritise expanding these sessions to further engage participants. Notable achievements include participation in business/industry events and growing social media engagement, laying a strong foundation for future dissemination efforts. Continued efforts are needed to align future activities with the project's objectives to enhance the visibility and impact of iPROLEPSIS.

For future reporting, deliverable D6.5, "Midterm report on project visibility and educational material", is scheduled for M32, and deliverable D6.6, "Final report on project visibility and educational material", is planned for M48.

4 Conclusions

The first report on project visibility and educational material, D6.3, accounts for the tasks carried out, communication and dissemination activities undertaken, as well as the progress achieved in developing educational content. It also highlights the progress made by the iPROLEPSIS consortium up to M18. Key achievements include:

- **Project identity:** A cohesive project identity, including logos, banners, and other branding materials, has ensured a unified and recognisable presence across all dissemination and communication channels.
- **Effective Dissemination and Communication:** The project has successfully promoted updates and achievements and engaged with a wide range of stakeholders by using media platforms and dissemination channels, such as social media, newsletters, the project website, interviews, and conferences.
- **Stakeholder Engagement:** Targeted communication activities have ensured project outputs visible to various stakeholders, including researchers, HCPs, industry representatives, people with PsA and the general public.
- **Development of educational materials:** PsA handbook and infographics aim to raise awareness and provide valuable support for patients diagnosed with PsA and people at increased risk. These materials are designed for non-specialist audiences and are available in English, Dutch, Greek, and Portuguese.
- **Networking and clustering:** Various networking activities have been initiated to foster collaboration, aiming to raise awareness, exchange knowledge and communicate the project's vision and outcomes to key stakeholder groups. A partnership with the DHU project and collaboration with other projects funded under the HORIZON-HLTH-2022-STAYHLTH-02-01 call has been established. Horizon Results Booster services are planned to be utilised to create a cluster of projects for joint dissemination activities.
- **Performance evaluation:** utilising KPIs has allowed the project to measure the impact of its dissemination and communication activities effectively. While there is steady progress in areas such as social media presence, newsletter subscriptions and focus groups, certain targets, such as event participation and publications, have not yet reached their goals. The phased nature of the project's activities contributes to the current progress levels. Going forward, efforts will be intensified to align activities with project objectives, particularly focusing on generating and submitting publications as solid scientific results become available.

The project has successfully increased its visibility and engaged a broad range of stakeholders. Moving forward, the project will aim to enhance its dissemination and communication activities and expand its stakeholder network. Continued collaboration and strategic planning will be key to maintaining the project's visibility and maximising its impact. Future reports, including deliverables D6.5 and D6.6, will provide further insights into the project's progress and impact.

Annexes

Annex 1 Infographics

What is psoriatic arthritis?

- Form of inflammatory arthritis ✓
- Causes joint inflammation and pain ✓
- Occurs with the skin condition psoriasis ✓

50:50
Men and women are affected at the same rate

30-50 YEARS
Age when PsA is commonly diagnosed



What are the symptoms of psoriatic arthritis?

Pitting and nail discoloration

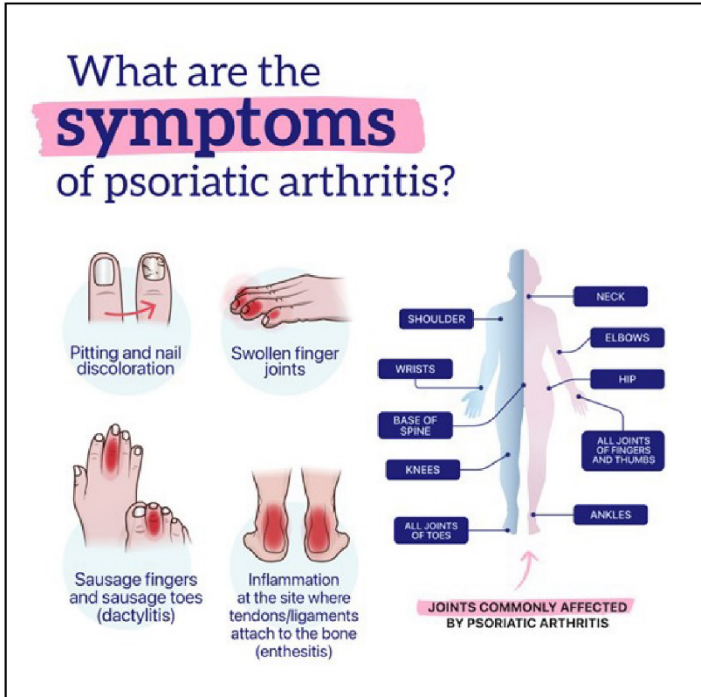
Swollen finger joints

Sausage fingers and sausage toes (dactylitis)

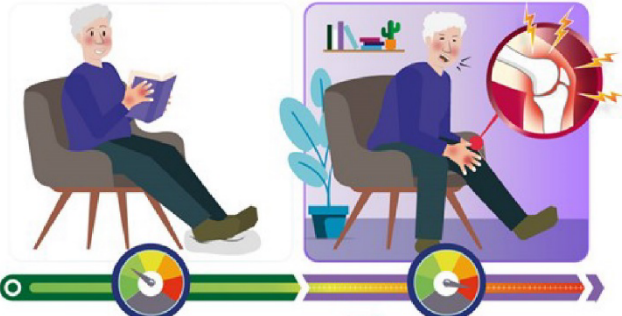
Inflammation at the site where tendons/ligaments attach to the bone (enthesitis)

JOINTS COMMONLY AFFECTED BY PSORIATIC ARTHRITIS

- SHOULDER
- WRISTS
- BASE OF SPINE
- KNEES
- ALL JOINTS OF TOES
- NECK
- ELBOWS
- HIP
- ALL JOINTS OF FINGERS AND THUMBS
- ANKLES



What is a flare?



A time period of increased inflammation and worsening of other symptoms.


A flare can last days or months

How is psoriatic arthritis diagnosed?

No single test can confirm psoriatic arthritis.

- X-rays, ultrasounds and MRI ✓
- Blood tests (including Anti-CCP antibody) ✓
- Tests of fluids around joints ✓

A diagnosis will be made based on your symptoms and a physical examination by your doctor.



