

## OBJECTIVE 02

To promote Human Rights and Democracy, involving citizens in policy dialogue, design and monitoring



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# INFORMING THE PUBLIC ABOUT ENDOMETRIOSIS

Cyprus Women's Health Research Society (COHERS)

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## THIS ACTION INVOLVED

Raising awareness on endometriosis

Conducting an online questionnaire, between 8 April and 15 May 2020 with 3735 women on the awareness level about endometriosis, period health and period pain perception. Analysing, reporting and disseminating the questionnaire results through mainstream and social media. Produce four short videos presenting the questionnaire's results.

Translating and re-making the World Endometriosis' awareness film, "What is endometriosis?" and share it on COHERS' website and social media.

Preparing a hardcopy and digital brochure on endometriosis and distributing it in clinics, schools and workplaces among others.

Updating COHERS' website to incorporate a specific section on endometriosis.

Translating, adapting and disseminating the endometriosis Covid-19 guide of the University of Oxford Endometriosis Pain Clinic. Disseminating the guide among doctors, for them to share with their patients.

## ABOUT THE CYPRUS WOMEN'S HEALTH RESEARCH SOCIETY (COHERS)

Cyprus Women's Health Research Society (COHERS) was founded in February 2017. Its objectives are to conduct scientific research to understand the prevalence of women's health conditions and access to health care systems and advocate for awareness around women's health risk factors and diseases. In addition, they aim to demonstrate the factors that may affect women's health conditions specific to the Eastern Mediterranean region is another objective.

## STORY OF THE ACTION

The action aimed to raise awareness of an "invisible" and "neglected" disease that globally affects 1 in 10 women of reproductive ages and is a subject of societal taboos. Some of the most common symptoms are very painful periods, painful sex and infertility.

According to COHERS principal investigator Dr. Nilüfer Ramizoğlu, there is a need to raise awareness around chronic severe period pain. It is not only impacting women's health but also their abilities to be productive in educational, professional and social life. "If women get timely diagnosis, then their quality of life can be improved, which will enable them to seek what they would like to achieve in life" she says.

Through this action, COHERS conducted an online questionnaire between 8 April and 15 May 2020 with 3735 women to identify the general level of public understanding of endometriosis and patients' experience in society. Four short videos presenting the data of the questionnaire were created and distributed through mainstream media and social media channels.

Dr. Ramizoğlu highlighted some of the key findings of the questionnaire:

"One in four women suffer from chronic period pain that stops/limits them from going to school/work. Of these women with severe chronic period pain, 39% are not seeking medical help from a professional because 87% do not think severe period pain on its own could be a symptom of a health problem! Only 27.7% of women had heard about endometriosis before. 50% of women heard about chocolate/ovarian cysts, which are only one subtype of endometriosis that can be seen by ultrasound imaging. However, only a fraction of endometriosis cases have these cysts and endometriosis is not a condition that is limited by chocolate cyst formations. 8% of the questionnaire participants had an endometriosis diagnosis that could be a proxy for the prevalence of the condition in our population."

COHERS translated and re-made an awareness film "What is endometriosis?" prepared by the World Endometriosis and disseminated it through COHERS's website and other social media channels. It further designed a brochure in hardcopy and digital forms, summarising the disease epidemiology, symptoms, treatment options and some typically misunderstood facts about the condition. It also translated and adapted two guidelines, prepared by the University of Oxford Endometriosis Pain Clinic, on medical and self-care advice and pelvic exercises that women with endometriosis could do at home during the Covid-19 pandemic. COHERS shared these information materials via its website, other social media channels, health clinics, schools and the public in general. COHERS's website has been updated to incorporate information on endometriosis to allow Turkish speaking women seeking information on the disease to access it any time.

## RIGHTS-BASED APPROACH

Dr. Ramizoğlu believes that this action has contributed to human rights and democracy by "empowering women about an overlooked biological phenomenon that severely affects some women's quality of life and holds them back. Gender equality in the public will be realised by recognising the rights that protect women in their full biological existence and by creating policy that provides women with needed human support. That is why we are advocating for 1 day a month paid severe period pain leave."

Furthermore, the action has built the capacities and raised health providers' awareness and relevant local bodies on paying more attention to women's health, specifically on endometriosis.

## WHAT'S NEXT?

COHERS will follow up with the local health and education bodies and the Cyprus Turkish Medical Association to advocate and promote period education, information about diagnosing endometriosis and care of women suffering from this critical female health condition in the society. COHERS, in collaboration with the University of Oxford and the Eastern Mediterranean University, is conducting a scientific project to look into the endometriosis epidemiology in the Turkish Cypriot population and measure the quality of life of women from various demographic backgrounds. The results should be published in 2021.

