



QSPainRelief

Effective combinational treatment of chronic pain in individual patients, by an innovative quantitative systems pharmacology pain relief approach.

H2020 – 848068

D9.7 - 2nd patient and layman event

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This report reflects only the author's views and the Commission is not responsible for any use that may be made of the information it contains.

Abbreviations

CHDR	Centre for Human Drug Research (project partner)
concentris	concentris research management gmbh (project partner)
COO	project coordinator
EC	European Commission
f2f	face-to-face
GDPR	General Data Protection Regulation
LUMC	Leiden University Medical Centre
NL	Dutch (language) or The Netherlands (country)
PAE	Pain Alliance Europe (member of the Scientific and Ethical Advisory Board)
PD-value	PD-value B.V. (project partner)
PPT	Microsoft PowerPoint
QSP	Quantitative Systems Pharmacology
SC	Steering Committee
ULEI	Leiden University (project partner and scientific coordinator)
Q&A	Questions & Answers
QR	quick response
WP	work package

Authors and contributors

Partner	Name	Contact information	Contribution
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concentris	Nina Donner, <i>WP9 Leader and Co-Author of D9.7</i> Sara Stöber, <i>Project Manager</i>	nina.donner@concentris.de sara.stoeber@concentris.de	Conceptualisation and remote organisation of the event, textual and graphical design of promotional materials, Social Media promotion, Set-up of participant registration, signature / GDPR sheets, remote participation in the event, and social media coverage of the event, Deliverable report writing / final edits / submission to EC
PAE	Deirdre Ryan <i>President</i>	president@pae-eu.eu	Conceptualisation and promotion of the event
PD-value	Jeroen Elassaiss-Schaap <i>Company Owner</i>	jeroen@pd-value.com	PPT lecture and Q&A session
Pijn patiënten naar één stem	Ilona Thomassen-Hilgersom <i>Chairwoman</i>	ilonathomassen@pijnpatientennaar1stem.nl	Panel discussion lead, promotion of the event, patient-language corrections of the registration & promotion materials
ULEI	Liesbeth de Lange <i>Project Coordinator</i>	ecmdelange@lacdr.leidenuniv.nl	Conceptualisation, textual edits of Dutch promotion materials, local promotion and photos of the event, PPT lecture, Q&A session

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1. Executive summary

This deliverable report discusses the organization and outcomes of the second patient event held as part of the Horizon2020 QSPainRelief project, where the Centre of Human Drug Research (CHDR) played a role in the coordination and organisation of the event together with the project coordinator (COO), the project management office (ULEI, concentris) and WP9 leader (concentris), partner PD-value, as well as Pain Alliance Europe (PAE) and the local Dutch patient organisation “Pijnpatiënten naar één stem”. The preparations for the event began in Q2 of 2023, with a meeting held on June 12, 2023, between the Dutch patient organization and the CHDR team. This meeting was followed by multiple meetings steering committee (SC) and the organising committee of the event (described above) to discuss, conceptualise, plan, promote, and organise the meeting in more detail. The event aimed to introduce QSPainRelief to the local Dutch patient community in their own language (NL), discuss pharmacotherapeutic modelling, demonstrate evoked pain tests used in clinical studies, and conclude with a panel discussion that was led by Ilona Thomassen-Hilgersom, the chairwomen of the local Dutch pain patient organisation “Pijnpatiënten naar één stem”.

Throughout 2023, concentris and CHDR provided updates on the progress of the patient event preparations during SC meetings. The agenda was established through SC discussions with the European patient organization PAE, the local Dutch patient organisation, and work package leaders. All promotional materials were designed and prepared with English texts first by concentris, and later translated into Dutch (NL) language by Liesbeth de Lange (COO) or Wouter Bakker (CHDR). The layman terminology of all content was assessed and improved by the local patient representative Ilona Thomassen-Hilgersom and by CHDR's recruitment department. Registration for the event was possible through electronic means via the [online registration form](#) set up by concentris or by calling CHDR, and it was organized as a hybrid event, allowing both physical face-to-face (f2f) attendance and virtual (remote) participation via Microsoft Teams.

Various promotional efforts were made, including multiple social media announcements of the event by concentris, PAE, and “Pijnpatiënten naar één stem”, a special newsletter edition distributed electronically by concentris, distributing print-out posters with quick response (QR) codes (plus CHDR's telephone number) for registration in the CHDR/Leiden region (especially in pain clinics and pharmacies), and by contacting subjects from previous neuropathic pain studies performed at CHDR directly.

At the day of the event on **6th December 2023** at CHDR's auditorium in Leiden, NL, the **total attendance was 34 people**. Of those, **19 people attended f2f**, while **15 people attended the event remotely** via Microsoft Teams. The panel discussion toward the end of the event addressed specific patient questions collected during the online registration process, covering topics such as the measurement of medication effects in healthy people and the inclusion of various pain-related conditions, such as COVID-19-related pain.