Treating psoriatic arthritis

Treatments focus on:

- Slowing down disease progression
- Reducing inflammation
- Relieving pain
- Treating skin symptoms
- Keeping joints as mobile as possible


Pharmacological treatments for psoriatic arthritis

NSAIDs	Steroids	DMARDs
Non-steroidal anti-inflammatory drugs	Corticosteroids	Disease modifying anti-rheumatic drugs
Reduce pain and inflammation ✓	Reduce pain and inflammation ✓	Reduce pain and inflammation ✓
Acts on the symptoms ✓	Act on the symptoms ✓	Can stop psoriatic arthritis from getting worse ✓
Might not be a sufficient treatment ✗	Might be directly injected into the affected joint	Can help prevent damage to joints ✓
	Only used as short term treatment	Some can treat both psoriasis and psoriatic arthritis ✓
		Can take up to 3 months before an effect is felt ✓

Non-pharmacological treatments for psoriatic arthritis

Physical therapy


- Improving mobility and restore the use of affected joints ✓
- Increasing muscle strength to support the joints ✓
- Maintaining fitness ✓
- Preserving the ability to perform daily activities ✓



Non-pharmacological treatments for psoriatic arthritis

Occupational therapy

- Maximising your ability to participate in daily activities and work ✓
- Learning to use assistive devices (e.g., braces, splints) ✓
- Modifying movements to help people protect their joints by performing tasks in different ways than they are used to (e.g., using both hands) ✓



Lifestyle and psoriatic arthritis

Always **warm up well** before practicing physical exercise. **Don't stop moving** just keep going even if in at slower pace.

DO PHYSICAL EXERCISE

DO EAT WELL

DON'T SMOKE

LIMIT YOUR CONSUMPTION OF ALCOHOLIC OR SUGARY DRINKS

Work and psoriatic arthritis

You can carry on working

Positive effects

- Can provide a sense of purpose
- Promotes full participation in society
- Contributes positively to your emotional and physical wellbeing
- Your employer is legally obligated to make reasonable accommodations to your working environment.

i You have options and rights! Get in touch with your labour union or lawyer, if you are unsure about your rights.

Sleep hygiene and psoriatic arthritis



Develop a regular sleep routine. that is, go to bed and get up at a similar time each day



Avoid caffeine, alcohol and large meals before you go to bed



If you smoke, try to **stop smoking**, or at least **do not smoke close to bedtime**



While you should avoid energetic exercise close to bedtime, **gentle exercises may help reduce muscle attention**



A **warm bath** before bedtime may help **ease pain and stiffness**



Listen to **soothing music** before going to bed



Avoid watching TV and using computers, tablets or smartphones in your bedroom



Make sure your **bedroom is dark, quiet** and at a **comfortable temperature**

How to better cope with fatigue



Problem solving

Identify factors / tasks / chores / activities that are contributing to your fatigue

Think about solutions that could help **minimise the impact** of these factors/tasks/chores/activities

Prioritising

Organise your tasks / chores / activities by order of importance

Planning

Plan the tasks/chores/activities you want to complete in a day or week

Make sure to include activities that you **enjoy and can improve** your mood/wellbeing

Do not beat yourself up if you cannot stick to the plan

Pacing

Do not use your energy all in one go

Break the planned tasks / chores / activities into smaller portions that can be spread out over the course of a day, a week or even longer

Psoriatic arthritis and mental health

Be kind to your joints and your mind.

Living with psoriatic arthritis can take a toll on your mental health.

You need to **treat mental health symptoms as seriously as physical symptoms.**

Remember that **you are not alone.** If you need extra support, we are here to help you.

256 573 881

24 Hour Hotline from X institution

Psoriatic arthritis and relationships

Difficulties are normal in any relationship. Don't let them and PsA affect yours and remember

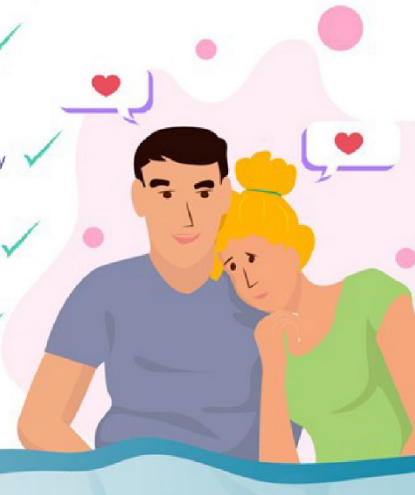
Talk it through with your partner

PsA might

- Reduce your enjoyment** of sex and other activities you share with your partner
- Affect your mood and self-esteem**
- Impact your ability to contribute to household** and family related duties
- Lead to financial worries** if your condition affects your ability to work

Sex and psoriatic arthritis

- ✓ **Talk openly with your partner** about your concerns
- ✓ **Keep active** as physical exercise can help you strengthen your muscles and support your joints
- ✓ **Take painkillers** approximately one hour before having sex to minimise pain
- ✓ **Try different positions and use cushions, pillows or furniture** to support your body
- ✓ Remember that there are **multiple ways to achieve sexual satisfaction**



Pregnancy and breastfeeding

- ✓ Many **arthritis medications are safe** during pregnancy and breastfeeding. Discuss your treatment plan with your rheumatologist.
- ✓ Although there isn't much information on how PsA affects pregnancy, a **normal pregnancy is the rule**
- ✓ **Don't stop taking your medication**
- ✓ Studies suggest that **PsA and its treatment won't impact your ability to breastfeed**, if you wish to do so.





Annex 2 PsA handbook

PsA handbook is available in project's SharePoint³⁰ and also presented below.



³⁰ <https://t.ly/ewqbl>

What causes psoriatic arthritis?

While psoriatic arthritis can occur at any age, most people present their first signs and symptoms at 30-60 years. Psoriatic arthritis is most likely to be diagnosed within the first ten years of the psoriasis diagnosis (3).

Psoriatic arthritis affects both sexes equally. However, the manifestations in terms of severity and impact of the disease differed between sexes. Men are more likely to have involvement of the lower and peripheral joints (e.g., fingers, knees and toes), whereas women are more likely to experience impaired quality of life and severe limitations in function (5).

