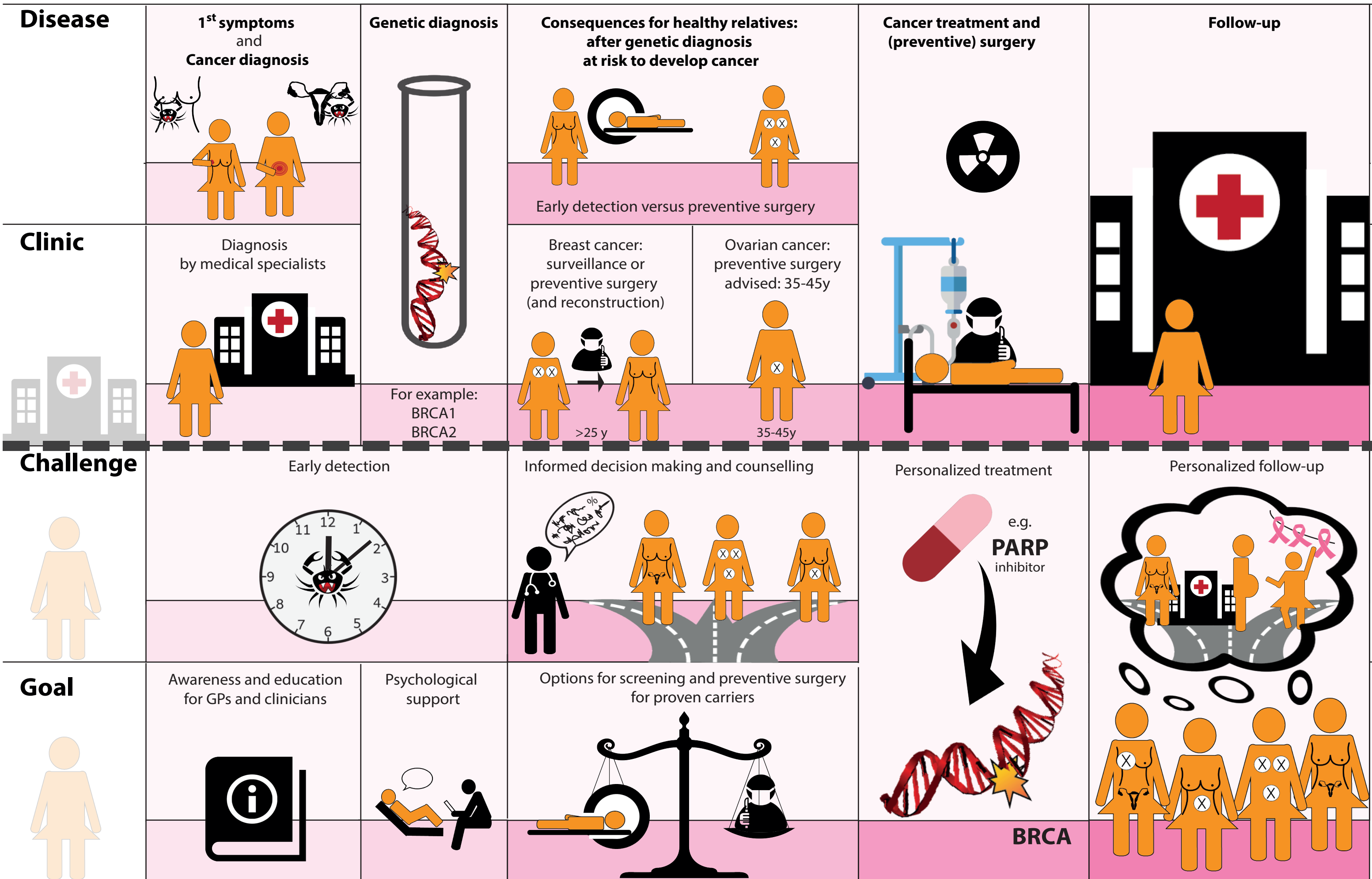

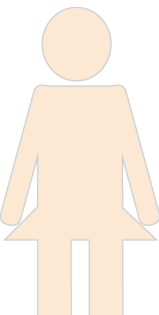
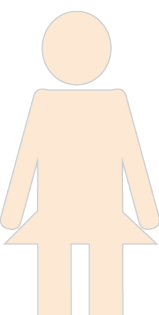