The patient event received positive feedback and the panel discussion was lively and well-received, but the involvement of patients and patient representatives could have been better, especially given the extensive promotional efforts that were taken beforehand. The time of year (cold winter weather) may also have dampened f2f attendance. Recommendations by both Deirdre Ryan (PAE) and Ilona Thomassen-Hilgersom (Dutch patient organisation) for future QSPainRelief patient-targeted events included further enhancing visibility and leadership roles for patient representatives during the event and further increasing their involvement in the planning stage. Suggestions were made to allocate more time and resources to reach patients, potentially by presenting QSPainRelief at already established, larger patient events or using more traditional promotion methods (printed newspaper) for the (in average) older target audience. Additionally, there is a call for emphasizing the translation of QSPainRelief findings into the daily lives of patients and how it may impact pharmacotherapy.



Figure 1. Photo collage of the 2nd QSPainRelief Patient and Layman Event. Top left: Host Geert Jan Groeneveld and volunteer Wouter Bakker (CHDR). Top right: Ilona Thomassen-Hilgersom, chairwoman of the Dutch patient organisation *Pijn patiënten naar één stem*, watching the PainCart live demo in astonishment. Middle row: Patients, consortium members, and scientific and ethical advisory board (SEAB) members listening to the presentations and watching Wouter Bakker's live demonstration of the [PainCart](#), evoked pain tests used in clinical studies (bottom row of pictures).

2. Deliverable report

2.1. Organisation, registration, and promotion of the event

As an integral component of the Horizon2020 QSPainRelief initiative, the Centre of Human Drug Research (CHDR) bears partial responsibility for orchestrating essential patient events. The second such event transpired at CHDR on December 6, 2023, with the initial internal preparations commencing in Q2 of 2023. A pivotal milestone was the inaugural meeting held on June 12, 2023, uniting the Dutch patient organization and the CHDR team.

Deliberations during this and future meetings and emails between CHDR, concentris, Liesbeth de Lange (ULEI), Jeroen Elassaiss-Schaap (PD-value), other SC members, PAE president Deirdre Ryan, and Dutch patient representative Ilona Thomassen-Hilgersom encompassed the identification of event topics, duration, format (hybrid), registration procedure, and promotional measures. The consensus was to incorporate the introduction of QSPainRelief's objectives, elucidate the application of pharmacotherapeutic modelling, provide live demonstrations of evoked pain tests employed in clinical studies (live demonstration of CHDR's so-called PainCart), and culminate with a panel discussion, allowing room for participant queries.

Throughout 2023, CHDR provided updates on the patient event preparations during SC telephone conferences involving various work package leaders. More details were strategized together with concentris, Liesbeth (ULEI), Jeroen (PD-value), Ilona (local Dutch patient organisation), and Deirdre (PAE) and other involved work packages via emails to meticulously plan and coordinate the patient event.

After concentris prepared and set up the [online registration](#) in early October 2023 via Google Forms, the registration process started and the event was announced on QSPainRelief's project website and social media channels (LinkedIn and X/Twitter) with various posts, but also on PAE's website and social media channels, and via print materials (posters and flyers) at ULEI, PD-value, CHDR, local pain clinics, and local pharmacies. Continuous promotion via these channels and materials, but also via email and word of mouth continued until the day of the event to reach the best possible number of attendees. The reason for this continued active promotion was that the consortium was aware of the challenging target group, namely elderly, less tech-savvy chronic pain patients who often have trouble travelling or leaving their home, who may suffer from comorbidities that limit active engagement with the outside world (such as depression or anxiety), and who may not be able to plan ahead or register in advance for an event because every day is different (with respect to their personal pain burden) and on the day of an event the pain may just be overwhelming.

2.1.1. Agenda

For the patient event agenda, please view Figure 2. This agenda underwent meticulous development through extensive discussions with the patient organizations and other work package (WP) leaders. The content of the event was rigorously assessed for clarity in laymen language by the organizing entities, patient representatives, and CHDR's recruitment department. This collaborative effort ensured a comprehensive and accessible agenda, aligning with the diverse perspectives of the anticipated attendees. The final agenda, as illustrated in Figure 2, reflects the culmination of these thorough discussions and evaluations, ensuring the event's content meets the standards of clarity and understanding for a broad audience.




AGENDA

Patiënten Evenement & Panel Discussie

Woensdag, 6 december 2023
14:00 – 16:00 h
 Centre for Human Drug Research (CHDR)
 Zernikedreef 8
 2333 CL Leiden, NL
 Locatie: Auditorium