Researchers are not sure why some people develop psoriatic arthritis. It is thought that certain genes inherited from parents and grandparents can make a person more likely to develop psoriatic arthritis (2, 6).

10

In people with a higher genetic predisposition to develop psoriatic arthritis, the condition can be triggered by environmental factors, such as:

- an infection (9),
- an accident or injury (10, 11),
- being overweight (12),
- smoking (13, 14).

Psoriasis and psoriatic arthritis are not contagious. You cannot catch psoriasis or psoriatic arthritis from other people.

11

What are the symptoms of psoriatic arthritis?

Psoriatic arthritis symptoms usually develop slowly, that is, many people are unaware that they are developing psoriatic arthritis (Figure 1). Although symptoms can develop suddenly in rarer cases.




Figure 1: Symptoms of psoriatic arthritis.

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Some of the main symptoms include (15):

- pain in one or more joints;
- swelling in one or more joints;
- stiffness in one or more joints that lasts for 30 minutes or longer.

These symptoms are caused by inflammation and can affect any joint in the body. See Figure 2 for the most commonly affected joints.

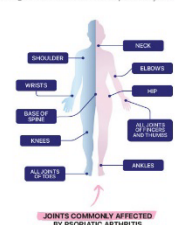


Figure 2: Joints commonly affected by psoriatic arthritis.

13

Psoriatic arthritis can cause pain and swelling in the entheses, that is, places in the body where tendons and ligaments connect to the bones (16). When the entheses become inflamed it is known as enthesitis.

Enthesitis pain can spread along a wider area than joint pain. It frequently occurs on the back of the heel or on the bottom of the foot, which can make standing or walking difficult. Affected areas feel tender to touch even when just a small amount of pressure is applied. The knees, hips, elbows and chest can also be affected by enthesitis. Many people with psoriatic arthritis have swollen fingers or toes, a condition that is known as dactylitis (16) (Figure 3).

Psoriatic arthritis can also cause small round dents in fingernails and/or toenails, a condition known as pitting. The nails can change colour, become thicker, or even lift away from your finger (16).

People living with psoriatic arthritis may feel very tired (fatigued) and some may have a low-grade fever. Fatigue does not get better with rest.

Psoriatic arthritis symptoms may come and go. A period of increased inflammation and worsening of other symptoms is called a flare. A flare can last for days or months.

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How is psoriatic arthritis diagnosed?

A timely and accurate diagnosis is an important step for optimising care and improving long-term health outcomes (16).

If you have been diagnosed with psoriasis in the past, and symptoms of arthritis (e.g., painful or swollen joints) have started more recently, you may have developed psoriatic arthritis. However, the symptoms of psoriatic arthritis can look like other health conditions. Make sure to see your healthcare provider for a diagnosis.

The doctor you see first may depend on whether you have previously been diagnosed with psoriasis. If you develop symptoms of arthritis in your primary care or skin-doctor should refer you to a rheumatologist – a doctor who specialises in joint conditions – for an assessment. Tell your doctor if you have a history of psoriasis and/or psoriatic arthritis in your family.

Currently, no single test can confirm psoriatic arthritis (16). A diagnosis will be made based on your medical history, symptoms, and a physical examination by your doctor.

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Your doctor may order X-rays or other types of imaging, such as ultrasound scans and magnetic resonance imaging (MRI), to look for changes to your bones and joints. Imaging studies will help your doctor determine the type and pattern of joint involvement, which can also help them distinguish between arthritis types.

Blood tests, such as erythrocyte sedimentation rate and C-reactive protein, can help to identify inflammation. Your doctor may also order tests for rheumatoid factor and the anti-CCP antibody to rule out rheumatoid arthritis and HLA-B types to look for your genetic predisposition to spondyloarthritis.

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How is psoriatic arthritis treated?

DRUG TREATMENTS

While there is no cure for psoriatic arthritis, there are multiple drug treatment options that work to control the disease and its symptoms (8). Drug treatments specific for psoriatic arthritis focus on:

- slowing down the progression of the condition;
- reducing inflammation;
- relieving pain;
- treating skin symptoms;
- keeping joints as mobile as possible.

For most people, treatment for psoriatic arthritis will involve trying several different medications. Since many people with psoriatic arthritis have psoriasis, managing the condition can seem like treating two diseases. Some treatments work on both diseases, while others work mainly on the arthritis or skin problems.

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Every person diagnosed with psoriatic arthritis is different. Doctors recommend certain treatments depending on:

- how many and which parts of the body are affected;
- how severe the disease is;
- drug allergies and other health conditions;
- current medication use.

Many times, people with psoriatic arthritis may need to take more than one drug at the same time to control the disease – this is called combination therapy. Combination therapy can allow for lower doses of each individual drug to be used.

During flares, additional medications may be added temporarily or for the longer term. It is important to be involved in shared decision making with your doctor and adhere to the treatment plan. You should communicate any issues with medications, such as side effects or difficulty adhering to the treatment plan, so the effective steps can be taken to address the problems).

TREATMENT FOR THE ARTHRITIS

The over the counter and prescription medicines for psoriatic arthritis include:

- non-steroidal anti-inflammatory drugs (NSAIDs);
- steroid medication (corticosteroids);
- disease-modifying anti-rheumatic drugs (DMARDs).

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Non-steroidal anti-inflammatory drugs (NSAIDs)

NSAIDs can help relieve pain and reduce inflammation, but they might not be enough to treat symptoms of psoriatic arthritis (PsA). There are two types of NSAIDs:

- traditional NSAIDs, such as ibuprofen, naproxen, and diclofenac;
- COX-2 inhibitors, such as celecoxib and etoricoxib.

Like all medicines, NSAIDs can have side effects. Your doctor will take precautions to reduce the risk of side effects by prescribing the lowest dose necessary to control your symptoms for the shortest time possible.

NSAIDs can sometimes affect the stomach and intestines, causing digestive problems such as indigestion and stomach ulcers (7). A medication called a proton pump inhibitor (PPI), such as omeprazole or lansoprazole, may also be prescribed to help protect the stomach.

