

Science Communication Plan of the COST Action CA18117

Each Action MC shall adopt a Science Communication Plan including a communication, dissemination, and valorisation strategy, as well as a plan to implement this strategy. The Science Communication Plan shall reflect the MoU in particular connecting to the aims and objectives of the Action. It is recommended that the Science Communication Plan is approved by the Management Committee not later than 6 months after the start date of the Action. It is recommended that the Science Communication Plan, including progress on implementation, is discussed on a yearly basis by the Action MC and reviewed or amended where necessary. (*Annotated Rules for COST Actions, article 5*)

VERSIONS AND HISTORY OF CHANGES

Version	Date of adoption by MC	Notes (e.g. changes from previous versions)	Lead author(s)*
1	2/11/2020		Prof Jean Calleja-Agius; Dr Vera Dimitrievska

** The Science Communication plan is developed, updated and its implementation monitored under the overall supervision of the Science Communication Coordinator, and in close collaboration with other relevant contributors.*

This document is based upon work from COST Action CA18117 European network for Gynaecological Rare Cancer research: From Concept to Cure (GYNO CARE), supported by COST (European Cooperation in Science and Technology).

COST (European Cooperation in Science and Technology) is a funding agency for research and innovation networks. Our Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers. This boosts their research, career and innovation.

1. SUMMARY

GYNO CARE aims to create a unique network between key stakeholders covering five distinct domains (from concept to cure): basic research on rare gynaecological cancer, biobanking, industrial dimension, legal and regulatory requirements for international trials and other research collaborative efforts, and high-quality, international, and innovative clinical trials. To achieve our ambitious goals, we have devised research coordination and capacity building objectives in accordance with mission and vision of the COST Action. In view of this, we developed a strategy for communicating, disseminating, and valorising the Action results, in spite of the complete change in leadership within one year of the start of this Action and right in the midst of the COVID-19 pandemic.

The Action Chair, together with the newly appointed Science Communication Co-ordinator, will work together in order to set up the GYNO CARE website (www.gynocare.net), and develop social media tools such as Facebook, Linked in, Twitter and Instagram. A series of webinars will be held. In addition, outreach will take place via invited TV and radio broadcasting to the general public. When possible, and especially following Training Schools and Conferences held by GYNO CARE, press releases will be held in order to increase dissemination.

All publications funded by COST will be open access, as well as the output and proceedings of all the conferences and meetings (eg Youtube channel). Special importance will be given to disseminate the work and output of the GYNO CARE consortium on occasions such as World Oncology Day (20th September) and Rare Diseases Day (28th/29th February).

The Action Chair and the Science Co-ordinator will liaise with ESGO-ENGAGE (<https://engage.esgo.org/>). The European Network of Gynaecological Cancer Advocacy Groups (ENGAGE) is the ESGO network of European patient advocacy groups. It represents all gynaecological cancers (particularly ovarian, endometrial, cervical, vulvar, and rare cancers). The main point of contact from ENGAGE will be the MC member from Ireland, Dr Sharon O'Toole, who is the Co-ordinator of INNOVATION- the Irish National Network for Ovarian Cancer Collaboration, and the Executive Committee Member of the Irish Society of Gynaecological Oncology (ISGO). There will also be co-ordination with many European networks, including the European Board and College of Obstetrics and Gynaecology (EBCOG); and the European Organization for Rare Diseases (EURORDIS).

A science communication team will be set up to help the Action Chair and the Science Co-ordinator. The MC members in charge of ensuring that the social media posts are up-to-date are: Prof Klejda Harasani from Albania, Dr Mariela Vasileva-Slaveva from Bulgaria and Dr Irina Tripac from Moldova. The dissemination of the proceedings of the GYNO CARE Training Schools and Conferences will be held in collaboration with the respective Local Organiser. The Local Organiser will also be responsible for organising a press release with a national public media outlet in order to disseminate to the general public especially in the country where the GYNO CARE meeting will be held. In addition, a meeting report will be included in the open access scientific publication Annals of Research in Oncology (<https://www.annals-research-oncology.com/>) edited by Prof Francesca Pentimalli and Prof Antonio Giordano, MC members from Italy, following each GYNO CARE conference and each training school, so that the proceedings will be even more widely disseminated. All these training schools and conferences will be held in hybrid format to reach out even those participants who will not be able to travel, and all meetings are record and accessible via the GYNO CARE website. We will aim that most of the hybrid GYNO CARE meetings will be held in ITC countries, in liaison with the local specialist and patient organisations, with the possibility of translation into the native language.

