



Cross-Border Video Consultation Tool for Rare Urology: ERN eUROGEN's Clinical Patient Management System Loes Oomen¹, Erik Leijte^{1,4}, Darren E. Shilhan², Michelle Battye³, Wout F.J. Feitz¹

 Department of Urology, Division of paediatric urology, Radboudumc Amalia Children's Hospital, Nijmegen, The Netherlands, coordinating centre of ERN eUROGEN
ERN eUROGEN Lead IT & Data Performance Analyst, Radboudumc
ERN eUROGEN Programme Manager, Radboudumc
Department of Urology, Canisius Wilhelmina Hospital, Nijmegen, the Netherlands

Corresponding author: Wout Feitz Address: Geert Grooteplein 10, Postbus 9101, 6500 HB Nijmegen (610) Phone: +3124 361 3735 / Fax: +3124 3635114 Email: <u>Wout.Feitz@radboudumc.nl</u>

EUROPEAN REFERENCE NETWORKS FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.





Co-financed by the Connecting Europe Facility of the European Union





TABLE OF CONTENTS

| 1. | KEY CLINICAL MESSAGES | 2 |
|------|---|------|
| 2. | INTRODUCTION | 2 |
| 3. | METHODS | 3 |
| 4. | RESULTS | 4 |
| 5. | DISCUSSION | 4 |
| 6. | CONCLUSION | 6 |
| DISC | CLOSURES & ACKNOWLEDGEMENTS | 6 |
| REF | ERENCES | 6 |
| FIGU | JRE 1. ERN EUROGEN ORGANISATIONAL STRUCTURE | 8 |
| FIGU | JRE 2. GRAPHICAL OVERVIEW OF USER REGISTRATIONS AND PANEL CREATIONS | 9 |
| FIGU | JRE 3. COMPARISON BETWEEN THE NUMBER OF ACTIVE USERS AND PANELS CREATED PER ERN (2017-2021) | . 10 |
| FIGU | JRE 4. OVERVIEW OF PANELS PER WORKSTREAM | . 11 |

1. KEY CLINICAL MESSAGES

The Clinical Patient Management System (CPMS) is a virtual multi-disciplinary consultation tool for experts within the European Reference Networks (ERNs), which includes ERN eUROGEN, the ERN for rare urogenital diseases and complex conditions. Our analysis showed that this new secure video consultancy tool offers great opportunities for sharing knowledge and expertise once urologists are confident in using it. However, adaptations to make the tool more user-friendly are needed to further implement this in daily care.

Keywords: Clinical Patient Management System (CPMS), Complex conditions, European Reference Network (ERN), Rare diseases, Urology, Urogenital, Video consultation, telemedicine, digital healthcare, European Commission, Connecting European Facilities program

2. INTRODUCTION

The <u>European Commission</u> (EC) aims to reduce healthcare inequalities for all patients with rare or complex conditions across Europe and in 2016, it launched a call to establish <u>European Reference Networks</u> (ERNs). Leading European urological HCPs pooled their knowledge and expertise to form an ERN focused on rare urogenital diseases and complex conditions, known by the acronym ERN eUROGEN (1) (See: <u>website & YouTube channel</u>). The aim was to build a European-level network to innovate and "Share. Care. Cure" (where possible) from birth until the end of life.

Because of the broad range of conditions, an estimated EU/EEA population of 30 million people are living with a rare disease (2,3) of which 10% might involve urological rare diseases or complex conditions. However, it can be challenging to maintain all expert care nationally; therefore, the ERNs assist by enabling consultations within and across European borders (2).

At its launch, ERN eUROGEN consisted of 29 healthcare providers (HCP) as <u>Members</u>, with 16 Affiliated Partners joining later (12 as <u>Associated National Centres</u> and 4 as <u>National Coordination Hubs</u>) (4). The UK withdrawal from the European Union took effect on 1 January 2021 and six UK healthcare providers ceased to be part of the network. Following a 2019 call for applications to join existing ERNs, 29 new Members joined ERN eUROGEN on 1 January 2022, giving a total of 52 HCPs in 20 Member States (some of these new Members were previously Affiliated Partners).

ERN eUROGEN consists of three workstreams (WS): <u>WS1</u> on rare congenital uro-recto-genital anomalies, <u>WS2</u> on functional urogenital conditions requiring highly specialised surgery, and <u>WS3</u> on rare urogenital tumours (<u>Figure 1</u>) (5,6).