14:00 h	Welkom Prof. Dr. Geert Jan Groeneveld (CHDR, Gastheer) Ilona Thomassen (Pijnpatiënten naar één stem) 5 min
14:05 h	Wat is QSPainRelief & hoe helpt het patiënten met chronische pijn? Prof. Dr. Liesbeth De Lange (Universiteit Leiden) 10 min presentatie + 10 min vragenronde
14:25 h	Introductie van het QSPainRelief platform Dr. Jeroen Elassaiss-Schaap (PD-Value) 10 min presentatie + 10 min vragenronde
14:45 h	Koffie pauze 15 min
15:00 h	Live Demonstratie van de PainCart Prof. Dr. Geert Jan Groeneveld en Wouter Bakker (CHDR) 15 min demonstratie + 5 min vragenronde
15:20 h	Panel discussie & Vragen van het publiek Focus: Het betrekken van patiënten bij pijnonderzoek en klinische studies <ul style="list-style-type: none"> Gastheer: Prof. Dr. Geert Jan Groeneveld (CHDR) Prof. Dr. Liesbeth de Lange (Universiteit Leiden), wetenschappelijk coördinator van QSPainRelief Ilona Thomassen (Pijnpatiënten naar één stem), vertegenwoordiger van Nederlandse pijnpatiënten 40 min
16:00 h	Afronding & Einde van evenement

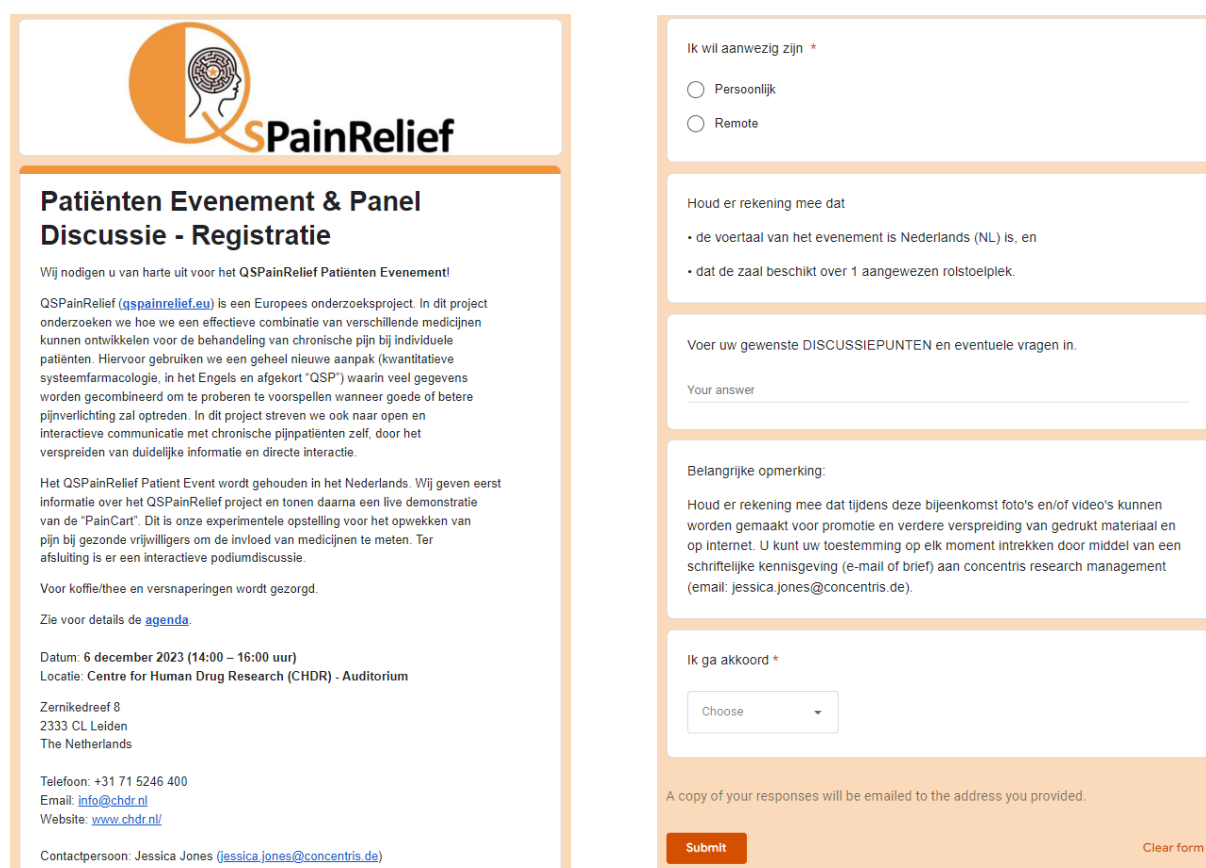
Vragen uit het publiek worden aangemoedigd!


Figure 2. Final agenda of Dutch patient event at CHDR on 6th December 2023 from 2-4 pm.

2.1.2. Registration

Patients had the flexibility to register for the events through various means. They could either electronically register via the [online registration form](#) that concentris set up or call CHDR directly for registration if they intended to attend the patient event. The event itself adopted a hybrid format, enabling patients to participate either in person at the CHDR auditorium or remotely through a shared Teams meeting.

Registration was facilitated by scanning a QR code on the event poster or advertisement text, detailed in Figure 3. During the registration process, participants were also given the opportunity to enter their own thoughts or topic-related questions, which were subsequently gathered and addressed during the panel discussion at the end of the patient event. This multi-channel registration approach and interactive question submission process aimed to enhance accessibility and engagement for participants.





QSPainRelief

Patiënten Evenement & Panel Discussie - Registratie

Wij nodigen u van harte uit voor het QSPainRelief Patiënten Evenement!

