## ALLEANZA CONTRO IL TUMORE OVARICO (ACTO)

Italy



"Acto (Alleanza contro il Tumore Ovarico) supports and is proud to be a Champion of the Charter which will help our patient organizations in Italy and beyond be heard. Our #PowerfulVoices will help change the future of ovarian cancer. We are more #PowerfulTogether."







Movimento e Salute (Exercise for Health)

## CHAMPION PROJECT: MOVIMENTO E SALUTE (Exercise for Health)

The Acto project "Movimento e Salute" (Exercise for Health), designed in Italy for ovarian cancer patients, is inspired by clinical evidence of the benefits brought to quality of life by a balanced and appropriate exercise programme set up by qualified trainers. It can mitigate anxiety and stress caused by the disease and the treatments, and improve the patient's mood. Benefits also include reducing fatigue, improving the blood and lymphatic flow, and strengthening the cardiovascular system including heart, muscle tone and respiratory function.

Now pivotal in the "care beyond treatment" programmes of the Acto network in Italy, this free to access 6-month project offers a personalized exercise programme – from walking to running – developed and controlled by a professional personal trainer. The main goals of the project are to reinforce motivation and resilience in cancer patients and to evaluate with scientific relevance the effect of exercise on their physical and mental status.

Patients are invited to participate by the medical team. After a functional evaluation, they receive an individual and personalized exercise programme, according to the evaluation results and the personal trainer's opinion. A dedicated app, named U4Fit, enables regular contact between patients and their trainer, and remote-monitoring of progress so the programme can be adjusted as required. This also means that any patient can carry out the exercise plan wherever she lives. A final evaluation of health and mental status is carried out at the end of the six months.

The first centres to be involved in the pilot programme are the European Oncology
Institute (IEO) in Milan and the National Cancer Institute in Naples.

Supervised by a Scientific Committee made up of renowned
Italian gynecological oncologists, and patronised by the
MITO and MANGO ovarian cancer research groups,
it is hoped the project will extend to other Italian
specialist ovarian cancer centres.

The Coalition chose to showcase this programme because it considers both the physical and mental wellbeing of women with ovarian cancer, is scientifically led, but explores the benefit of non-pharmaceutical treatment to supplement standard care. The programme is tailored to suit each individual and is made as simple for women to participate as possible.

www.acto-italia.org



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Ricerca In-Acto (access to clinical trials)

## CHAMPION PROJECT: RICERCA IN-ACTO (Access to Clinical Trials)

Developed by the national patient advocacy group ACTO and some of its regional groups in conjunction with clinicians, this is a multicentre, prospective survey about women's knowledge, attitudes and experience of randomized controlled trials. Despite several previous initiatives by various groups to engage patients in clinical research, it was felt the uptake of trials was not as strong as it could be.

It explores levels of trust in trials, the motivation behind taking part and the obstacles that may prevent women from taking part, as well as the level of satisfaction with information about trials, and patient participation in the development of the trials.

The development of the survey followed a literature review, and a validation process involving clinicians, researchers and some of the regional ACTO groups (Bari, Campania, Lombardia, Piemonte and Roma). The survey involves a clinician led intervention during the first follow up visit (post treatment) or first therapy session for women whichever is sooner, and then a follow up questionnaire three months later, by post.

Launched in early 2019, there are now 39 centres involved in this programme, from the MaNGO (Mario Negri Gynecologic Oncology) group and the MITO

We chose to showcase this programme because it will help the clinical and patient advocacy community understand the barriers to women participating in clinical trials and potential ways to overcome them. Our own Every Woman Study™ showed that most women were interested in trials, with only 3% not at all interested, but few were asked by clinicians about trials (less than one in four) and overall only 12% of respondents had participated in one. Ricerca in-acto, because it is conducted via a wide network of hospitals, in itself should improve the levels of discussions between women and clinicians about trials, and offer insight into how such discussions can be standardised in

future.

group (Multicentre Italian Trials in Ovarian Cancer). The study, which is carried out by the Mario Negri Research Institute in Milano, is due to report early in 2021, slightly later than planned due to the detrimental impact of COVID-19 on cancer care in Italy.

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