A new secure video consulting tool was provided to all ERN members to enable cross border virtual consultations by EU Member State expert teams. This <u>Clinical Patient Management System</u> (CPMS) allows urological experts to upload anonymised patient information (when patients have given their informed consent), clinical data and very short videos. This enables experts to discuss individual patients online and provide written advice as well as video consultations within an incorporated video consulting module.

A report is produced and delivered to the treating physician for inclusion in the patient files and to be discussed with the patient in an outpatient setting, when applicable.

To allow the timely identification of both successes and pitfalls, continuous monitoring of ERN eUROGEN activities is crucial. The EC defined 18 key indicators to form a process that allows periodical self-assessment and reporting to the EC and the Board of Member States for ERNs (BoMS), and closer follow-up of the activities performed by the networks.

This article aims to provide an overview of ERN eUROGEN's CPMS activities between 2017-2021, to provide insights into the current progress, successes, pitfalls, future challenges, and expected innovations.

3. METHODS

CPMS

The initial and current versions of CPMS were developed by <u>OpenApp</u> (Dublin, Ireland). Each clinician within an HCP can request access to the system and create a panel on a clinical case after obtaining <u>informed consent from the patient</u> (7). A patient nickname needs to be entered to provide anonymity and the case is described in a structured manner (e.g., consultation request, primary thematic area, comorbidities etc.) in UK English. The clinician requesting advice decides which WS the case belongs to and who should be invited to give advice. The full patient information can only be seen by a clinician who is both within the HCP uploading the case and a registered user of the ERN to which the case relates.

Attachments such as graphical patient abstracts, PowerPoints and/or PDFs with information and pictures, or surgical videos, can be uploaded, preceded by a warning that no identifying patient information should be present.

Subsequently, all clinicians within the CPMS can be invited to become panel members which allows them to comment on the case, give advice, or request additional information. Additionally, an online video meeting can be scheduled within the CPMS platform where clinicians can discuss the case live.

A panel consists of a panel lead (the clinicians asking for advice), a panel manager (for administrative purposes), and panel members (invited expert clinicians providing advice).

When the panel lead has an outcome for the panel, this can be recorded and saved. This produces an outcome document, stating that the case was discussed using CPMS and including the panel outcome e.g., treatment advice. This outcome document can be added to the local patient file and be discussed with the patient by the treating clinician. After signing off the panel, the panel can be closed and archived.

Data Extraction

The data used for this study are extracted from the current CPMS platform. Data was prospectively collected between November 2017 and June 2021 by the ERN eUROGEN CPMS Operational Helpdesk (OH) which is supported by grants (2017, 2018, 2020) from the EC Connecting European Facilities (CEF) program. The recorded data concern CPMS performance indicators as outlined by the EC (8) and comprise both user and panel activity.

In addition, in Quarter 4 of 2020 a survey was sent to the CPMS helpdesk coordinators of the 24 ERNs to identify any problems with using the available system. Every ERN has a helpdesk coordinator that manages the panels and provide guidance for clinicians using CPMS.

Due to the rare cases discussed and the difficulty of maintaining anonymity, privacy and security, no internal panel data can be discussed.

Data Analysis and Definitions

The CPMS data from 2017-2021 were analysed using descriptive statistics. Data were analysed for all patients in ERN eUROGEN's CPMS and stratified for the different WS (6). The analysis uses the following definitions:





- Registered users are all individuals who completed registration for ERN eUROGEN's CPMS.
- Active users are defined as those who logged in during the most recent month.
- Total number of panels captures the total number of panels that were created, regardless of whether advice was provided to the treating clinician (8).
- Closed panels were those where the case was subsequently reviewed by a panel that consisted of at least three experts or bilateral consultation between two experts, for which an outcome report was produced, and the panel closed by the panel lead (8).
- In the case of 'sign off', the review and outcome were finished but the panel was still waiting to be officially closed.
- Panel success rate was calculated as the percentage of closed panels in which the panel lead answered 'yes' to the question asking if the panel was a success.

4. **RESULTS**

Since the launch of ERN eUROGEN's CPMS a total of 148 users have registered, shown in <u>Figure 2</u>. Although this number is increasing every quarter year, the number of active users only increased by a limited amount from 16 at the start of Q4 2017 to 35 at Q2 2021. This means a percentual decrease of active users. The number of panels has increased over time up to 152 in total, which is above average compared to other ERNs (<u>Figure 3</u>).

However, there is a considerable discrepancy in activity between the different workstreams.

WS1 (rare congenital uro-recto-genital anomalies) made the largest contribution, initiating 49% of panels (Figure 4). This scattering of activity was also seen between the 29 different HCPs: 54% of the panels were created by the five most active HCPs.

