

Background

The World Health Organisation (WHO) describes genetic counselling to be a process through which knowledge about the genetic aspects of conditions is shared by trained professionals with those who are at an increased risk of either having a heritable disorder or of passing it on to their unborn offspring.

This process can include some or all of the following:

1. Collection and interpretation of personal and family medical histories to assess the chance of disease occurrence or recurrence.
2. Education about the natural history of a specific condition, inheritance pattern, testing, management, prevention, support resources and research.
3. Counselling to promote informed choices in view of risk assessment, family goals, ethical, cultural, and religious values.
4. Support to encourage the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder

The role of a genetic counsellor also includes educating other healthcare professionals to improve knowledge about genetics.

Resta et al, (2006) A new definition of genetic counselling: NSGC task force report, J Gen Couns.

Privacy & Confidentiality

You will be required to confirm your full name and date of birth at the start of the session to confirm your identity. The session cannot proceed if you do not provide this information.

Your genetic counsellor is bound by confidentiality, and everything discussed is kept in confidence. Your identity and all clinically relevant data referring to your personal information will be confidential and only Juno personnel and your clinical team – who are similarly bound by confidentiality - will be permitted access to this information. Please be aware that if during your conversation, the genetic counsellor feels that you or someone you know is at risk of harm or requires immediate medical attention, your genetic counsellor is bound by duty to share with the appropriate individual(s) to ensure adequate support or medical attention is provided. If you have any questions about this, please speak with your genetic counsellor who will provide you with further information. We may be required to share anonymised information with regulatory and professional bodies that review genetic counselling practices.

When you request genetic counselling, we will process your data to: (1) Fulfil the obligations arising from the provision of the services contracted by you; (2) Check and guarantee the quality of the services provided (internal audits, quality controls); (3) For educational purposes, provided that it remains anonymous throughout and you cannot be identified during the analysis of the data; (4) Personally address any doubts or suggestions you made during the process and monitor the proper performance and resolution of the counselling. Please be aware that your data and information gathered from your appointment may be stored for a period of time as governed by Juno Genetics data storage policy.

You may, at any time, exercise your rights regarding access, rectification, opposition, deletion, automated decisions, limitation, or portability, by sending an email to

support@junogenetis.com including a copy of a nationally recognised identification document as proof of your identity such as a passport or photo driving licence.

General Information

During the booking process you may be sent a family history questionnaire which you will be asked to kindly complete to the best of your knowledge. If you have any additional documentation, reports, or information that you think may be helpful for the genetic counsellor to review, please feel free to contact our team at falak.arshad@junogenetis.com

You will be informed of the duration of your counselling session during the booking process. This is the maximum duration of your session although it may be shorter. Additional sessions or extensions can be booked separately. Should your counselling session seem likely to overrun, your genetic counsellor will highlight this point and discuss the options moving forward.

Your genetic counsellor will be present in the session at the agreed start time and the allocated time for your session will begin at this point. The session cannot be extended if you are late. If you do not attend the session within 10 minutes of your allocated start time; then this will be considered a cancellation without prior notice.

Your genetic counsellor may postpone and reschedule your session if they feel that you are overwhelmed by emotional pressure during the counselling session. If this is required, your genetic counsellor will likely provide you with a courtesy call to ensure you are safe, well and feeling able to reschedule a second appointment. For genetic counselling appointments where more than one person is required, all persons must be present for counselling to commence. If you are unsure about whether this applies to you, please contact our customer support team (support@junogenetis.com) who will be happy to clarify.

Online genetic counselling sessions

Your genetic counselling session will use the secure Teams platform. Your appointment will be scheduled with advance notice which will enable you time to download and/or set up the free Teams platform on your smartphone/tablet or device ahead of your appointment. It is your responsibility to ensure that you have set up the platform correctly and your microphone and camera are functioning correctly. You may contact our customer support team with any questions if you are experiencing any difficulties.

We strongly recommend that you receive counselling in a comfortable, private environment. It is your responsibility to ensure that you are in a suitable location to discuss personal information. If you are unable to identify a safe, private environment for the appointment, please do let our team know and we will reschedule your appointment for another more suitable time. We recommend you prepare in advance a hot drink or have access to drinking water during the call.

In the unlikely event that either you or your counsellor experience technical problems during an online session, your counsellor will contact you on the phone number you have provided to decide how to continue. If you do not receive this call, then you should e-mail our genetic counselling team at falak.arshad@junogenetis.com.

If unforeseen circumstances require your counsellor to cancel the session, then you will be contacted as soon as possible to reschedule your session. Please be reassured that our genetic counsellor(s) understand that this may be a period of time where you are keen to proceed as quickly as possible and therefore will be working to speak to you as quickly as possible if this is required. If you do not hear from our genetic counselling or customer support team to reschedule this appointment, please feel free to contact our customer support team on +44 203 743 1944 who will be happy to provide you with an update.

Online genetic counselling will only be offered to individuals who are over the age of 18. If small children or vulnerable adults are present during the appointment it is your responsibility to assess whether the information discussed during your appointment is appropriate to be discussed in their presence. If your genetic counsellor feels that you are overwhelmed with the information with the presence of other individuals in the vicinity, it is at your genetic counsellor's discretion to stop and reschedule your appointment.

Interpreter service

If you require an interpreter for your appointment, in the first instance, please liaise with your clinic/hospital to support you in arranging this for your scheduled day and time.

It is your responsibility to ensure that the interpreter company/service you use is able to effectively translate to and from English for the full duration of the appointment which will involve translating complex medical and genetic concepts. If you are unsure about whether the interpreter service can translate medical terminology, please contact the company directly for clarification.

If an interpreter is arranged for the appointment, please let your genetic counsellor know by emailing the team at falak.arshad@junogenetics.com Once your appointment has been booked with our team, your genetic counsellor will provide you with another opportunity to confirm that you are happy for the individual(s) to attend the session and the interpreter will be required to confirm their full name and the company they work for prior to the session commencing.

Cancellation policy

A minimum of 24 hours' written notice is required for re-scheduling or cancelling an appointment. If you need to reschedule or cancel your appointment, please write to our genetic counselling team at: falak.arshad@junogenetics.com. Rescheduling/cancellation requests within less than 24 hours of your booked session will not be accepted and the session will be charged at full price.

Consent to share information

In some instances, information collected from a genetic counselling appointment may support other relative(s) who are referred to Juno Genetics genetic counselling services. If your relative(s) or their General Practitioner (GP) would benefit from having access to information collected from your appointment, would you consent to the genetic counsellor sharing this information? This may include but is not restricted to collection and exploration of the family medical history.

Yes

No

Declaration

I have read and agree to the terms included in this consent form and I voluntarily request genetic counselling. If multiple persons are to receive counselling, this form must be signed by all patients. All fields are mandatory.

First patient's signature	
First patient's full name (please print)	
Date	
First patient's e-mail address	
First patient's telephone number	

Second patient's signature	
Second patient's full name (please print)	
Date	
Second patient's e-mail address	
Second patient's telephone number	