



➔ FACTSHEET 1

Identifying your needs





Every gynaecological advocacy group starts with one person or a few people who want to improve the lives of affected women and their families. This vision is often the result of personal experience from having cancer yourself or seeing someone close to you affected by the disease.

You may have received little information about options for treatment or practical support for you and your family, or you may believe that you would not have been affected by cancer if there had been better prevention, care or research. You may also feel that the general public, health system and government in your country do not understand the special problems faced by women with gynaecological cancer. You might also see that some issues faced by women and their families are not decided by your country's government, but at the European level.

Making your vision a reality by starting a new group is very rewarding because of the real differences you can make to women and their families, but it can be challenging and hard work. So before you begin, establish what is already available and the key facts and challenges in your country.

➡ Do you need to start a new group?



While some advocacy groups are large, well-known organisations, others are smaller and less able to publicise their work. So find out what already exists to support women with gynaecological cancer in your country by:

- Getting in touch with ENGAGe at engage@esgo.org.
- Asking existing general cancer advocacy and support groups in your country.
- Asking the national association of gynaecology health professionals, the national study group on gynaecological cancer, or professionals at your local cancer centre.
- Asking your government if they have a directory of voluntary groups.
- Checking the membership list of pan-European cancer networks such as the European Cancer Patient Coalition at www.ecpc.org.
- Searching the internet (try "gynaecological cancer support groups" and your country's name).

You may find that there is already a gynaecological advocacy group that would welcome your enthusiasm and participation. If not, before going ahead and starting your own group, it makes sense to identify and influence any individuals or organisations that would be helpful in supporting your plans and who might have concerns that you need to address:

- Would health professionals and hospitals help you in providing advocacy for your members?
- Are there any existing organisations (for example, local or national voluntary groups) that might feel that your new group is entering their space? How could you encourage them to support your plans?
- Will you need to raise awareness among local and national policy makers who think that women with gynaecological cancer do not need the support of an advocacy group?



FactSheet

You may not be able to overcome everyone's concerns and potential opposition, but do not let this deter you if you are convinced that your group is needed. Focus on what women with gynaecological cancer really need, and you will be successful. In any case, being aware of, acknowledging and addressing potential concerns and oppositions will help you to formulate your response as your group grows.

➡ Establishing the key facts and challenges for your country

The next step is to find out the key facts and challenges concerning gynaecological cancers in your country. You probably have your own views, but a good start is to:



- Ask the opinions of women you have met at your cancer centre or hospital.
- If possible, arrange to circulate a short survey at your cancer centre. But be aware that this may not be possible because of ethical rules that govern health professionals and general data protection regulations in your country.
- Ask general cancer organisations in your country if they can share the results of any surveys or market research they have done about the challenges faced by patients in your country.
- Join online groups - perhaps in other countries or languages, where women meet to share experiences or discuss issues that matter most to them.
- You can talk to your gynecologist / oncologist how does she / he see the need of having a new group.

Then support these experiences with the facts by visiting the ENGAGE website, and downloading a copy of our European facts and figures report, Women's silent cancers. This report gives the latest information on the causes, diagnosis and treatment of each gynaecological cancer and shows how your country compares to others in Europe. It also provides information on organisations such as EUCAN, provided by the World Health Organization and the International Agency for Research on Cancer. EUCAN's website has freely available information to download on specific cancers in each European country.

The resources section of Women's silent cancers also includes a list of European advocacy groups and other sources of information on cancer. These organisations can provide information themselves or signpost you to other resources to help you as you begin to develop your new gynaecological cancer advocacy and support group.

Women's silent cancers

European facts and figures on gynaecological cancers:

<https://engage.esgo.org/resources/cancer-fact-sheets/>

EUCAN

Factsheets about each country and cancer and country:

<https://ecis.jrc.ec.europa.eu/>

Contact information of ENGAGE:

Web: <http://engage.esgo.org/>

Email: engage@esgo.org

Facebook: <https://www.facebook.com/groups/155472521534076/about/>