The overall success rate of the closed panels was 81%, with the lowest percentage in WS3 (rare urogenital tumours). The median time to close a panel was 18 weeks.

Panel closure happened in 53% of panels, whereas 68% were signed off. Nine (27%) of the open panels were open for more than one year.

The majority of consulting clinicians (panel leads) requested advice with regard to treatment (67%) or diagnoses and treatment (21%). Panel leads spent on average around 130 minutes on a panel.

Survey

In total, 23 helpdesk coordinators completed the survey. Respondents saw great advantages in using CPMS as it enables advice to be received from multiple experts in a protected environment and provides HCPs from countries with low populations to have quick access to expertise and support from all ERN members.

The survey found that a smaller number of HCPs than expected were actively using the system, as only a minority of network members were active in CPMS (ERN eUROGEN: 24% in Q2 of 2021).

The main factors that negatively affected the level of engagement were the complexity of the platform (70% of respondents) and the time required to create a panel (70% of the respondents). Other factors that might have contributed were a lack of incentive and motivation, the COVID-19 pandemic, technical malfunctions, and the initial instability of the platform.

A common view amongst respondents was that there is a need to improve the platform's current functioning to make it simpler to use. Other suggestions for increasing the use of the platform were paying the HCPs for participating in panels, integrating the ERNs within national healthcare systems, and promoting the platform among patient organisations.

5. DISCUSSION

The EC has provided a secure online video consulting tool (CPMS) for innovating cross-border healthcare and the exchange of knowledge. This allows experts to discuss their complicated cases, which improves international collaboration and the quality of care for patients with a rare or complex disease.





The number of registered CPMS users has increased over time. However, the number of active users and panels created remains stable. Activity is scattered between WS and HCPs, with a small, active group of fervent users. The use of the panels appears to be satisfactory as they have a success rate of 81%. However, a considerable number of panels were not closed after discussion, so these numbers must be treated with caution.

This overview showed that although the numbers of registered users are increasing, CPMS activity did not. This is in line with previous literature on CPMS activity in ENDO-ERN (9). One possible explanation for this might be that HCPs are encouraged to register to the CPMS but forget about it afterwards. A survey showed that most clinicians find the system difficult to work with. Panel creation requires multiple steps which might demotivate busy clinicians. The time investment for leading a panel was on average 130 minutes per panel. Furthermore, for many experts, the use of video-consulting for online advice requires a change in habits and time investment to get familiar with new software, for which they are not compensated.

Another explanation might be that the need for international consultation is limited because of the ability to deliberate with expert colleagues locally. Willingness to ask peers for help differs among cultures, which for some could cause a reluctance to use CPMS.

When clinicians do use the expert panels, the majority are satisfied with the outcome and find it to be a helpful and convenient method of cross-border collaboration. Only a small number of panels were aborted prematurely, and panel meetings usually took place within three months.

Pitfalls and Future Solutions

The goal of the CPMS platform is to transfer knowledge and expertise to increase the quality of care for patients across Europe whilst also reducing costs. To achieve this goal an increase in the number of clinicians actively participating and a concomitant increase in the number of panels are required. Despite the positive experiences of the experts that took part in panel meetings, there are still multiple hurdles to overcome.

Improving the system

The most pressing problem appears to be the complexity of the system which makes it difficult to use and thereby also timeconsuming. To improve this process, the CPMS workflow was updated in March 2021 with a reduced number of mandatory steps needed to process a panel from creation to sign-off. This update allowed all actions involving panel creation such as inviting panel members, uploading files, and scheduling meetings to be performed simultaneously.

Currently, the EC and ERN IT Coordination Team is working on the development of new software in which they are incorporating user feedback to create a more user-friendly system. The aim is that the new CPMS will have clinical functions, management functions, a centralised database, and connections to both electronic health records and the ERN registries. There will be both desktop and mobile interfaces that are multilingual, allowing panel discussions, secure instant messaging, a smooth workflow, and simplified data entry.

A CPMS mobile application is also under construction. This will enable clinicians to log in to video consultations more easily and thus reduce the barriers to active participation.

The new system is expected to be up and running in the first quarter of 2023.

Training

In addition to improving the system, the direct training of clinicians might also help increase activity. The ERN Operational Helpdesks enable clinicians to seek help when they encounter difficulties. Multiple guidance manuals have been created and are <u>accessible on the ERN eUROGEN website</u> to guide users through both the registration and panel creation processes. Additionally, individual and/or group training is available to help new members to use the system and make CPMS usage a regular part of their daily work. The expansion of the network at the start of 2022 should lead to a significant increase in the amount of both users and panels.