Finally, dissemination grants will be awarded so that MC members can present the outputs of the GYNO CARE COST Action during international congresses, such as the European Board and College of Obstetrics and Gynaecology (EBCOG) congress (<https://ebcog.eu/>) and others.

2. GENERAL AIM AND TARGET AUDIENCES

GYNOCARE aims to create a unique network between key stakeholders covering five distinct domains (from concept to cure): basic research on rare gynaecological cancer, biobanking, industrial dimension, legal and regulatory requirements for international trials and other research collaborative efforts, and high-quality, international, and innovative clinical trials. The aims and specific objectives related to the communication, dissemination and valorisation of GYNOCARE Action results are to increase awareness around prevention, early diagnosis, research and cure among all stake holders involved in the field of rare gynaecological cancers. This will be achieved via: webinars, hybrid conferences and training schools, open access publications, dissemination grants in order to disseminate our results in international ongoing congresses, press releases, broadcasting on TV and radio, website (both the dedicated project website and university webportals), social media and others.

Taking into account the nature of the Action challenge, its objectives and deliverables, the target audiences include clinicians (such as oncologists, surgeons, pathologist), pharmacists, trainees and medical/science students, lawyers, ethicists and all the team involved in designing informed consent for biobanking of tissues and clinical trials, the pharma and biotech industry, policy makers and health regulators, academia and researchers, and of course, patient advocacy groups. There will be specific activities related to effective communication, dissemination and valorisation of Action results. Given the present advances made in online communication and the increased acceptability of online meetings, we will ensure that these activities will happen online, and when it is possible to held them physically, there will also be hybrid facilities.

A science communication team will be set up to help the Action Chair and the Science Co-Ordinator. Specific MC members will be in charge of ensuring that the social media posts are up-to-date. The dissemination of the proceedings of the GYNOCARE Training Schools and Conferences will be held in collaboration with the respective Local Organiser. The Local Organiser will also be responsible for organising a press release with a national public media outlet in order to disseminate to the general public especially in the country where the GYNOCARE meeting will be held. In addition, a meeting report will be included in an open access scientific publication soon after the end of that particular meeting.

This comprehensive communication plan defines clear objectives with key messages addressed to relevant target audiences and sets out a description and timing for each activity. This will help to create a communication strategy that can be adapted to each identified target audience. By calling the attention of various audiences, the visibility of the Action and its results are multiplied and can be understood also by non-specialists such as patient groups and the general public.

Special importance will be given to disseminate the work and output of the GYNOCARE consortium on occasions such as World Oncology Day (20th September) and Rare Diseases Day (28th/29th February).

The Action Chair and the Science Co-ordinator will liaise with many European networks, including the European Board and College of Obstetrics and Gynaecology (EBCOG), the European Organization for Rare Diseases (EURORDIS) and the European Network of Gynaecological Cancer Advocacy Groups (ENGAGE). ENGAGE is the ESGO network of European patient advocacy groups and it represents all gynaecological cancers (particularly ovarian, endometrial, cervical, vulvar, and rare cancers).

3. PLAN FOR THE COMMUNICATION OF ACTION RESULTS

Communication deals with raising awareness and promoting the GYNOCARE Action and its results towards the general public, stakeholders, end-users, civil society and mass media. Hence, the information is conveyed in the English language in a format that is widely accessible, with translation to the local languages when necessary (eg during conferences involving local patient advocacy and support groups). The key messages associated to the Action aim, approach, (expected) results and impact, together with the link between the plan and any Action deliverable related to communication listed on e-COST, is defined as follows:

- Advances in basic research have helped to further increase the understanding of rare gynaecological cancer, especially in the field of prevention and early detection (screening), and in the management, particularly diagnosis and in some cases, even treatment. These breakthroughs need to be made accessible to all, in order to decrease the health inequalities and lack of access to care within different groups in the same countries and among different European Countries (Aim and Deliverables of Working Group 1);
- Biobanking of samples derived from rare gynaecological cancers: this requires a robust and standard legal and ethical guidelines in order to ensure data protection while attracting participation and funding for maintenance of the infrastructure (Aims and Deliverables of Working Groups 2 and 3)
- Bridging the gap between researchers, clinicians and industrial partners, particularly the pharma and biotech industries (Aim and Deliverables of Working Group 4);
- Setting the scene for eventual high-quality, international, and innovative clinical trials aimed specifically at addressing the issues in the management of rare gynaecological cancers (Aim and Deliverables of Working Group 5).

