

February 2023

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

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GUARD-Heart

Gateway to Uncommon And Rare Diseases of the Heart



ERN GUARD-HEART NEWSLETTER – SPECIAL EDITION

YEAR 2023 NUMBER 1

Clinical Patient Management System (CPMS)

Amsterdam, February 2023

This special edition newsletter is completely focussed on CPMS. The system was built for the 24 ERNs in order to discuss rare disease patients across borders in a secure web-based application. Currently a complete new version is under construction, however this will take quite some time. All of us discuss cases among each other on a weekly basis and it would be so nice if we can upload our cases in the current CPMS system. After all, the EU considers the use of CPMS as a parameter of esteem (see last page of this newsletter). For the 23 HCPs which join our ERN since last year, this might still be new and therefore we will try to summarize all the information and instructions in this newsletter. For those who were already used to the system, we possibly have a lot of 'old news'. However: the number of patients entered to the CPMS should increase significantly. Hopefully this will boost the initiative and take away your questions. ♥

Accessing the CPMS

To be able to start the first requirement is an EU login. In order to register for the one, first go to <https://cpms.ern-net.eu/login/> and click on the link to create an EU login.

For a detailed description, please follow the steps in document: *'Requesting access to CPMS'*, which is attached separately. It is important to follow all the steps, otherwise it is not possible to approve the account. Once you requested access, the ERN management team can approve it and (usually within a few hours max.) you can enter the system. The initial *'CPMS userguide'* is attached as well. ♥

Approval of CPMS by your HCP

All the HCPs have to approve CPMS by their own HCPs Medical Ethical Committee (MEC) or Data Protection Officer (DPO). The centres who started in 2017 have done this already, the centres who came into the ERN last year, will receive the background information and approval form separately by e-mail, directly after receiving this newsletter. Please return the signed form to our project management team (n.hofman@amsterdamumc.nl).



ERN Informed Consent Forms

Informed consent must always be obtained in order to be allowed to enroll your patient in the CPMS. Consent for care is obligated, consent for ERN registries and (to be contacted for) research is optional. There are specific ERN consent forms available in 25 European languages. They can be found in the CPMS homepage (<https://cpms.ern-net.eu>), under the button 'help and support' in the upper right corner (see screenshot below). ♥

User de-activation

Keeping the CPMS open for users comes with a significant cost. Therefore the CPMS-support team will de-activate the accounts of those users that have been inactive (have not logged in the CPMS) in the past 12 months to free space for recent access requests. The concerned users will be locked in SAAS. Don't worry if your account is inactive: with a short request-e-mail to the ERN GUARD-Heart projectmanagers (n.hofman@amsterdamumc.nl) your account can be re-activated easily again without repeating all the administrative steps. ♥

← → ↺ 🏠 🔒 <https://cpms.ern-net.eu/login/> A★ 🔒 ⚙️ ☆ 📄 👤 ...

CPMS Help & Support

Clinical Patient Management System (CPMS)

IT Platform for Clinical Consultations between ERN Members

The CPMS aims at supporting ERNs in improving the diagnosis and treatment of rare or low prevalence complex diseases across national borders of Member States in Europe.

The CPMS is a secure Software as a Service (SaaS) that enables health professionals to enroll patients using comprehensive data models. Health professionals can use the CPMS to collaborate actively and share patient within and across ERNs.

The CPMS is supported by Virtual Communication Tools and DICOM viewers to facilitate the interaction between clinicians. Reporting tools are among the functionality of the system to seamlessly empower users to generate reports of interest for administrative and clinical purposes.

The site may change as we endeavour to incorporate suggestions from our Clinical Advisors, particularly in the area of Graphics and Reporting.

Supported Browsers 🌐
Please make sure you are using the latest version of Google Chrome, Firefox or Safari to avail of all CPMS functionalities.

Working for patients with rare, low-prevalence and complex diseases
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Secure Login

You can Login to the CPMS ERN through the EU Login Authentication Service.

[Login via EU Login](#)

- Video: Getting Set-Up and Logged In to CPMS
- Only ERN members and ERN guest users can be authorised users of the CPMS.
- To access the CPMS you need to have an EU login. To create an EU login, [click here](#).
- To request authorisation to use the CPMS, [click here](#).
- To request access to the ERN Collaborative Platform (ECP) to exchange non clinical data with the other members of your ERN, [click here](#).
- For more information on the European Reference Networks, please visit ec.europa.eu.