Promotion

It is essential to create awareness of the availability of the CPMS for both ERN members and non-ERN experts. Promotion of the system could include translation of current materials into multiple languages, information desks, presentations at





(inter)national conferences, reaching out to patients directly by contacting patient advocacy groups and organisations, as well as the use of social media.

Monitoring

Alongside this, strict monitoring of activity and participation is also required. Furthermore, a termination process for noncompliant HCPs (e.g., those not providing data and not using CPMS) has been introduced within the network to ensure that all ERN members will be able to use the system in the future.

6. CONCLUSION

This overview of CPMS activity within ERN eUROGEN shows that this new secure video consultancy tool offers great opportunities for sharing knowledge and expertise once urologists are confident in using it. The care of over 140 patients with rare urological diseases and complex conditions has so far been optimised by using the system. These are a combination of adult and paediatric cases, and all involved complex and challenging questions and discussions relating to highly specialised surgeries that were planned or have been carried out on these patients.

However, there are still many challenges in using CPMS to improve patient care. The most important factor is the technical improvement and simplification of the system which is currently under development and expected to be available in 2023. Additionally, the expansion of the network, the future integration of the ERNs into national healthcare systems, and increased awareness of the availability of CPMS among both urologists and patients will also play important roles.

DISCLOSURES & ACKNOWLEDGEMENTS

The authors are all employed by Radboudumc, the HCP Network Coordinator for ERN eUROGEN, to work for the network. The authors are grateful to Jen Tidman, ERN eUROGEN Business Support Manager, for her editorial support with this paper. We would like to acknowledge the EC for providing the CEF grants (2017, 2018 and 2020) to support the CPMS Helpdesk staff.



Co-financed by the Connecting Europe Facility of the European Union

REFERENCES

- Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare. [Online]. Available from: <u>https://eur-lex.europa.eu/legalcontent/EN/TXT/?uri=celex%3A32011L0024</u>.
- 2. EURORDIS. Rare Diseases: understanding this Public Health Priority. [Online]. Available from: https://www.eurordis.org/sites/default/files/publications/princeps_document-EN.pdf.
- 3. Kaplan W. Priority Medicines for Europe and the World "A Public Health Approach to Innovation. [Online]. Available from: https://www.who.int/medicines/areas/priority_medicines/BP1_introduction.pdf.
- 4. European Commission. European Reference Networks. [Online]. Available from: <u>https://webgate.ec.europa.eu/ernsd/cgibin/ern_public.cgi?npage=ern_portal.html#!/</u>.
- 5. Ashley S, Shilhan D, Battye M, Meyer C, Mancini M, Ayres B, et al. Clinical performance in ERN eUROGEN for penile, testicular, adrenal and soft tissue cancers. European Journal of Surgical Oncology. 2021.
- 6. Oomen L, Leijte E, Shilhan D, Battye M, Feitz WFJ, Members of ERN eUROGEN. Rare and Complex Urology: Clinical Overview of ERN eUROGEN. European Urology. 2021 Feb; 81(2): 204-212.





- 7. ERN eUROGEN. Consent Forms. [Online]. Available from: https://eurogen-ern.eu/for-our-clinicians/consent-forms/.
- ERN Continuous Monitoring Working Group of the ERN Coordinators Group & the Board of Member States. Continuous Monitoring of ERNs ERN Continuous Monitoring and Quality Improvement System (ERN CMQS): Set of ERN core indicators (18) Version V.7. [Online]. Available from: <u>https://ec.europa.eu/health/system/files/2020-</u>01/continuous monitoring en 0.pdf.
- 9. Mönig I, Steenvoorden D, de Graaf JP, Ahmed S, Taruscio D, Beun JG, et al. CPMS-improving patient care in Europe via virtual case discussions. Endocrine. 2021 Mar; 71(3): 549-554.











FIGURE 2. GRAPHICAL OVERVIEW OF USER REGISTRATIONS AND PANEL CREATIONS



CPMS: Clinical Patient Management System





FIGURE 3. COMPARISON BETWEEN THE NUMBER OF ACTIVE USERS AND PANELS CREATED PER ERN (2017-2021)



ERN eUROGEN is highlighted.

CPMS: Clinical Patient Management System, ERN: European Reference Network, HCP: Health Care Provider





FIGURE 4. OVERVIEW OF PANELS PER WORKSTREAM