The suitable communication tools/channels to be used for communication purposes and the tentative timeline for their development, production and use, are as follows:

- The GYNOCARE Action website (www.gynocare.net): Deliverable of Working Groups 1 to 5 - to be set up within 6 months of the re-starting of the Action (previous website set up by the previous Chair and MC was closed and not passed on to the new MC and Chair);
- New action logo and visual identity after a call for 3 quotes from different media companies. This is to be finalised and endorsed by MC within 6 months of the restart of the Action : Deliverable of Working Groups 1 to 5;
- Social media: Facebook, Linked in, Twitter and Instagram – new accounts set up within 3 months of the restart of the Action and managed by Science-coordination team : Deliverable of Working Groups 1 to 5;
- Press releases, including translations in the national language of where the meeting is held ; Deliverable of Working Groups 1 to 5 following the respective conference and/or training school focusing on the aims of the individual working groups, which are held in the agreed time period;
- Infographics, as well as the products to be developed for communication purposes
- Templates especially for powerpoint presentations and invitations. This is to be finalised and endorsed by MC within 6 months of the restart of the Action: Deliverable of Working Groups 1 to 5;
- Podcasts and Webinars : Deliverable of Working Groups 1 to 2;
- Videos/animations especially to explain the need of biobanking – Deliverable of Working Group 2, to be presented during the fourth year of the Action.

4. PLAN FOR THE DISSEMINATION OF ACTION RESULTS

The Science co-ordinator and Action Chair, together with the team of MC members will ensure that the dissemination of this Action enables the knowledge and results to be made public towards its target audiences, who could benefit and use them. The information is conveyed in a language that is customised to the specific target audience (e.g. scientific publication for researchers; lay terms for patient support and advocacy groups and the general public). The GYNOCARE Action will adopt an Open Science and Open Access approach, ensuring openness, accessibility, adherence to FAIR principles and IPR.

All scientific publications which are produced as outputs of this COST Action and which are funded by COST will be open access. There will be a minimum of 10 open access scientific publications which will be published in high impact scientific journals. It is envisaged that the majority of the scientific papers will emerge from Working Group 1, given that it is focused on basic research and scientific advances made in the field of rare gynaecological cancer. The journals to be targeted include *Cancers* (Impact Factor 6.6) and the *International Journal of Molecular Sciences* (Impact Factor 5.6). A number of MC members will themselves also be guest editing special issues related to the field of gynaecological cancer. In addition, at the end of the Action, the Chairperson will guest-edit a special issue in the *European Journal of Surgical Oncology* (Impact Factor 4.2), together with other co-editors who are also MC members. In addition, following the end of the Action, a subgroup of the MC members from Working Group 1 will be writing up the 2nd edition of the Springer reference textbook on 'Rare and Uncommon Gynaecological Tumours'.

Working Groups 2 and 3 will be responsible for the content of the first GYNOCARE conference which will be held in Malta, where the main focus will be on registration of rare gynaecological cancers and biobanking. This will be held in May 2021. In addition, the lead of WG2, Dr Sharon O'Toole, who is the MC member from Ireland, and the co-ordinator of INNOVATION - the Irish National Network for Ovarian Cancer Collaboration, and the Executive Committee Member of the Irish Society of Gynaecological Oncology (ISGO) ESGO-ENGAGE (<https://engage.esgo.org/>), will be the bridge between GYNOCARE COST Action and the European Network of Gynaecological Cancer Advocacy Groups (ENGAGE). ENGAGE is the ESGO network of European patient advocacy groups which represents all gynaecological cancers (particularly ovarian, endometrial, cervical, vulvar, and rare cancers).

Working Group 4 will organise a conference on 'Bridging the Gap between Research and Pharma' which reflects the aim of this working group. It will be held in Naples, Italy in February 2023 and the local host will be the lead of WG4, Prof Antonio Giordano.

