

ERN GENTURIS PLAIN LANGUAGE SUMMARY OF GUIDELINE ON COUNSELLING ON REPRODUCTIVE OPTIONS FOR INDIVIDUALS WITH A CANCER PREDISPOSITION SYNDROME (INCLUDING GENTURIS)

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Disclaimer: The content of this plain language summary is based on the "ERN GENTURIS GUIDELINE ON COUNSELLING ON REPRODUCTIVE OPTIONS FOR INDIVIDUALS WITH A CANCER PREDISPOSITION SYNDROME (INCLUDING GENTURIS)_ final version_august2025".

INTRODUCTION

Cancer predisposition syndromes are genetic conditions, that can cause multiple concerns for affected family members: Not only is there an increased risk of developing cancer compared to the general population - many individuals with these syndromes also have a high risk of having a child with the same condition, which makes the process of family planning more complex. Moreover, other non-tumorous manifestations may affect clinical care as well as counselling.

The family therefore relies on health care professionals to inform and guide them through the many options that are available. However, not all healthcare professionals have the specialised knowledge needed to offer this counselling.

GUIDELINE AIMS

The aim of this guideline is to assist healthcare professionals in providing both relevant and timely counselling for individuals with a cancer predisposition syndrome.

SUMMARY

The guideline group consist of experts with experience in multiple areas surrounding the care of individuals with cancer predisposition syndromes as well as individuals with a cancer predisposition syndrome and their representatives. The following recommendations regarding reproductive counselling are made based on scientific literature and expert consensus obtained via a modified Delphi process.

It is recommended that all individuals with a cancer predisposition syndrome, and those family members for whom it is relevant, are offered counselling about their options with respect to family planning – it is up to them to accept or decline the offer. It is also recommended that there are several opportunities for counselling throughout a person's life, as perspectives and relevance regarding family planning can change over life.

KEY RECOMMENDATIONS / GUIDELINE SUMMARY

Reproductive decision making - content and framework of reproductive counselling	Recommendation	Strength
Reproductive counselling should be offered to all individuals with a cancer predisposition syndrome * and relevant family members.	1,2, 11	Strong (1,2), moderate (11)
Couples should have access to a multidisciplinary team of healthcare experts.	6, 13	Strong

Timing of reproductive counselling provision		
Reproductive counselling should be offered longitudinally with multiple opportunities for counselling throughout life, ideally starting before family planning	7, 8	Strong
Children at risk should be offered counselling once they reach adulthood, or earlier if appropriate	10	Moderate
Presentation of reproductive option		
Reproductive counselling should provide follow-up opportunities, and access to psychological support.	12, 13	Moderate (12), strong (13)
Range of assisted reproductive technologies		
Fertility preservation options should be included in reproductive counselling.	15, 16	Strong (15), moderate (16)

* Counselling is especially relevant in the reproductive age but can be relevant in other age group as well, such as adolescence and older individuals informing their relatives.

PSYCHOLOGICAL NEEDS

It is important to consider the impact of a cancer predisposition syndrome on both mental and social wellbeing. A delayed diagnosis, uncertainty about future health problems and/or fear of developing cancer may cause anxiety or depression. Living with a long-term health condition may also have social challenges. There may be financial concerns such as cost of insurance and impact on employment. There may also be feelings of guilt and concerns when making plans for starting a family.

Addressing the psychological needs of patients and families with cancer predisposition syndromes should form a key element of their care and should also be part of the genetic counselling process. Healthcare professionals should ask about wellbeing at each clinical contact and be aware of signs of anxiety and depression. Patients should be referred for professional support if needed. Peer-to-peer support through patient support groups can also play a key role in wellbeing.