QSPainRelief (qspainrelief.eu) is een Europees onderzoeksproject. In dit project onderzoeken we hoe we een effectieve combinatie van verschillende medicijnen kunnen ontwikkelen voor de behandeling van chronische pijn bij individuele patiënten. Hiervoor gebruiken we een geheel nieuwe aanpak (kwantitatieve systeemfarmacologie, in het Engels en afgekort "QSP") waarin veel gegevens worden gecombineerd om te proberen te voorspellen wanneer goede of betere pijnverlichting zal optreden. In dit project streven we ook naar open en interactieve communicatie met chronische pijnpatiënten zelf, door het verspreiden van duidelijke informatie en directe interactie.

Het QSPainRelief Patient Event wordt gehouden in het Nederlands. Wij geven eerst informatie over het QSPainRelief project en tonen daarna een live demonstratie van de "PainCart". Dit is onze experimentele opstelling voor het opwekken van pijn bij gezonde vrijwilligers om de invloed van medicijnen te meten. Ter afsluiting is er een interactieve podiumdiscussie.

Voor koffie/thee en versnaperingen wordt gezorgd.

Zie voor details de [agenda](#).

Datum: 6 december 2023 (14:00 – 16:00 uur)
Locatie: Centre for Human Drug Research (CHDR) - Auditorium
Zernikedreef 8
2333 CL Leiden
The Netherlands

Telefoon: +31 71 5246 400
Email: info@chdr.nl
Website: www.chdr.nl

Contactpersoon: Jessica Jones (jessica.jones@concentris.de)

Ik wil aanwezig zijn *

☐ Persoonlijk

☐ Remote

Houd er rekening mee dat

- de voertaal van het evenement is Nederlands (NL) is, en
- dat de zaal beschikt over 1 aangewezen rolstoelplek.

Voer uw gewenste DISCUSSIEPUNTEN en eventuele vragen in.

Your answer

Belangrijke opmerking:

Houd er rekening mee dat tijdens deze bijeenkomst foto's en/of video's kunnen worden gemaakt voor promotie en verdere verspreiding van gedrukt materiaal en op internet. U kunt uw toestemming op elk moment intrekken door middel van een schriftelijke kennisgeving (e-mail of brief) aan concentris research management (email: jessica.jones@concentris.de).

Ik ga akkoord *

Choose

A copy of your responses will be emailed to the address you provided.

Submit

Clear form

Figure 3. Exemplary excerpts of the online registration form for the patient event.

2.1.3. Promotion of the event

Various promotional strategies were implemented to connect with patients and disseminate information about the patient event. Initiated by concentris, the Dutch consortium partners CHDR, ULEI, and PD-value, as well as PAE at the European level and the local Dutch patient organisation all announced the patient event, mostly via websites, social media, newsletters, and locally distributed posters and flyers (partner institutions, pain clinics, pharmacies). CHDR specifically reached out to individuals who had recently participated in a clinical study focused on neuropathic pain at CHDR, notifying them via email as outlined in the conceptual email provided. Posters advertising the patient event (refer to Figure 4) were strategically placed in key locations within the CHDR/Leiden region, including local pharmacies, Leiden University (ULEI), Leiden University Medical Centre (LUMC), and

CHDR itself. This multi-faceted promotional approach aimed to ensure widespread awareness and engagement, tapping into different channels to effectively reach and inform the target audience about the upcoming patient event.

PATIËNTEN EVENEMENT & PANEL DISCUSSIE

Woensdag, 6 December 2023
14:00 – 16:00 h

Centre for Human Drug Research (CHDR)
 Zernikedreef 8
 Leiden, The Netherlands
 Locatie: Auditorium (en online / hybride)

CHDR
 Centre for Human Drug Research

Wij nodigen u van harte uit voor het **QSPainRelief Patiënten Evenement!**

QSPainRelief (qspainrelief.eu) is een Europees onderzoeksproject. In dit project onderzoeken we hoe we een effectieve combinatie van verschillende medicijnen kunnen ontwikkelen voor de behandeling van chronische pijn bij individuele patiënten. Hiervoor gebruiken we een geheel nieuwe aanpak (kwantitatieve systeemfarmacologie, in het Engels en afgekort "QSP") waarin veel gegevens worden gecombineerd om te proberen te voorspellen wanneer goede of betere pijnverlichting zal optreden. In dit project streven we ook naar open en interactieve communicatie met chronische pijnpatiënten zelf, door het verspreiden van duidelijke informatie en directe interactie.

Het QSPainRelief Patient Event wordt gehouden in het Nederlands.

Wij geven eerst **informatie over het QSPainRelief project** en tonen daarna een **live demonstratie van de "PainCart"**. Dit is onze experimentele opstelling voor het opwekken van pijn bij gezonde vrijwilligers om de invloed van medicijnen te meten. Ter afsluiting is er een **interactieve podiumdiscussie**.

Voor koffie/thee en versnaperingen wordt gezorgd.