Working Groups 1 and 5 will organise the two training schools, focusing on the pathology of rare gynaecological cancers, patient outreach and informed consent for registration and biobanking. These training schools will specifically be held in ITC countries, North Macedonia and Bulgaria, in order to enable dissemination especially in the Balkans, where there is a higher incidence of gynaecological cancers, especially cervical cancer due to multiple issues. One of these training schools will specifically overlap with the date of the 20th September so that it coincides with World GO Day, which is World Gynaecology Day. This will encourage the attendance of local and international media and the possibility of press releases on public broadcasting such as TV, radio and newspapers.

International congresses such as the European Board and College of Obstetrics and Gynaecology (EBCOG) and congresses organised by the national societies will be targeted.

5. PLAN FOR THE VALORISATION OF ACTION RESULTS

Since valorisation deals with the exploitation of Action results by specific target audiences, creating potential significant societal, health-economic and policy impact, GYNOCARE COST Action is fully committed to support the envisaged scientific, technological and/or socio-economic impacts.

The potential end users include clinicians (eg. Oncologists, surgeons, pathologists, geneticists, gynaecologists, general practitioners) who are already established professionals or still in training; pharmacists and stakeholders in the pharmaceutical industry; lawyers and legal advisers, ethicists, data protection officers, public health specialists (especially those involved in maintaining registries for cancer and/or rare diseases), biobankers, researchers, academics and of course patients and patient advocacy and support groups.

Both during and after the lifetime of the GYNOCARE Action, the (expected) Action results will be disseminated in the form of peer reviewed publications in high impact scientific journals, and specifically a special issue and a book after the end of the GYNOCARE Action. MC members will be encouraged to attend radio and TV programmes, talks to the general public during events such as Café Scientifique to discuss the deliverables of GYNOCARE, which may be relevant outside the strict scientific sphere and methods and formats to promote synergies between the Action and partners for valorisation.

Data protection issues will be discussed in great detail in Working Group 3 which will be concerned with the legal and ethical issues around informed consent and data protection, when it comes to biobanking of tissue samples derived from rare gynaecological cancers, and the inclusion of patients in clinical trials. A video to describe what biobanking is (in lay terms) will be disseminated.

Press releases done during World Gynae-oncology Day (20th September) and Rare Diseases Day (28/29th February) will be held in order to increase awareness on rare gynae cancer. Also, the Pink October campaign will incorporate screening for cervical cancer, and looking out for the signs of ovarian cancer, apart from education on breast self-examination and imaging such as mammography.

ANNEX 1

Table 1 highlights the different scope of Dissemination and Communication activities, while Table 2 underlines key questions to be addressed in each plan.

TABLE 1. COMMUNICATION – DISSEMINATION – VALORISATION

	COMMUNICATION	DISSEMINATION	VALORIZATION
Objectives	<p>Promotion of the Action and its results. Raise awareness about the topic.</p> <p>Inform, promote and communicate – Visibility</p>	<p>Public disclosure about the Action results only.</p>	<p>Make concrete use of results for research, knowledge transfer or commercial use.</p>
Expected Impact	<p>Show the success of research collaboration. Engaging with society to show how it can benefit from the Action results.</p>	<p>Maximise result's impact. Allow researchers to go a step forward. Make Action results a common good.</p>	<p>Further research, norms setting, and standardisation particularly in cancer prevention and screening, and management. Represents society's direct & indirect return on the public sector's investment in research.</p>
Audiences	<p>Reaching multiple audiences from healthcare professionals, scientists, academics, the general public, citizens, civil society, and mass media</p>	<p>Groups that may use the results in their own work including peers, industry, stakeholders.</p> <p>Regarding policymakers, engage and share evidence-based results during the legislative process.</p>	<p>Not only researchers: incubators, venture capital, local, national or EU-related innovation ecosystems including policy-makers, pharma and biotech industry, SMEs, and civil society.</p>
Languages	<p>Understandable, non specialist language, layman – avoid jargon</p>	<p>Scientific and specialist language/jargon.</p>	<p>Combines both general and technical language to present reports, results, prototypes, software, data, etc.</p>
Channels & Tools	<p>Public debate, TV channels, radio, newspapers, websites, social media targeting general public.</p> <p>Infographics, multimedia (podcast, webinars, videos)</p>	<p>Peer-review journals, scientific and stakeholder conferences, online open access repository of results.</p> <p>Infographics, multimedia (podcast, webinars, videos)</p> <p>EU related platforms and services such as Open Research Europe, European Open Science Cloud.</p>	<p>Stakeholder groups and events, industry publications/reports, competitions/awards.</p> <p>EU related platforms and services such as, Innovation Radar, Horizon Results platform, European Organization for Rare Diseases (EURORDIS: www.eurordis.org), e European Board and College of Obstetrics and Gynaecology (EBCOG) and ENGAGE (European Network of Gynaecological Cancer Advocacy Groups).</p>