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Project on LQT Syndrome and Sports

In 2021, ERN GUARD-Heart has relaunched the project inviting physicians to seek advice on sports participation for their patients with Long QT Syndrome (LQTS). Physicians can do this by entering their patients diagnosed with LQTS who wish to participate in sports and exercise into the Clinical Patient Management System (CPMS) and inviting several experts from the Advisory Panel to provide recommendations on the following key questions 1) Should the patient with the diagnosis of LQTS limit or restrict his or her participation in sports and exercise?; If so: 2) To what limit should participation in sports be restricted (answer in minutes/hours per week)? 3) What types of sports can the patient still do (see Figure 1. → A1, AII, AIII, B1, BII, BIII, C1, CII, CIII)? 4. Is the patient allowed to take part in a competitive sport or a recreational? Cases are uploaded and presented to the expert panel using the CRF and a PDF.

The CRF and PDF contain data on the patient's personal background, personal and family history, current sporting activities (type, level and hours/week), use of medication, genetic mutation (if present), ECGs over time (including measured QTc times), X-ECG (preferably including measured QTc times at rest, peak exercise and recovery) with maximum watts or METS and Holter monitoring if available.

Last month, we conducted a small sample analysis of patients already reviewed by the Panel, which demonstrates the challenge and lack of consensus in advice on sports and exercise for patients with LQTS, as shown in Figures 2 and 3.

This year we hope to include at least 100 LQTS patients to analyse these results and to show and learn from the challenge of advising on sports participation in patients with LQTS. **We would like to encourage all ERN GUARD-Heart members to upload cases to the CMPS system for the LQTS Sports Expert Advisory Panel.** If you need help uploading your cases, please contact us (j.c.vanhattum@amsterdamumc.nl). ❤