Chronic treatment with NSAIDs can also increase the risk of heart attacks, strokes, and other heart problems (7). Please, let your doctor know if there are risk factors that may increase your overall risk, for example, smoking, high blood pressure, high cholesterol, diabetes, or a family history of heart disease.

Some people have found that taking NSAIDs made their psoriasis symptoms worse. Inform your doctor if this happens to you.

19

Steroid medication (corticosteroids)

Like NSAIDs, corticosteroids can help reduce inflammation and pain (18).

If you have a single painful and/or swollen joint, your doctor may inject the medication directly into the joint. The effect can last from a few weeks to several months. However, having too many steroid injections in the same joint can damage the surrounding tissue and, then, your doctor will usually not recommend more than three injections per year.

When lots of joints are inflamed, corticosteroids can be taken as a tablet, or as an injection into the muscle. However, doctors are cautious about this because corticosteroids can cause side effects, such as weight gain and osteoporosis, increased risk of infection and cardiovascular events, if used for long periods of time. Because of these side effects, your doctor will prescribe you the lowest dose necessary to control your symptoms for the shortest time possible. Psoriasis can flare up when you stop using oral corticosteroids.

Disease modifying anti-rheumatic drugs (DMARDs)

DMARDs are powerful medications that reduce inflammation and can stop psoriatic arthritis from getting worse (19). DMARDs can help prevent damage to your joints.

Many DMARDs will treat both psoriasis and psoriatic arthritis. Because the type of medicine treats the cause of your condition and not the symptoms, it can take up to three months before you feel an effect. Therefore, it is important to keep taking the medication, even if it does not seem to be working at first.

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Like all drugs, DMARDs can have some side effects. While DMARDs can be very effective, these medications reduce the activity of the immune system (immunosuppressant) and raise the risk of an infection. However, it is important to remember that not treating psoriatic arthritis could lead to permanent bone and joint damage. There are three types of DMARDs as described in Table 1.

Table 1: Types of disease modifying anti-rheumatic drugs.

Traditional	Biologic	Targeted
Traditional DMARDs (sDMARDs) have been used the longest and have a broad immunosuppressing effect. These medicines are usually taken by mouth. Example: methotrexate, sulfasalazine.	Biologic DMARDs (bDMARDs) change key steps in the inflammatory process and generally work more quickly than traditional DMARDs. These drugs are usually injected. Example: adalimumab, etanercept.	Like biologic DMARDs, targeted DMARDs (tDMARDs) block key steps in the inflammatory process. These medications are usually taken by mouth. Example: tofacitinib.

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TREATMENT FOR THE PSORIASIS

The over-the-counter and prescription medicines for psoriasis include:

- topical medications made from vitamin D, derivatives of vitamin A, salicylic acid, coal tar or corticosteroids;
- phototherapy that uses ultraviolet light (UVB) may be prescribed to treat and lessen skin rashes. Only your doctor should prescribe phototherapy, do not try to use sunlight or tanning beds to treat your skin on your own;
- some DMARDs and biologic therapies used for arthritis can also help the psoriasis.

VACCINES

If you have psoriatic arthritis, you may have a higher risk of infection and infections may be more severe (20). This can be due to the arthritis itself or its treatment.

Psoriatic arthritis, which caused by a fault of the immune system, can make you more vulnerable to infections. In addition, some of the drugs used to treat psoriatic arthritis (e.g., DMARDs and/or biologics) dampen down the immune system. That is, they act as immunosuppressants, which can also make you more prone to infection.

An increased risk of infection due to a medical condition and/or drug is called immunosuppression.

Your rheumatologist can provide guidance based on your age and your risk for getting certain infectious diseases (e.g., COVID-19, flu, pneumonia, shingles, or hepatitis B). Vaccines are safe and can help you avoid serious infections.

22



NON-PHARMACOLOGICAL TREATMENTS

Drugs are not the only way to treat or manage the symptoms of psoriatic arthritis. There are many things you can do, alongside taking prescribed medication, that can improve your life quality by lessening pain and inflammation, and improving your overall health.

YOUR VOICE MATTERS

Your experiences – how your therapies are working, what side effects you are experiencing, how your symptoms are affecting you, what challenges you are facing in your daily life due to psoriatic arthritis – are very important pieces of information.

This information is called patient reported outcomes (PROs) and it may be collected via a questionnaire prior to your rheumatology appointment. PROs can help your doctor assess the impact of your disease and better evaluate your treatment plan. These questionnaires can also help you self-manage your condition.

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Some of the questionnaires your rheumatologist may use are:

- **PSAID (Psoriatic Arthritis Impact of Disease)**: measures the impact of your disease on your physical and psychological health;
- **VAS (Visual Analogue Scale)**: a simple tool to track and measure your pain;
- **IPAQ (International Physical Activity Questionnaire)**: measures the types of intensity or physical activity and sitting time that people do as part of their daily lives;
- **HAFQ (Health Assessment Questionnaire)**: measures your physical function and disability due to arthritis;
- **FACT-F (Functional Assessment of Chronic Illness Therapy - Fatigue)**: measures your fatigue that is caused by the arthritis;
- **WPAI (Work Productivity and Activity Impairment)**: measures impairments in work and activities;
- **HADS (Hospital Anxiety and Depression Scale)**: measures the levels of anxiety and depression;
- **PsAQoL (Psoriatic Arthritis Quality of Life)**: measures the quality of life in people with psoriatic arthritis;
- **EQ-5D (EuroQol-5 Dimensional)**: measures quality of life in relation to 5 dimensions: mobility, usual activities, self-care, pain and discomfort, and anxiety and depression;
- **SF-36 (Short Form-36)**: measures quality of life and covers 8 domains of health – physical functioning, physical role, pain, general health, vitality, social functioning, emotional role, and mental health.

So, if your doctor or nurse asks you to fill out a questionnaire, please

25

take the time to do it and be honest!

PHYSICAL AND OCCUPATIONAL THERAPY

Inflammation of joints and soft tissues can often lead to extreme pain, immobility, and dysfunction. Additionally, the arthritis can lead to difficulty in daily activities in the home and workplace. Physical and occupational therapy can help you get moving safely and effectively.