Registreer hier

Meer informatie

SCAN MIJ

QSPainRelief
www.qspainrelief.eu

Dit project heeft financiering ontvangen van het onderzoeks- en innovatieprogramma Horizon 2020 van de Europese Unie onder subsidieovereenkomst nr. 848068.



PATIËNTEN EVENEMENT & PANEL DISCUSSIE

Woensdag, 6 December 2023
14:00 – 16:00 h

Centre for Human Drug Research (CHDR)
 Zernikedreef 8
 Leiden, The Netherlands
 Locatie: Auditorium (en online / hybride)



CHDR
 Centre for Human Drug Research



Wat is QSPainRelief & Hoe helpt het patiënten met chronische pijn?
 Prof. Dr. Liesbeth De Lange (Universiteit Leiden)

Introductie van het QSPainRelief platform
 Dr. Jeroen Elassaiss-Schaap (PD-Value)





Live demonstratie van de PainCart
 Wouter Bakker (CHDR)

Panel discussie & Vragen van het publiek
 Focus: Het betrekken van patiënten bij pijnonderzoek en klinische studies
 Ilona Thomassen, Pijnpatiënten naar één stem
 Prof. Dr. Geert Jan Groeneveld (CHDR)




Registreer hier



Tel +31 71 5246 400
E-mail info@chdr.nl
Website www.chdr.nl
Meer informatie



QSPainRelief
www.qspainrelief.eu

SCAN MIJ

Dit project heeft financiering ontvangen van het onderzoeks- en innovatieprogramma Horizon 2020 van de Europese Unie onder subsidieovereenkomst nr. 848068.




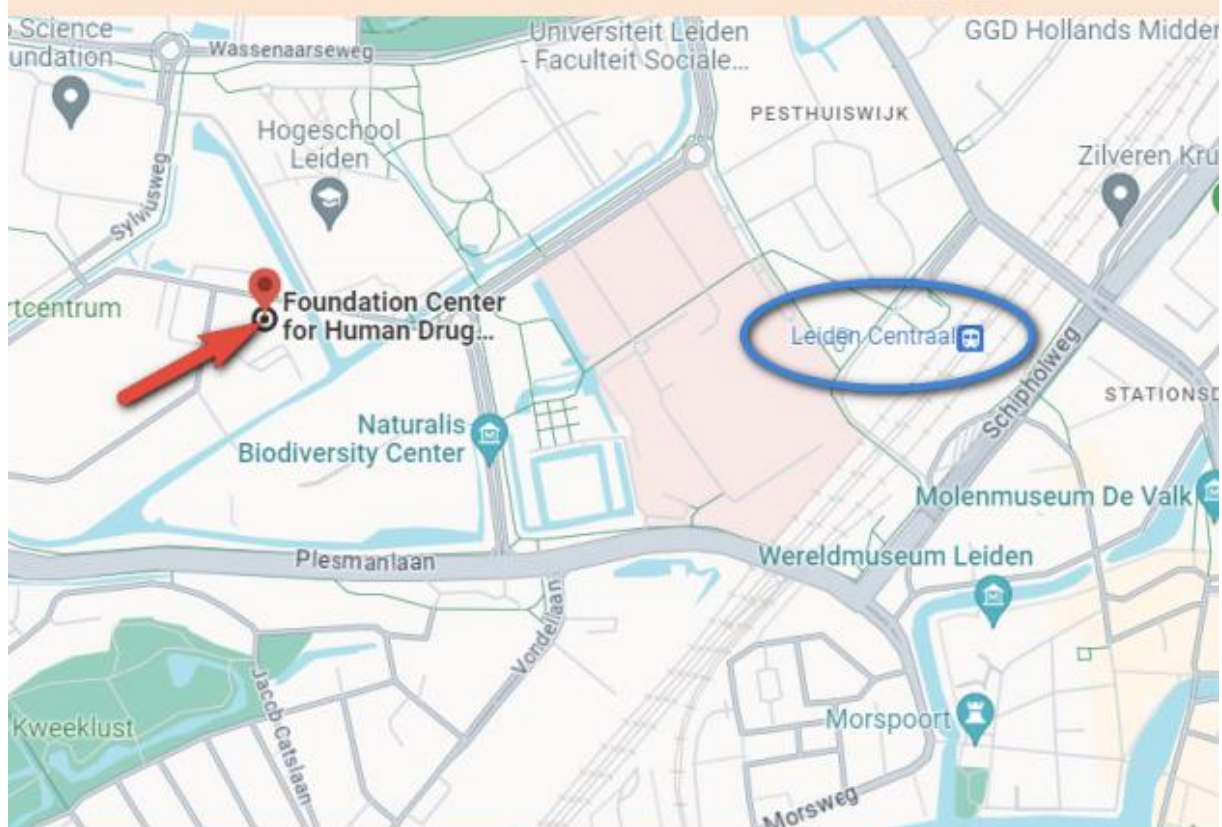
Adres, Locatie en Contact

Centre for Human Drug Research (CHDR)
Zernikedreef 8
Leiden, The Netherlands
Locatie: Auditorium