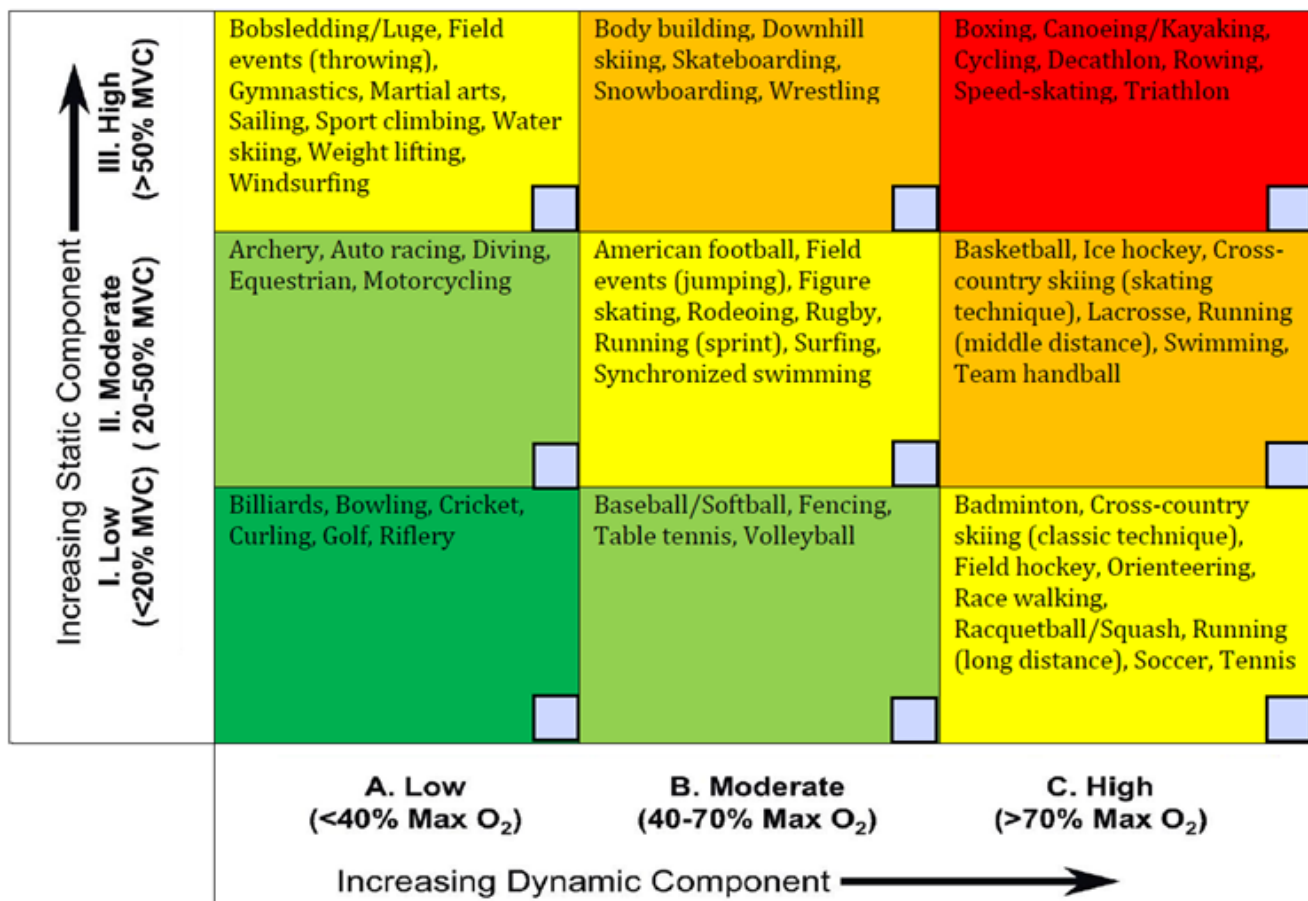


Figure 1. Sports are categorised according to the Mitchell Classification.