# Patient Journey Hereditary Breast and Ovarian Cancer Syndrome (HBOC)



# Patient Journey Hereditary Breast and Ovarian Cancer Syndrome (HBOC)

<b>Disease</b>	<b>1<sup>st</sup> symptoms and Cancer diagnosis</b>  Patient experiences symptoms:  <b>Breast cancer:</b> palpable lump in breast or found by incidental screening;  <b>Ovarian cancer:</b> vague symptoms such as feeling bloated, etc	<b>Genetic diagnosis</b>  Woman without symptoms who have a <b>family history</b> , or family members can be tested from 18 onwards. Surveillance starts from 25 or 30 onwards, depending on country regulations.  Woman <b>diagnosed with cancer</b> who fulfil certain criteria (e.g. early age) will be tested. These criteria vary from country to country within Europe.	<b>Consequences for healthy relatives: after genetic diagnosis at risk to develop cancer</b>  Women with HBOC can choose between - <b>Enhanced screening for breast cancer:</b> cancer can be detected and treated at an early stage. No prevention of cancer development - <b>Risk reducing surgery:</b> both breasts or the breast without cancer will be removed and reconstructed. This operation greatly reduces the risk of breast cancer occurring.		<b>Cancer treatment and (preventive) surgery</b>  Surgery and/or neoadjuvant chemotherapy  <b>Breast cancer surgery:</b> Removal of only the breast with cancer, or preventive surgery of both breasts. Optional reconstruction of the breasts	<b>Follow-up</b>  <b>Surveillance for patients without preventive surgery</b>  <b>Breast cancer</b> No surveillance under 30 years of age. Surveillance is performed using physical examination, MRI and/or mammography. Surveillance protocols are country specific. See <a href="http://www.genturis.eu">www.genturis.eu</a> : Overview of hereditary breast and ovarian cancer (HBOC) guidelines across Europe doi.org/10.1016/j.ejmg.2021.104350  <b>Ovarian cancer</b> Removal of ovaries and falopian tubes may be advised. Surveillance protocols are country specific.
<b>Clinic</b>  	<b>Diagnosis by medical specialists</b>  Biopsy / lab results and imaging will confirm cancer diagnosis.	See <a href="http://www.genturis.eu">www.genturis.eu</a> : Overview of hereditary breast and ovarian cancer (HBOC) guidelines across Europe doi.org/10.1016/j.ejmg.2021.104350	<b>Breast cancer: surveillance or preventive surgery (and reconstruction)</b>  No surveillance under 30 years of age. Surveillance is performed using physical examination, MRI and/or mammography. Surveillance protocols are country specific.	<b>Ovarian cancer: preventive surgery advised: 35-45y</b>  Removal of ovaries and falopian tubes may be advised. Surveillance protocols are country specific.	<b>Ovarian cancer surgery</b> removal of both ovaries and both falopian tubes	<b>After preventive surgery:</b> follow up care depends on cancer diagnosis.
<b>Challenge</b>  	<b>Early detection</b>  <b>Before genetic diagnosis:</b> Long time passes before diagnosis; early detection and treatment are crucial for outcome!  <b>Breast cancer:</b> Breast cancer may not always be suspected in young woman <b>Ovarian cancer:</b> symptoms are very vague. Woman are subjected to tests that rule out other disorders, while ovarian cancer is initially overlooked		<b>Informed decision making and counselling</b>  Counselling: - Clarify risks associated with HBOC genes - Clarification about options for gene carriers - Surveillance options - Preventive surgery - Hormone replacement therapy - Provide reliable information - Referral to the respective patient organization - Counselling about consequences for family members - Family planning - Preimplantation genetic diagnosis		<b>Personalized treatment</b>  - Personalized treatment options for HBOC (e.g. PARP inhibitors for BRCA) - Long term effects of treatment - Coping with inevitable side effects - Fertility - Surgical options: - Preventive surgery as part of treatment - Reconstructive options - QOL during treatment - Psychological support - Information about how to improve the healing process - Include partner in counselling to cope better with a new reality (sexual activity, mood swings, etc.)	<b>Personalized follow-up</b>  - Management of post-op complications: - wound surveillance - Physician- patient communication: - regular appointments - Support after treatment - anxiety after cancer treatment - anxiety after preventive surgery - Family planning  - Adaption to the new reality - Back to "normal" - Enjoying life!
<b>Goal</b>  	<b>Awareness and education for GPs and clinicians</b>  To achieve early stage diagnosis, every GP and clinician should know: - Young women do get breast cancer - Ovarian cancer symptoms - Risks associated with HBOC - Family history associated with HBOC	<b>Psychological support</b>  - Support on dealing with new reality - Counselling on communication with family members - Share experiences with other gene carriers	<b>Options for screening and preventive surgery for proven carriers</b>  Choose between screening and risk reducing surgery based on personal preference: <b>Enhanced screening:</b> + breasts are preserved - at each MRI or mammography there is the possibility of a bad result . <b>Risk reducing surgery:</b> + reduces the risk of breast cancer - change in body image			