



➔ INTRODUCTION

Starting a Gynaecological cancer patient advocacy group.

➔ Why form a gynaecological cancer advocacy group?

Ovarian, uterine (womb), cervix and other gynaecological cancers are among the most common cancers to affect women. But these cancers do not attract the attention they deserve from the public and policymakers, and women with gynaecological cancer and their families continue to face many challenges in obtaining the care and support that they need.

Patient groups can support people throughout their cancer journey by increasing their knowledge and coping skills. At the same time, patient groups can act as advocates for patients in discussions with health professionals, researchers, the healthcare system, and local and national government.

There may already be general cancer advocacy groups in your country, but these groups frequently include participants diagnosed with many different types of cancer. Women with gynaecological cancers have specific advocacy and support needs and may be reluctant to share their experiences as members of general cancer groups, especially in countries where these cancers still evoke shame, embarrassment or stigma.

By starting a gynaecological cancer advocacy group, you can work in partnership with women and their families to:

1. Help them feel less alone by putting them in touch with others with similar experiences and concerns
2. Support them to improve communication with health professionals about their preferences and needs for care
3. Ensure they secure their rights to financial, social and practical support from local and national government
4. Help decision makers understand what is important for women affected by gynaecological cancer
5. Campaign for change at the local, national and European level.

Introduction

➔ How ENGAGe can help you

It can be challenging to start a patient advocacy and support group, but women across Europe share many of the issues that face women with gynaecological cancer in your country. The European Network of Gynaecological Cancer Advocacy Groups (ENGAGe) can help you start a successful gynaecological cancer advocacy and support group.

Established in 2012, ENGAGe is a network of European patient advocacy and support groups representing all gynaecological cancers, and was established by the European Society of Gynaecological Oncology (ESGO), the principal European society for health professionals contributing to the study, prevention and treatment of gynaecological cancer.

Under the ENGAGe Initiative 'Join the community - start a GYN cancer advocacy group' you can apply to use the gynaecological cancer symbol for your group and also apply for a small grant.

ENGAGe can help you to start your gynaecological cancer advocacy group by:

- Facilitating networking and collaboration between you, your supporters and other gynaecological cancer advocacy groups in your country and across Europe.
- Sharing best practice to empower you to campaign to improve prevention, early diagnosis, access to treatment and the quality of care for women with gynaecological cancers in your country, and build on the achievements and successes of other advocacy groups.
- Signposting you to available educational and information resources to help you support your members.
- Helping you to join forces with other advocacy groups to influence health policy and research priorities in your country and/or in Europe.

This new series of ENGAGe factsheets is a practical guide for anyone who wants to start a new gynaecological patient advocacy group. The toolkit begins by explaining how to establish the key facts and challenges in your country and hold your first meeting, and then shows you how you build firm foundations to grow and sustain your group.

Starting a new patient group is exciting and fulfilling but, like any pioneering work, the road ahead will not always be straightforward. But remember, the gynaecological cancer advocacy groups that are now large and successful organisations began just like you and your supporters: a few people inspired by the common vision of improving the lives of women with gynaecological cancer and their families.

ENGAGe means that you are not alone in your advocacy work, and that you can share your achievements and learn from the successes of others.

All the best,



Prof. John Green: ENGAGe Chair



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ENGAGe is here to help you:

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