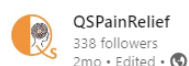


CHDR
Centre for Human Drug Research

10 minuten met de bus vanaf Leiden Centraal Station  **38 90**



Website www.chdr.nl Tel +31 71 5246 400 E-mail info@chdr.nl



Please register here: https://lnkd.in/e_Mbcyzh

🔊 ⚡ Suffering from **#ChronicPain** and living near **#Leiden**, The Netherlands? Then attend our **#PatientEvent** at the **Centre for Human Drug Research** on Wednesday, 6th December 2023 (2-4 pm), to learn about the EU-funded **#QSPainRelief** project and to participate in the discussion. We are looking forward to meeting you, hosting you, and listening to what you have to say. Important: 🗣️ The event will be in Dutch language! 🗣️

Elizabeth (Liesbeth) De Lange
Coen van Hasselt
Jeroen Elassaiss-Schaap
Berfin Gülave
Divakar Buddha
Geert Jan Groeneveld
Ilona Thomassen-Hilgersom
Wouter Bakker
Rafael Maldonado
Andrea Bedini
Beltrán Álvarez Pérez
André Mouraux
Solemn Gousset
Carlo Matej Rinaudo
Jessica Jones
Monica Baiula
Elisabetta Cuna
Jesus Giraldo
Jan Freijer
Dr. Petra Bloms-Funke
Albert Dahan
Erwin J.O. Kompanje, PhD



Post Analytics

QSPainRelief @QSPainRelief · Oct 13
🇳🇱 🇪🇺 🗣️ Suffering from **#ChronicPain** & living near **#Leiden**, The Netherlands? Then attend our **#PatientEvent** @CHDR_NL. Learn about the EU-funded **#QSPainRelief** project & participate in the discussion! Please register here: [Show more](https://lnkd.in/e_Mbcyzh)
[Show this thread](#)

5 4 6

Impressions ⓘ **1,265** Engagements ⓘ **37** Detail expands ⓘ **16**

Video

Metrics for the video you shared

Unique views ⓘ **101** Views ⓘ **161**

Audience retention ⓘ ⓘ

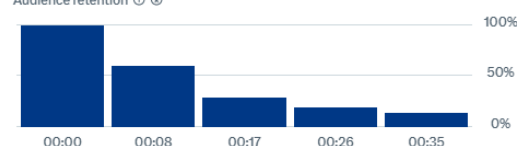


Figure 4. Screenshots of exemplary print and online promotional materials for the patient event, including an [overview poster](#), an [agenda poster](#), an [info flyer](#) (web and print version), and a [promo video](#) for social media posts. The LinkedIn Post received 27 responses, 2 comments, and was shared 15 times, while the promo video on X/Twitter received 1,265 impressions and 161 views.

Beste mevrouw/meneer,

Wij benaderen u omdat u in het verleden interesse heeft getoond in, of deelgenomen heeft aan een onderzoek naar pijn bij het CHDR in Leiden.

Bij deze willen wij u van harte uitnodigen voor het **QSPainRelief Patiënten Evenement**.

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Voor koffie, thee en versnaperingen wordt gezorgd.



Zie voor details de bijgevoegde agenda.

Datum: **Woensdag 6 December 2023**
Tijd: **14:00 – 16:00 uur**
Locatie: **Centre for Human Drug Research ([CHDR](#)), Auditorium**
Zernikedreef 8
2333 CL Leiden
The Netherlands

Schrijf u [hier in](#) en vul in wat u bezighoudt en welke eventuele vragen u heeft.

Tot ziens en hartelijke groet,

Geert Jan Groeneveld, CSO/CMO van CHDR en hoogleraar klinische neurofarmacologie in het LUMC



CHDR ONDERZOEKSCENTRUM	CHDR KEURINGSCENTRUM	+31 (0)71 524 64 64
Zernikedreef 8	Bargelaan 10	recruit@chdr.nl
2333 CL Leiden	2333 CT Leiden	proefpersoon.nl

Figure 5. Concept of email invitation sent to neuropathic pain patients by CHDR.

2.2. Event description from 06 December 2023

2.2.1. Outcome of the registration versus actual attendance of the hybrid event

Before the commencement of the patient event, a collective of **19 participants registered for in-person attendance**, accompanied by an additional 5 participants who opted for the online format. A total of **19 people attended the event in person**. At the actual day of the event (6th December 2023), the virtual version of the event drew active engagement from not only 5 but **15 participants who followed the proceedings remotely** through the Microsoft Teams platform, meaning 3 times more than anticipated (partially probably also caused by chronic pain conditions). In total, this resulted in **participation of 34 individuals** in the event, showcasing a diverse and engaged audience comprising both physical and virtual attendees. This mixed attendance format further enriched the overall experience and accessibility of the patient event, fostering inclusivity and ensuring a broader reach for the valuable insights presented.