TABLE 2. THE 5 W TO STRUCTURE YOUR PLAN

<p>WHY It is relevant to communicate about the Action?</p>	<ul style="list-style-type: none"> • Research needs to be scattered across Europe, especially in ITC countries, or in areas within non-ITC countries where there are issues in equitable access to appropriate healthcare; • There is an urgent need for a coordinated and joint effort to build a collaborative platform linking science, industry, and management, especially in the field of data protection, informed consent for biobanking and participation in smart and innovative clinical trials in the field of rare gynaecological cancers; • Raise awareness among the general public, and specific patient groups, and young adults about cancer prevention and screening for early detection, particularly in the cancer of the uterine cervix; • Raise awareness among policy makers on the fact that rare cancers are in fact not rare (more than 9 million patients are diagnosed each year with a rare gynaecological cancer); • Bring added value of belonging to a multidisciplinary network involving numerous countries; • To spark new collaborations in order to help capacity building among young upcoming professionals within the clinical, scientific and academic fields, and even with other disciplines, such as biomedical engineering, artificial intelligence, and many others • Bridge the gap between researchers and the and the pharmaceutical and biotech industries in order to pave the way forward for smart innovative clinical trials in order to make advances in personalised medicine even in patients with rare gynaecological cancer
<p>WHAT is the key message?</p>	<p>The GYNOCARE COST Action MoU will be used to set the objectives and develop the main key message which is to explore new techniques in treating cancer; and to decrease the health inequalities which are present especially in the field of rare gynae cancers.</p>
<p>WHO is the target audience?</p>	<ul style="list-style-type: none"> • Scientific community, Scientists, Academia; • Biotech businesses, pharma industry, SMEs; • NGOs, Citizen organisations, patient advocacy groups eg the National Alliance for Rare Diseases Support in collaboration with the European Organization for Rare Diseases (EURORDIS: www.eurordis.org) and ESGO-ENGAGE (https://engage.esgo.org/). The European Network of Gynaecological Cancer Advocacy Groups (ENGAGE) is the ESGO network of European patient advocacy groups. It represents all gynaecological cancers (particularly ovarian, endometrial, cervical, vulvar, and rare cancers). • Authorities, Policymakers and specify at local; regional; national; European and international level.
<p>WHERE and how to communicate & disseminate?</p>	<p>The Action Chair and Science Co-ordinator will attend the courses organised by COST Academy, online or in person in Brussels, in order to learn more on how to engage with the media and how to best co-ordinate science communication. The following tools and channels will be used to convey the key message of the GYNOCARE network:</p> <ul style="list-style-type: none"> • Public debate; • Local TV channels, radio, newspapers from different MC countries • Websites such as the dedicated GYNOCARE website: www.gynocare.net ; university websites such as https://www.um.edu.mt/newspoint and websites of international research organisations https://www.newswise.com/SHRO#! • Social media, including Facebook, Linked in, Twitter and Instagram • Workshops, training schools, conference, science fairs, festivals and campaign such as the European Researchers' Night in different member countries

WHEN it is appropriate to start communicating & disseminating?

Communication and dissemination will be given the utmost importance from the start to the end of the Action, and even beyond.

Timeliness is very important. The key moments during the lifetime of the Action when there is something new to release are as follows:

- When setting the network to introduce the Action;
- When the website & social media are set;
- When there are some results to release;
- When participating to an activity that has a wider scope with key stakeholders;
- When a joint scientific publication is published;
- When other evidence-based results and output are available.

Planning is key: a dissemination calendar will be set up, which is based on the Action planned activities and milestones is helpful to identify key moments.