Physical therapy is the most impactful if you are experiencing (21):

- loss of motion due to inflammation in the shoulder, wrist, hand, knee, or foot;
- severe arthritis or dystrophy;
- rehabilitative back pain.

Physical therapy will focus on (21):

- improving mobility and restore the use of affected joints;
- increasing muscle strength to support the joints;
- maintaining fitness;
- preserving the ability to perform daily activities.

Occupational therapy can also be helpful, especially if you are experiencing difficulties with everyday activities.

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Occupational therapy can help you maximize your ability to participate in daily activities. Strategies include the use of assistive devices (e.g., braces, splints), and movement modification to help people protect their joints by performing tasks in different ways than they are used to (e.g., using both hands).

SURGERY

Most people diagnosed with psoriatic arthritis will never need joint surgery. However, if joints are severely damaged by the arthritis, or if other treatments do not reduce pain, damaged joints can be replaced by plastic, metal, or ceramic prostheses to reduce pain, and improve function and quality of life.

COMPLEMENTARY TREATMENTS

Some people with psoriatic arthritis feel that complementary therapies can be helpful. However, you should always talk to your doctor before trying complementary therapies.

There is no scientific evidence to support that taking any kind of dietary supplement, such as fish body oil capsules, works in treating psoriatic arthritis.

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In addition, there is not enough scientific evidence to support the use of complementary therapies, such as balneotherapy or acupuncture, as treatments for psoriatic arthritis. Complementary therapies can react with other treatments, so you should talk to your doctor if you are using or thinking of using any.

SELF-CARE AND LIFESTYLE

Sedentary behaviour	Physical inactivity
Sedentary behaviour refers to low-energy activities involving sitting or reclining postures.	Physical inactivity refers to not meeting the recommended levels of physical activity necessary to maintain good health.

Sedentary behaviour

Sedentary behaviour, characterised by prolonged periods of sitting, when accumulated daily for more than 3 hours uninterrupted for periods longer than 30 minutes without interruption, constitutes a risk to health and well-being.

In people living with psoriatic arthritis, studies suggest that sedentary behaviour may contribute to increased joint stiffness, reduced muscle strength, and compromised joint function. Additionally, a sedentary lifestyle may exacerbate symptoms such as fatigue and depression, which are common in psoriatic arthritis. While the exact mechanisms are not fully understood, maintaining an active lifestyle is generally considered beneficial for managing psoriatic arthritis symptoms.

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The risks of sedentary behaviour increase even more when people are inactive, that is, they do not comply with the World Health Organization's (WHO) recommendations for physical activity, described below.

Physical activity

Engaging in regular physical activity has been shown to have numerous benefits for people living with psoriatic arthritis. Physical activity concerns all body movements resulting from muscle contraction regardless of the context in which they are carried out: leisure, transportation to and from places, or as part of a person's work.

Physical activity can help increase joint flexibility, reduce inflammation, and enhance overall joint function. Moreover, physical activity may contribute to better mental health, as it can help alleviate symptoms of depression and anxiety that are often associated with chronic conditions like psoriatic arthritis. Physical activity also plays a role in weight management, which is essential as excess weight can increase joint stress (22).

According to the WHO, it is recommended to accumulate at least >20 minutes per day of physical activity, such as brisk walking (23). This recommendation is also adopted by the European Alliance of Associations for Rheumatology (EULAR).

A 20-minute physical activity of moderate intensity corresponds to an accumulation of around 2000 steps. Considering a functional activity of 4500 steps per day associated with carrying out activities

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of daily living such as grooming, cooking, cleaning, travelling to and from work/school, the WHO recommendations, when expressed in total number of steps per day, represent the sum of the two types of activity and correspond to an accumulation of 6500 daily steps under normal living conditions.

Physical exercise

The most beneficial types of exercise for psoriatic arthritis focus on improving flexibility, strength, and cardiovascular fitness without causing excessive joint stress. Low-impact activities such as swimming, walking, and cycling are often recommended. Strength training exercises, including resistance training and gentle yoga, can help enhance muscle support around the joints.

Water-based exercises are particularly advantageous as they provide buoyancy, reducing impact on the joints. The benefits of these exercises include increased joint mobility, reduced pain and stiffness, improved muscle tone, and better overall well-being.

People living with psoriatic arthritis should adopt a tailored physical activity routine, considering their specific symptoms and limitations.

The IROLEPSIS app intends to help you limit sedentary behaviours, increase physical activity, and improve daily functional capacity with specific and safe training program recommendations (for more information see section "IROLEPSIS").

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Since mechanical stress in the case of an inflammatory crisis can promote the appearance of enthesitis, it is necessary to control inflammation before increasing the level of usual physical activity or starting an exercise programme. In any case, the beneficial effects of physical activity and exercise on disease, well-being and associated comorbidities outweigh the risk of enthesitis induced by mechanical stress, which is low (25).

Diet

While there is no specific diet that can treat psoriatic arthritis, adopting a nutritious and balanced eating plan can play a vital role in managing symptoms and improving overall well-being.

Research suggests that adopting a Mediterranean-style diet (Figure 3, left-hand side), which includes fruits, vegetables, fish, high-quality fats, and vitamins, might lessen the impact of your psoriatic arthritis (26). This type of diet has anti-inflammatory benefits that help manage disease activity. So, trying this eating approach might help you ease your psoriatic arthritis symptoms.

Incorporating omega-3 fatty acids, commonly found in oily fish (such as salmon, mackerel, or sardines), can also have anti-inflammatory effects, potentially reducing joint stiffness and tenderness (27).

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Antioxidants found in colourful fruits and vegetables (such as berries, spinach, and kale) also offer potent anti-inflammatory properties that could alleviate joint inflammation and discomfort in people living with psoriatic arthritis.

Overall, it is recommended to aim for a balanced intake of 2-5 portions of fruits and 3-5 portions of vegetables daily, as these nutrient-rich foods provide essential antioxidants that may contribute to managing joint inflammation and overall health.

Figure 3: Beneficial (on the left side) and harmful (on the right side) dietary patterns. Adapted from Guilliams et al., 2023 (28).

