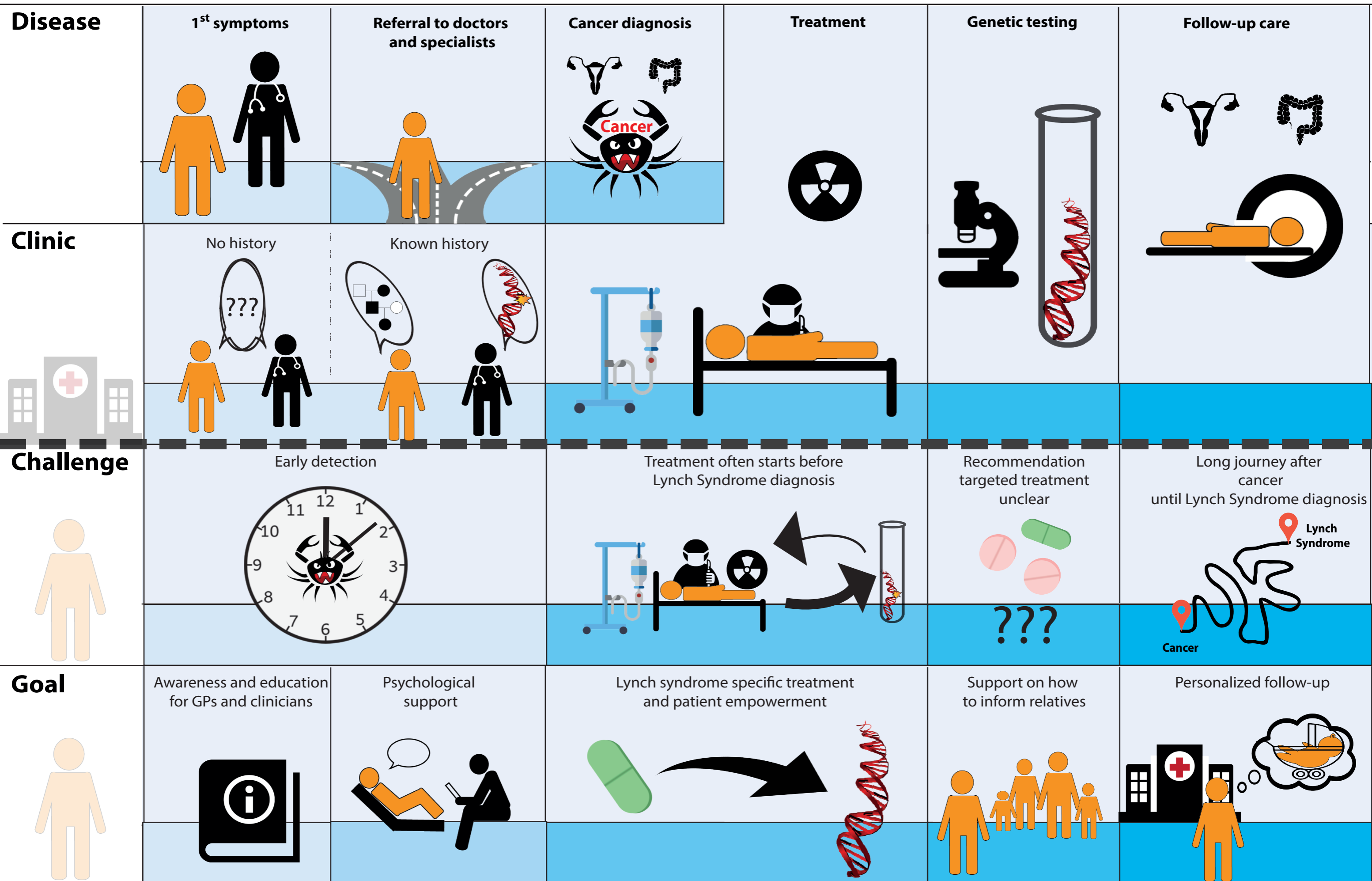

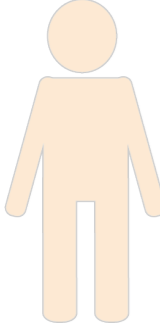
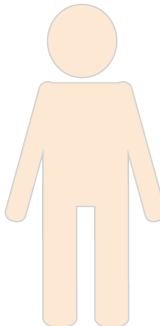