Important: Since this Deliverable Report (D9.7) is public (as opposed to confidential reports), in alignment with the European General Data Protection Regulation (GDPR), we cannot disclose the names of the attendees in this report. We are, however, happy to provide photos depicting the f2f attendees, the record of the online attendees, and the list of signatures by the attendees who voluntarily signed in when joining the event in person to the project officer or to expert reviewers hired by the European Commission (EC) if desired.

2.2.2. GDPR compliance and photos of the hybrid event

Everyone who registered through the online form, was informed about GDPR and that photos might be captured during the event. With their registration, they agreed on the fact that photos may be captured. During the patient event, photos were captured of both the f2f event and the online event. The photos were taken by concentris, Liesbeth de Lange, WP leaders, and by CHDR.

Since not everyone who attended the event officially registered (= agreed) beforehand OR provided a signature-agreement during their f2f attendance, we only share photos of the f2f attendees in this report who in fact agreed to photos.



Figure 6. Welcome words by host Geert Jan Groeneveld (CHDR) to the 2nd QSPainRelief Patient Event.

2.2.3. Example slide of the presentation by Liesbeth de Lange



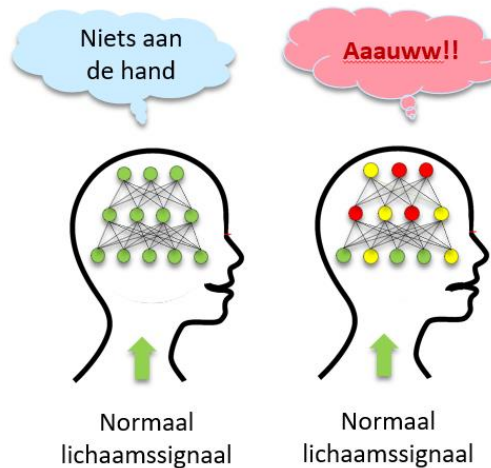
Chronische pijn - wat is er anders?



Chronische pijn

- Verkeerde vertaling van normale lichaamssignalen in de hersenen

“Het is alsof de volumeknop op het pijnsysteem op de hoogste stand is blijven staan!”

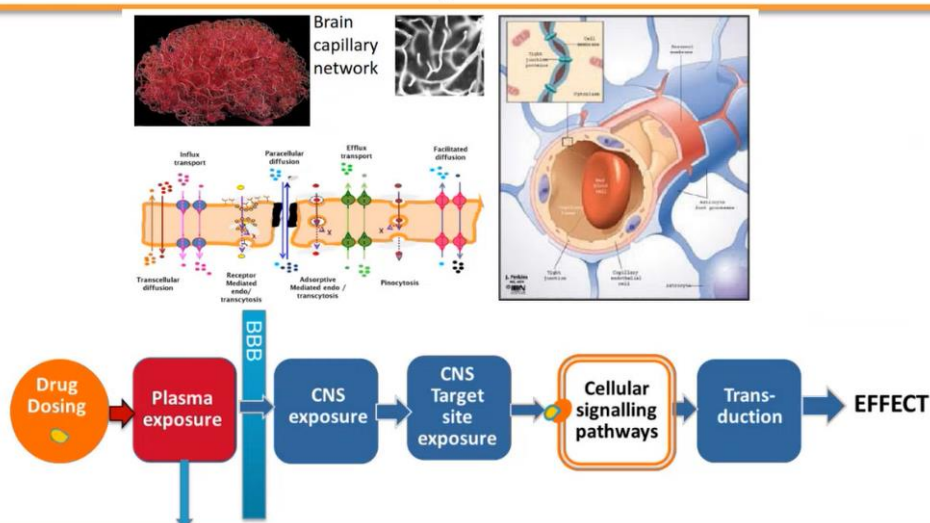


4

2.2.4. Example slide of the presentation by Jeroen Elassaiss-Schaap



Centraal zenuwstelsel? Bloed-brein barriere!



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 848068.

2.2.5. Live Demonstration of CHDR's PainCart® by Wouter Bakker

Human pain models are an important tool for assessing the analgesic effect of drugs and providing information about a drug's pharmacology. However, no single experimental model can replicate the complex nature of clinical pain. CHDR's PainCart® provides the solution: a multi-modal, standardised, comprehensive battery of tests for studying the efficacy of analgesic compounds for several types of pain, including thermal, electrical, chemical, and mechanical pain. A key advantage of PainCart over other pain batteries is that it is fully mobile, allowing researchers to perform the complete test battery on the go. Meanwhile, the integrated software ensures testing consistency, as well as the reliable capture, handling, and storage of data.



Figure 7. During the live demonstration of CHDR's [PainCart®](#), meaning various evoked pain tests employed in clinical studies, nociceptive stimuli included electrical (left), thermal (middle), and mechanical pain (right side). These types of pain and their thresholds were tested and demonstrated on CHDR's PhD student and volunteer Wouter Bakker (who was always in full control of terminating the respective painful stimulus himself whenever it became too unpleasant).