Reducing the intake of sugar, saturated fats, and sodium can help you maintain a healthy weight. Obesity is linked to a higher chance of developing psoriatic arthritis, and limiting the influence of weight management, especially for psoriasis patients who often suffer from

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metabolic syndrome and obesity (29). Excess weight can increase joint discomfort and inflammation, particularly in load-bearing joints such as the hips, knees, and spine). Thus, be mindful of your dietary choices, as these can help you manage your symptoms.

Vitamin D aids in calcium absorption, which is necessary for maintaining healthy bones. Additionally, vitamin D helps boost our immune system, fight off viruses, and control fatigue. It has even been linked to good mood, with a deficiency potentially leading to anxiety and depression.

Vitamin D is a fat-soluble vitamin that our bodies produce when the skin is exposed to sunlight. It can also be obtained from certain foods or supplements. This vitamin has several forms, but the most important ones are vitamin D2 (ergocalciferol) and vitamin D3 (cholecalciferol). Vitamin D3 is the form that our skin produces naturally in response to sunlight. Research indicates that people with psoriatic arthritis often have lower vitamin D levels than others (30).

Having enough vitamin D might help ease some psoriatic arthritis symptoms. The best way to ensure this is through adequate sun exposure. Spending around 10 to 30 minutes in the sun between 10 AM and 3 PM, at least twice a week, is generally sufficient for most individuals to produce enough vitamin D. The exact time needed depends on factors such as skin type, latitude, altitude, and season.

The Medical Board of the National Psoriasis Foundation recommends vitamin D supplementation for psoriatic arthritis patients and encourages overweight or obese patients to explore weight reduction through a controlled diet (8). However, you must seek advice from your doctor.

Hydration is another key aspect often overlooked, but crucial in managing psoriatic arthritis. Though there are no specific hydration guidelines for people with psoriatic arthritis, drinking around two litres of water daily not only supports maintaining overall health (32), but also helps in joint lubrication and efficient functioning, easing

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discomfort associated with movement.

Some individuals find that certain foods may trigger or exacerbate their psoriatic arthritis symptoms. While these triggers can vary among individuals, common contributors include red and processed meat, low-quality fats, salt and additives, and refined carbohydrates (Figure 3, right-hand side). Monitoring your diet and identifying potential trigger foods through a systematic dietary approach or under the guidance of a healthcare professional can help manage pain, fatigue, and flare-ups (33).

It is essential to find guidance from a healthcare provider or a dietitian with expertise in psoriatic arthritis to develop a personalised dietary plan (28) aligned with individual preferences and needs. A personalised plan aims to guarantee sufficient nutrient intake, manage weight, and promote overall well-being, addressing the unique challenges associated with psoriatic arthritis. Moreover, embracing a healthy lifestyle, including consistent physical activity, stress management, and a well-balanced diet, holds significant potential to improve the quality of life for people with psoriatic arthritis.

Smoking and alcohol consumption

Smoking is bad for your overall health, as it increases the likelihood of potential complications, such as heart problems and cancer. Smoking can also make you less sensitive to treatment and worsen your psoriasis symptoms (34, 35).

Alcohol can interfere with the effectiveness of some drugs or increase side effects (36, 37). Some studies also suggest that alcohol may act as a trigger for flare-ups (38).

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How will psoriatic arthritis affect me?

WORK

Work can provide a sense of purpose, identity, achievement, and a supportive social network, contributing positively to your emotional and physical well-being.

While your condition may pose some challenges, people living with psoriatic arthritis can continue to work as long as their profession does not exacerbate their symptoms and worsen their health. People with certain health conditions have direct rights set out in law, designed to protect them against direct and indirect discrimination in the workplace.

Your employer is legally obligated to make "reasonable accommodations" to your working environment and practices to ensure your condition does not prevent you from doing your job to the best of your ability and in a comfortable and safe environment.

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In the European Union, the definition of reasonable accommodation at work was introduced by Article 5 of the Employment Equality Directive (Directive 2000/26/EC): "shall take appropriate measures, where needed in a particular case, to enable a person with disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer". This directive has been transposed into national law in all EU member states.

Research has shown that people who need workplace accommodations and effectively use them are more likely to keep a job and stay productive than those who do not use workplace accommodations (39).

However, asking for workplace accommodations can be difficult. You may be concerned about being treated differently and negative reactions from your supervisor or colleagues. For this reason, you may prefer to negotiate informal workplace accommodations rather than seeking formal accommodations.

Some of these accommodations may include those supported by the American College of Sports Medicine guidelines for physical activity and public health (40) and the GO! (2020) initiative, which defines joint limits to safeguard musculoskeletal health. By aligning workplace practices with these scientifically supported guidelines, employers and healthcare professionals can better accommodate the needs of their employees, fostering an inclusive and supportive work environment.

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Some examples follow:

Recommendation #1:
Avoid working for prolonged periods in the same position, whether sitting or standing. During the work shift:
 • a continuous period of time in the standing position should not exceed 1 hour;
 • the total time spent in a standing position should not exceed 4 hours;
 • continuous sitting should be limited to 2 hours;
 • when periods are dedicated to holding meetings, the duration of which should be reasonable, consideration should be given to the possibility of having them while standing or walking (41).

Recommendation #2:
Take frequent breaks throughout the shift. Please note that the definition of "breaks" must consider the following characteristics:
 • Frequency: number of breaks/interruptions during the working day;
 • Duration: micro-breaks (less than 2 minutes); short breaks (typically those that occur in the morning or afternoon, lasting between 7 and 10 minutes); or long breaks (meal breaks); and
 • Type: passive or resting and active (including stretching or walking) (42).

Thus, in an 8-hour working day, a worker should take at least a 7-10 minute break after consecutive 90-minute work periods. Recovery periods can include moments of rest or the performance of any other task to recover the muscle groups that have been worked. Within a period of at least 90 minutes, a worker should enjoy at least 30 seconds after 20 minutes of work.

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Both recommendations aim to address the prolonged exposure to low-intensity static load by limiting the duration of this exposure. These interventions help to alleviate fatigue and pain symptoms in the short term, and to prevent work-related musculoskeletal injuries in the long term. Active breaks add value; however, they do not replace the need to introduce diversity in the intensity of the mechanical load, such as rotational planes related to the job's demands (43).