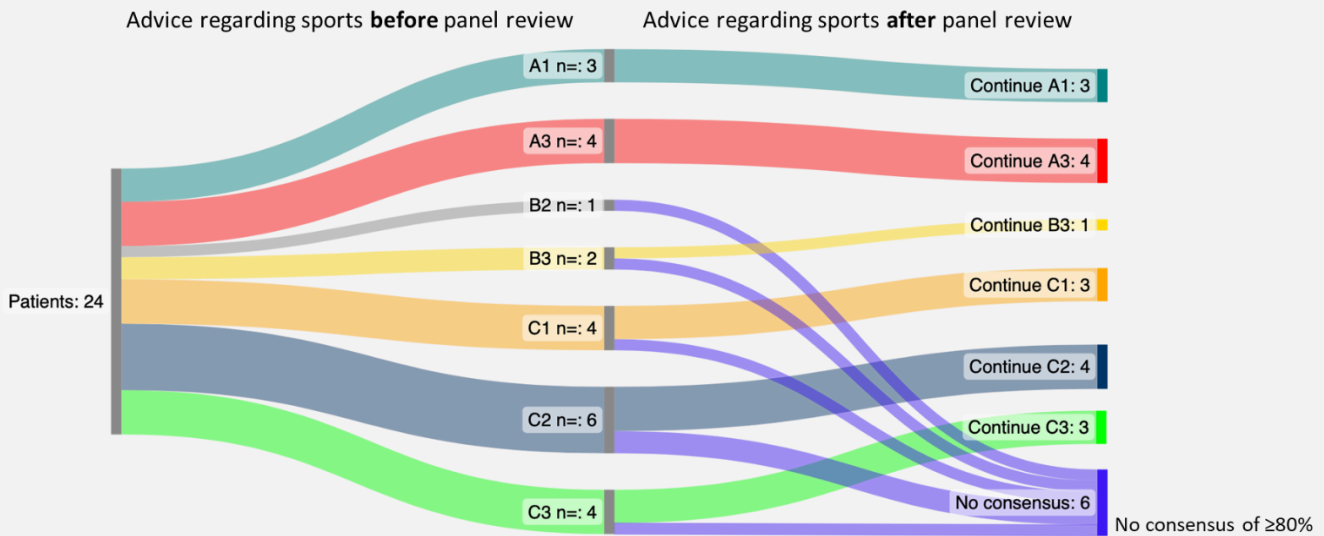


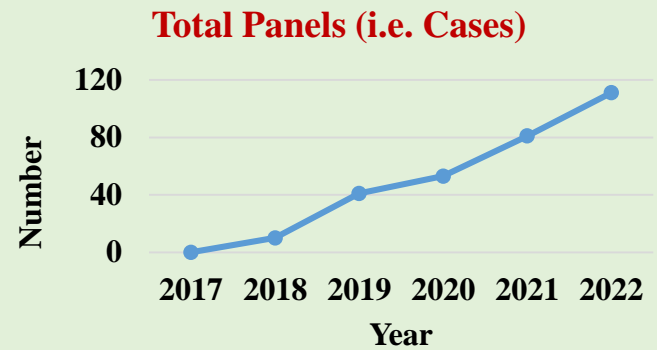
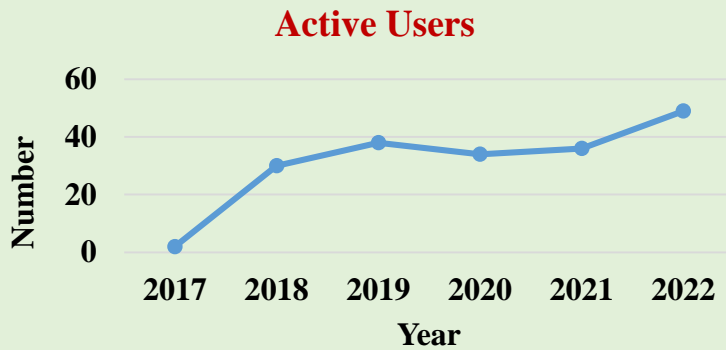
Figure 2. Transition plot showing sports advice before (left) and after (right) CMPS panel review of 24 patients with LQTS classified according to the Mitchell classification (Figure 1). Low dynamic sports (A1-A3) show panel consensus (≥ 80 of panel experts) in all patients. In contrast, panel consensus was not reached in all patients with LQTS participating in medium- or high-dynamic sports.



Figure 3. Transition plot showing advice regarding recreational and competitive level of sports before (left) and after (right) CMPS panel review in 24 patients with LQTS. Patients participating at a recreational level showed panel consensus (≥ 80 of panel experts) in all patients. In contrast, no consensus was reached after panel review of all patients with LQTS participating in competitive sports.



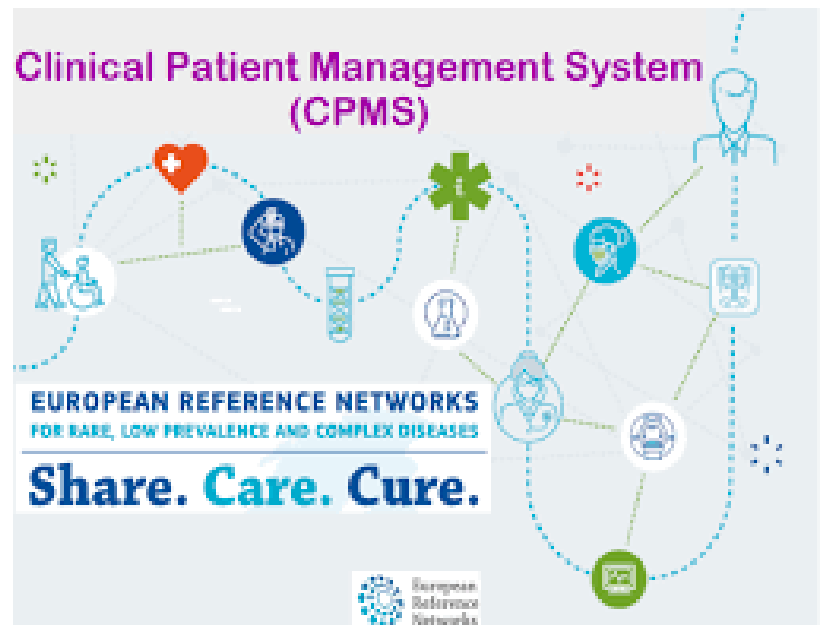
CPMS update ERN GUARD-Heart



Number of ERN GUARD-Heart active CPMS users in January 2023 and the total number of completed cases. ♥

EU-Pilot with budget for CPMS cases

CPMS activity is an important indicator within the ERNs. During the current grant-period (until September 2023) there is budget available for a (small) fee for completed CPMS-cases. As presented during the ERN GUARD-Heart board-meeting last August in Barcelona, we propose that each HCP presents at least 5 cases in CPMS (before September 2023) and when these cases are completed (outcome report available) the HCP can reimburse 200 EURO per case. In principle there is not a maximum number of reimbursable cases per HCP. This money is only available for the HCP, and cannot be transferred to private accounts. At the end of the summer an invoice can be sent to the projectmanagement team for the reimbursement of the number of completed cases. It is unsure if the reimbursement per case will remain after the pilot period. ♥



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