2.2.6. Panel Discussion led by patient representative Ilona Thomassen-Hilgersom & Questions by the audience

During the registration process, participants submitted questions that were subsequently addressed in the panel discussion. For a detailed account of the discussion, kindly refer to the video recording of the event that will be online soon (by 31 January 2024). Amongst many other questions, Prof. Groeneveld of CHDR and Prof. De Lange from Leiden University adeptly responded to the following inquiries:

- Why is there a need to measure the effect of medication on healthy individuals? Does this not pose challenges when testing more potent drugs?
- Does the ongoing research encompass the study of polyneuropathy (CIAP)?
- Is Tietze's syndrome and fibromyalgia within the scope of this research?
- Does the study include individuals experiencing pain symptoms attributable to lung-related COVID complications?

These and other questions not only contributed to a dynamic and informative panel discussion but also showcased the engagement and curiosity of participants regarding the diverse facets of the QSPainRelief project.

2.3. Social media coverage

Deirdre Ryan (PAE president) or Ilona Thomassen-Hilgersom (Chairwoman of the Dutch patient organisation “Pijn patiënten naar één stem”) as well as scientific coordinator Liesbeth de Lange (ULEI) and WP9 leader Nina Donner (concentris) took several pictures before or during the event to share stories on social media. See Figure 8 for a few examples of the social media coverage of the patient event. The [QSPainRelief roll-up poster](#), brought from ULEI by Liesbeth, created a perfect backdrop.



Figure 8. QSPainRelief’s social media visuals about the live event (with photos captured with a bird’s view via the camera that streamed the event to the online audience via Microsoft Teams), and a post on X / Twitter by Deirdre Ryan (president of PAE) who was able to attend the event in person.

3. Reception and evaluation of the hybrid event

Overall, the patient event was well-received and very successful because of the lively Q&A sessions after the two PPT presentations and the PainCart live-demo, as well as an interactive and interesting panel discussion. The combination of a general introduction about the QSPainRelief project itself, with a more in-depth explanation of pharmacokinetic and pharmacodynamic modelling, followed by the live demonstration of different evoked pain tests (the PainCart), provided a comprehensive agenda. The panel discussion at the end, led by the local Dutch patient representative Ilona Thomassen-Hilgersom, plus the time for questions after the talks and live-demo - which were moderated by COO Liesbeth (ULEI), Jeroen (PD-value), and host Geert Jan Groeneveld (CHDR) - was highly appreciated.

The involvement and participation of patient representatives and chronic pain patients could be improved at a future patient-targeted event. During the event itself, the patient representative should have been visible (also to the online audience) at the podium or in a central role – a goal that was not entirely met due to the position of the camera that recorded the event for the online audience. In addition, during the planning and promotion of the event, local patient organisations and representatives should be involved even further since the network they have is perfectly suited to spread the information to the right target groups and gain interest in the event. For the next patient event, even more time and resources may therefore have to be spent on reaching the patients.

A great idea for improved efficiency is to present QSPainRelief, for example, during a satellite event of a larger, already established event of a well-known patient organisation. This way, the consortium can reach an even wider audience with less promotional effort. Another suggestion was to use more “old-fashioned” promotion next time (newspaper advertisements / articles / press releases to announce an event better to the (in average) elderly target group of chronic pain patients (55 years and older).

Furthermore, the consortium must take into account the translation step, meaning to convey in layman terms the findings of the QSPainRelief model to how this could improve or affect the daily life of patients. We have to emphasize in more detail what patients will experience and how patients will benefit from the outcomes of the QSPainRelief project, for example: How will our project change pharmacotherapies for patients suffering of different types of chronic pain? How “personalised” will the resulting novel combinatorial treatments be?

4. Conclusion

In conclusion, the second patient event organized by the Centre of Human Drug Research (CHDR) and colleagues from ULEI, PD-value, concentris, PAE, and the Dutch patient organisation “Pijn patiënten naar één stem” within the Horizon2020 QSPainRelief project stands as a successful endeavour in patient engagement and research dissemination. The meticulous planning, initiated in Q2 of 2023, culminated in a comprehensive agenda that effectively introduced QSPainRelief, delved into pharmacotherapeutic modelling intricacies, and provided live demonstrations of evoked pain tests (the PainCart). The event's hybrid format, accommodating both physical attendance and virtual participation, showcased adaptability in reaching a diverse audience.

While the event produced interesting questions from the audience, resulted in lively discussions, and received positive feedback, insightful recommendations for improvement surfaced. Enhancing the visibility and roles of patient representatives (both during the event itself and in its planning stages) emerged as a crucial consideration for future initiatives. The call for increased collaboration with patient organizations and the exploration of traditional promotional methods (newspapers, press releases, printed advertisements) demonstrate a commitment to reaching a wider less tech-savvy demographic target group, particularly those chronic pain patients (and relatives) that are aged 55 or older.

Looking ahead, it is evident that refining strategies to effectively communicate QSPainRelief findings and emphasizing their translation into tangible changes in pharmacotherapy will further strengthen the connection between research outcomes and patient communities. This successful event lays a robust foundation for future patient engagement efforts, reflecting a commitment to continuous improvement in fostering meaningful dialogue and understanding between the researchers and the individuals they aim to ultimately help lead a pain-free and more enjoyable life.