Please note that these recommendations refer to low-intensity, physically demanding tasks. Other recommendations apply to high-intensity tasks, such as those involving manual force.

Recommendation #3:
Physical changes to workstations
 • work surfaces (desks) that allow alternation between standing and sitting, alone or combined with a training and information program for workers, reduce sitting time by approximately 60 minutes per working day (in the medium term, i.e., up to 2-12 months). This change in physical working conditions can bring about a behavioural change, with repercussions in an average reduction of 80 minutes in total sitting time per day (not new from work) and in the average duration of consecutive periods of sitting (67 minutes) (42, 44).

Even though workplace adaptations are consigned in the law, many people living with rheumatic and musculoskeletal diseases report a lack of understanding from their employers, colleagues, and workplace doctor(s).

You have options and rights. It is important to understand them and fully explore all available alternatives. If you are unsure about your rights in the workplace, please get in touch with your HR or occupational health department. More information can be found below: The Advisory, Conciliation and Arbitration Service (ACAS) <https://www.acas.org.uk/reasonable-adjustments>

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If you require workplace adaptations, please talk to your assistant doctor about the difficulties you have been feeling and request reports to present to your employer and/or workplace doctor.

SLEEP AND FATIGUE

Pain, anxiety, and side effects of the medication can make it more difficult for a person with psoriatic arthritis to fall asleep and stay asleep throughout the night. In fact, about 40% of people living with psoriatic arthritis report sleep difficulties (45).

Good sleep hygiene habits may help to improve sleep:

- develop a regular sleep routine, that is, go to bed and get up at a similar time each day;
- avoid caffeine, alcohol, and large meals before you go to bed;
- if you smoke, try to stop smoking, or at least do not smoke close to bedtime;
- a warm bath before bedtime may help ease pain and stiffness;
- listen to soothing music or sounds before going to bed;
- avoid watching TV and using computers, tablets, or smartphones in your bedroom;
- make sure your bedroom is dark, quiet, relaxing, and at a comfortable temperature.

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The impact of exercising before bedtime can vary among individuals. It is essential to listen to your body, establish a consistent routine, and pay attention to how evening workouts affect your sleep patterns. If you have specific concerns about your sleep or exercise routine, it is also advisable to consult with a healthcare professional or a fitness expert.

Pros:

- **Improved sleep quality:**
 - For some people, engaging in moderate-intensity exercises a few hours before bedtime may promote better sleep quality. It can help reduce stress and anxiety, leading to a more relaxed state conducive to sleep.
- **Body temperature regulation:**
 - Exercise increases body temperature, and the subsequent drop in temperature after exercise can signal the body that it is time to sleep. This mimics the natural temperature drop that occurs during the evening.
- **Establishing a routine:**
 - Regular exercise, regardless of the time of day, can contribute to better sleep quality. Establishing a consistent exercise routine is often more important than the specific time of day.

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Cons:

- **Stimulating effect:**
 - For some people, intense exercise close to bedtime may have a stimulating effect, making it more challenging to wind down and fall asleep.
- **Body temperature:**
 - While the drop in body temperature after exercise can promote sleep, exercising too close to bedtime may disrupt the body's natural cooling process, potentially interfering with sleep.
- **Individual variability:**
 - People respond differently to exercise timing. Some may find that late-night workouts do not impact their sleep, while others may experience difficulty.

Recommendations (46):

- **Timing matters:**
 - Try to finish exercising at least 2-3 hours before bedtime to allow your body temperature to return to normal and your adrenaline levels to decrease.
- **Listen to your body:**
 - Pay attention to how your body responds to evening workouts. It might be a good fit for you if it helps you relax and improves your sleep.

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- **Experiment:**
 - Everyone is different. Experiment with varying timings of exercise to see what works best for you. If evening workouts regularly impact your sleep, consider shifting them earlier.
- **Moderation is key:**
 - Intense or vigorous exercise close to bedtime might be more likely to interfere with sleep. Opt for moderate-intensity activities in the evening (47).

Nearly 60% of patients living with psoriatic arthritis report high levels of fatigue five or higher on a 10-point scale and consider fatigue a high ranking problem, after joint pain and before skin issues (48).

Problem solving, planning, prioritising, and pacing may help you cope better with your fatigue:

PROBLEM SOLVING

- Identify factors/tasks/chores/activities that are contributing to your fatigue;
- Think about solutions that could help minimise the impact of these factors/tasks/chores/activities.

PLANNING

- Plan the tasks/chores/activities you want to complete in a day or week;
- Make sure to include activities that you enjoy and can improve your mood/wellbeing;
- Do not beat yourself up if you cannot stick to the plan.

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PRIORITISING

- Organise your tasks/chores/activities by order of importance.

PACING

- Do not use your energy all in one go;
- Break the planned tasks/chores/activities into smaller portions that can be spread out over the course of a day, a week or even longer.

EMOTIONAL WELLBEING

Living with psoriatic arthritis can take a toll on your mental health (49, 50). You need to treat mental health symptoms as seriously as physical symptoms.

Poor mental health can cause your psoriatic arthritis to flare, increase pain and fatigue, negatively affect your work and personal relationships, and limit your ability to manage your overall health.

If you feel sad, hopeless, and lose interest in things you used to enjoy, talk to your doctor, and let your loved ones know what you are going through. Your doctor may refer you to useful mental health services such as cognitive behavioural therapy (CBT) and/or they may prescribe you an antidepressant.

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Remember that you are not alone. We are here to help you:


NHS Mental Health services

- <https://www.nhs.uk/its-our-aim-to-improve-mental-health-services/>

VERSUS ARTHRITIS / Psoriatic arthritis

- <https://www.versusarthritis.org/>
- +44(0)20520620

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RELATIONSHIPS AND SEX

Psoarthritis can present a number of challenges in a relationship, namely:

- reduce your enjoyment of sex and other activities you share with your partner;
- affect your mood and self-esteem;
- impact your ability to contribute to household and family related duties;
- lead to financial worries if your condition affects your ability to work.

Although your relationship may change because of psoriatic arthritis, you should remember that most couples go through phases in their relationship that are more or less positive, depending on a number of factors such as stress, work-life balance, or other health conditions.