Patient Journey Lynch Syndrome



Patient Journey Lynch Syndrome

Disease	1st symptoms Variety of cancer related symptoms Associated cancers: Colorectal (20-80%) Endometrial (15-60%) Ovary (1-38%) Stomach (1-13%) Small intestine Urinary tract etc.	Referral to doctors and specialists Patient often has to see numerous doctors and specialists. Patient is subjected to numerous clinical tests.	Cancer diagnosis Treatment / therapy plan is outlined. Patient has to decide on / agree to therapy options. Possibility to get a second opinion.	Treatment If Lynch Syndrome is diagnosed patient can decide on combined prophylactic surgery, dependent on gene involved: - Colon - Ovaries - Endometrium	Genetic testing 1. Counselling interview (1h) 2. Patient receives result (approx. 2 month later) 3. Patient is prompted to inform relatives about: - genetic tumour risk - genetic testing - preventive examinations In 30%-40% genetic mutation is not (yet) detected. Relatives cannot or do not want to be tested, but are also recommended to follow screening programs for cancer prevention: - Colonoscopy: 1-2 y - Helicobacter pylori infection - Skin examination	Follow-up care After regular cancer treatment, Lynch syndrome patient should go into surveillance: Regular intervals for 5 years: - Physical examinations - Clinical tests Surveillance: Colonoscopy: 1-2 y Helicobacter pylori infection Skin examination Risk reducing surgery dependent on gene involved: Uterus Ovary Colon
Clinic 	No history Initially cancer is not assumed because of atypical clinical appearance: - Young age - Lack of classical risk factors (e.g. overweight, smoking)	Known history Screening: Colonoscopy: 1-2 y Helicobacter pylori infection Skin examination Risk reducing surgery: Uterus Ovary Colon	If there is cancer diagnosis without Lynch Syndrome diagnosis patient is treated according to general guidelines. Patient can only decide on prophylactic surgery when Lynch Syndrome diagnosis is confirmed.			
Challenge 	Early detection Physicians should be aware of genetic tumour risk syndromes and consider cancer at early age, especially in case of positive family history. Quick and correct referral to specialists. Early detection and treatment are crucial for outcome!		Treatment often starts before Lynch Syndrome diagnosis Not every Lynch Syndrome patients is aware of Lynch Syndrome before cancer treatment. Referral to expert to receive a valuable second opinion. Awareness of both physical and psychic side effects.		Recommendation targeted treatment unclear Recommendations for treatment of Lynch Syndrome tumours Considering its characteristics: - High immunogenicity - Lower metastasis rate - High risk of developing another cancer after treatment	Long journey after cancer until Lynch Syndrome diagnosis Every patient should receive their diagnosis as soon as possible, to be able to have benefit from screening programs and/or preventive surgery. Currently not all patients are diagnosed and they and their family members do not receive the care they need.
Goal 	Awareness and education for GPs and clinicians GPs and clinicians should identify red flags associated with tumour risk syndromes. Education and raising awareness of genetic tumor risks among GPs and physicians.	Psychological support Physician directly suggests psychological support in diagnosis phase to deal with consequences for patients and relatives.	Lynch syndrome specific treatment and patient empowerment Genetic tumour risk and tumour characteristics are taken into account when deciding on treatment. Routine immunohistochemistry for MMR proteins in colorectal cancer and endometrial cancer helps to recognise Lynch Syndrome patients. Full diagnostics in every MSI-H tumour. Clear recommendation concerning hormone replacement. Next to guidelines.		Support on how to inform relatives Psychological support on coping with lifetime tumor risk for patient as well as for family. Clear recommendations on when, and how to inform relatives.	Personalized follow-up Organize follow-up together with the patient, consider: Physical care Psychological care Family planning Social consequence e.g. mortgage