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talking to your partner about any changes or challenges you may be facing is a great way to improve communication in the relationship and arrive at solutions to please both of you.

If you are not in a relationship and worry about how your condition may affect your prospects of finding a romantic partner, especially if you have visible signs of the condition, keep in mind that most relationships develop gradually and that shared interests are more important than physical considerations.

While sex will not make your psoriatic arthritis worse, it can sometimes be painful when you move an affected joint. Besides the physical aspect, psoriatic arthritis may decrease your sex drive, affect your self-confidence, or make you feel less attractive.

Psoriatic arthritis can sometimes lead to a dry vagina, and thus to uncomfortable sex. If this is the case, water-based lubricants can help you and/or your partner. Oil-based lubricants may irritate your skin or damage condoms.

To help you overcome difficulties with sex, you should:

- talk openly with your partner about your physical and/or emotional concerns;
- keep active as physical exercise can help you strengthen your muscles and support your joints;
- take painkillers approximately one hour before having sex to minimise pain;
- try different positions and use cushions, pillows, or furniture to support your body.

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remember that there are multiple ways to achieve sexual satisfaction, such as kissing, caressing, mutual masturbation, oral stimulation, or even sex aids such as vibrators.

FERTILITY, PREGNANCY, AND BREASTFEEDING

If you are planning to start a family, you should discuss your treatment plan with your rheumatologist, as some medications are not safe in pregnancy. It is completely normal to feel concerned about the effect of your condition on your ability to start a family.

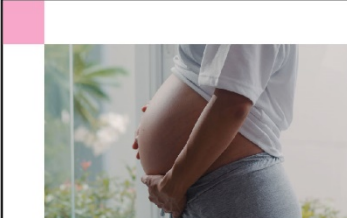
People with arthritis may take slightly longer to become pregnant. It is best to try for a baby when your condition is not very active.

There is a genetic contribution to psoriatic arthritis, that is, the presence of certain genes makes a person more likely to develop the condition. However, this is not a strictly hereditary condition. There are many factors involved in the development of psoriatic arthritis, not just the genes inherited from parents. Therefore, in the vast majority of cases the chances of passing it on to your children are relatively low.

FERTILITY

In women, there is no evidence to support that psoriatic arthritis affects fertility (37). However, a recent study indicated that untreated inflammatory arthritis, such as psoriatic arthritis, may decrease male fertility (32).

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In both women and men, fertility does decrease with age or may be affected by other health conditions. Therefore, some people living with psoriatic arthritis will need fertility treatments. If your psoriatic arthritis is under control, there should be no problem to initiate fertility treatments. Discuss any plans for fertility treatments with your rheumatologist. They can offer specific advice, review your treatment plan, and base with the medical team responsible for your fertility treatment.

PREGNANCY AND BREASTFEEDING

Discuss your plans to start a family with your rheumatologist so that your treatment plan can be adjusted. If you become pregnant unexpectedly, talk to your rheumatologist as soon as possible. All women get aches and pains during pregnancy. As the baby grows, you may feel additional strain on some of your joints, especially on your hips and knees.

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While there is not a lot of information on the effects of pregnancy in psoriatic arthritis, studies have shown that the majority of women living with rheumatoid arthritis experience some form of symptom improvement during pregnancy. However, some women will have a flare after giving birth.

Psoriatic arthritis usually does not affect delivery and you can still give birth through your vagina. If you are considering a caesarean, you should discuss this with your doctors (rheumatologist and obstetrician). It may be necessary to stop some of your medications before the surgery.

You should continue anti-rheumatic drugs that are safe in pregnancy during pregnancy and breastfeeding. This will reduce your chances of any complications during pregnancy and will make flares less likely after giving birth.

Many mothers feel sad, fearful, or anxious in the first two weeks after having a baby. However, if these symptoms last for longer or start later on, you may have post-natal depression, which affects 1 in 10 women after giving birth. It is important to seek medical help if you feel this way.

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Remember that you are not alone. If you need extra support, please speak to your GP or Health Visitor. More information can be found below:

NHS Mental Health services
<https://www.nhs.uk/nhs-services/mental-health-services/>

NHS Postnatal depression
<https://www.nhs.uk/mental-health/conditions/post-natal-depression/overview/>

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iPROLEPSIS

The iPROLEPSIS project, <https://www.iprolepsis.eu/>, which stands for "Psoriatic Arthritis: Information Explained Through Multisource Data Analysis Guiding a Novel Personalised Digital Care Ecosystem", is a collaborative initiative that brings together a diverse research team to address critical questions around psoriatic arthritis.

Currently, early diagnosis of psoriatic arthritis is particularly challenging because there are no specific tests to diagnose this condition and/or to predict which patients with psoriasis are likely to develop arthritis.

The absence of precise diagnostic tools and the challenge of predicting arthritis development contribute to delays in diagnosis and suboptimal responses to treatment, ultimately leading to poorer outcomes for patients.

The iPROLEPSIS project aims to address these unmet needs to improve patient's quality of life by:

- discovering inflammatory drivers of psoriatic arthritis through the digital collection of health and environmental data, and through the analysis of genomics and microbiomes;
- developing and validating digital biomarkers for tracking inflammatory symptoms and disease activity;
- investigating the role of mast cells in the skin-microvasculature network/joints in inflammatory processes in psoriatic arthritis;
- building trustworthy artificial intelligence models for the prediction, early diagnosis, and high-disease activity prognosis;

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- developing personalised interventions to sustain or even improve quality-of-life in people living with psoriatic arthritis;
- developing and validating a digital ecosystem to empower persons with psoriatic arthritis or at risk of developing the condition, and healthcare professionals.

To gain a deeper understanding of the iPROLEPSIS project, we encourage you to explore our official website and connect with us on various social media platforms such as [LinkedIn](#), [X](#), [Facebook](#), and [YouTube](#).

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Other resources

In English:

- Psoriatic arthritis
- Versus Arthritis
- A patient guide to psoriatic arthritis and psoriasis
- Walgreens
- [Raising the Voice of Patients - A Patient's Guide to Living with Psoriatic Arthritis](#)
- Global Healthy Living Foundation
- [A Patient's Guide to Treatments for Psoriatic Arthritis](#)
- Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA)

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