

1. GENETIC COUNSELLING DEFINITION

The Association of Genetic Nurses and Counsellors (AGNC) describe Genetic Counsellors to be an internationally recognised group of healthcare professionals who are highly skilled in genomic medicine and counselling skills. Genetic Counsellors are skilled and trained in:

- Calculating genetic risk
- Explaining inheritance patterns
- Ordering genomic testing
- Interpreting variants
- Arranging medical and/or diagnostic testing
- Predicting risk of genetic disease
- Referring patients for appropriate disease screening
- Handling subsequent psychosocial and ethical issues raised for individuals and their families

Genetic Counsellors take pride in also providing educational services/opportunities to other healthcare professionals from within embedded clinical genetics departments but also in a mainstream setting and the wider healthcare service.

The Genetic Counsellor Role in the United Kingdom, A statement from the Association of Genetic Nurses and Counsellors (AGNC), August 2020 Endorsed by the Genetic Counsellor Registration Board (GCRB) and Academy for Healthcare Science (AHCS).

2. APPOINTMENT BOOKING

Once you have completed this genetic counselling consent form, please send it to falak.arshad@junogenetics.com. Once this consent form is received completed and signed, the genetic counsellor will be in contact to explain how to book an appointment.

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@junogenetics.com. This will be used to prepare for your appointment ahead of the scheduled session.

At the time of booking the appointment, you will be told the maximum duration of the genetic counselling appointment. Follow up appointments can also be arranged at an additional cost.

If you require any special assistance or considerations due to medical reasons, please inform our team. We will do our utmost to ensure we can support you and find ways in which we can liaise with you to ensure you are able to access this support.

3. Virtual genetic counselling session(s)

Your genetic counselling session will be held via the Microsoft 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 electronic device ahead of your appointment. Please take the time to check that you have set up the platform correctly and your microphone/camera are in full working condition. If you would like to access the session ahead of time to check this, please write to the genetic counselling team who will be happy to support you with this. If you experience any issues on the day or during the appointment, please write to falak.arshad@junogenetics.com who will be happy to support you by providing options to overcome these or may offer you the option to conduct the appointment by telephone instead or to reschedule the session.

It is strongly recommended that you receive genetic counselling in a comfortable, private environment. Please ensure that you are in a suitable private location to discuss personal/ confidential 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. If at any point you would like the genetic counsellor to stop because you are no longer able to discuss personal information where you are, please inform the genetic counsellor verbally who will stop. We recommend you prepare in advance a hot drink or have access to drinking water during the call.

In the 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 below to decide how to continue. If you do not receive this call, then please e-mail our genetic counselling team at falak.arshad@junogenetics.com.

If your genetic counselling appointment is cancelled due to unforeseen circumstances, you will be informed as soon as possible and provided alternative times/days to reschedule your appointment. 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.

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.

If you find yourself feeling unsafe/unable to discuss personal information due to other individuals being present during the time of the appointment, please inform the genetic counsellor that you would like to reschedule verbally or via the text box in the session. If you feel unable to write or say verbally, please log out of the session and inform the genetic counsellor by email at your soonest convenience. If you would like support, please ask the genetic counsellor to telephone you at a time which is convenient/safe for you to attend to enable us to provide support to you. Your safety and security is of utmost importance to us, your genetic counsellor will treat you with the upmost respect and dignity and provide you with support and care.

4. Interpreter service

If you require an interpreter for your appointment, in the first instance, please liaise with your clinic/clinician to support you in arranging this for your scheduled day and time. Please 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 an interpreter is arranged for the appointment, please let your genetic counsellor know prior to the session by emailing the team at falak.arshad@junogenetics.com. Once your appointment has been booked, 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.

5. Your genetic counselling appointment

At the beginning of the appointment, the genetic counsellor will start by introducing themselves and will ask you to confirm your full name(s), date of birth(s) and the location from which you are joining from.

The genetic counsellor will be present in the virtual session at the scheduled start time for the genetic counselling appointment to begin at this time. If you are unable to attend within the first ten (10) minutes of the start of your appointment, this will be considered cancellation without notice and you will be charged the full price of the appointment. As there are likely to be other consultations/meetings following your appointment, the session cannot be extended.

The genetic counsellor may postpone and/or 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 after the session 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 liaise with our team, we will be happy to help.

If you would like to reschedule or cancel the appointment, please write to our genetic counselling team at: falak.arshad@junogenetics.com. Please ensure a minimum of 24 hours' notice is provided, any requests with less than 24 hours of your booked session will be charged at full price.

The information discussed during the appointment will be kept in strict confidence along with any personal/ clinically relevant documentation for you. Please note, other Juno Genetics personnel and your clinical team will be able to access this information who are similarly bound by confidentiality. It is important to note that if the genetic counsellor feels that either you or someone else is at risk of harm or requires urgent support, the genetic counsellor is bound by a duty of care to share with the appropriate personnel and/or emergency services to ensure the appropriate medical support is provided as quickly as possible.

A summary letter of the session will be sent to you and the referring clinician by e-mail after the appointment. The document will be password protected and the password will be sent in a second e-mail shortly after the first. Please note, recording of the session is strictly prohibited.

Anonymised information may be shared with regulatory, accreditation or professional services for the purpose of review of services provided by Juno Genetics, professional development, publications in a peer reviewed journal. Anonymous data gathered may be used to audit purposes, to improve services and may also be stored for a period of time as per the Juno Genetics data storage policy. If you would like more information about this, please liaise with our team who will be happy to help.

6. Privacy Notice

All personal and genetic information is kept by Juno Genetics Ltd under strictly confidential and will be processed in accordance with the General Data Protection Regulation and applicable national laws. The only people who are allowed access to this information are the staff of Juno Genetics, and relevant authorities when the laws of the applicable jurisdiction require this. More details about Juno Genetics' Privacy Policy as well as and the way to exercise your data protection rights can be found at <https://www.junogenetics.co.uk/privacy-policy> This information can also be provided upon request to the email address Juno.DPO@junogenetics.com.

Personal data will only be processed for the following purposes:

- a) To manage your booking and prepare for your appointment before the scheduled session. (art. 6.1.b and art. 9.2.h. of the GDPR)
- b) to comply with arising from the provision of the services requested by you. (art. 6.1.c. of the GDPR)
- c) to review and guarantee the quality of the services provided (in-house processes, quality management checks, laboratory validation studies); (art. 6.1.f of GDPR)
- d) educational/training purposes, at all times subject to anonymisation before use, which will make impossible to identify the patient concerned.
- e) research purposes, scientific publications, and presentations, at all times subject to anonymisation applied in advance, thus ensuring that identification of the individual is not possible. The research will be carried out in compliance with the General Data Protection Regulation and national data protection laws; (art. 9.2. j of the GDPR)
- f) to provide a personalised response to any doubts raised or suggestions made by the patient requesting the test, to monitor that the test was carried out correctly and any concerns were addressed; (art. 6.1.b and art. 9.2.h. of the GDPR) and
- g) to follow up with patients in the future to obtain feedback concerning the service received. (art. 6.1.f of GDPR)

Data will be stored for a minimum of five (5) years unless local laws in the applicable jurisdiction dictate otherwise.

If you believe your data protection rights have been violated or have any complaint regarding your personal information, you may contact the Data Protection Officer, whose contact details are: Juno.DPO@junogenetics.com. You may also contact the Information Commissioner's Officer regarding any queries. Please, see our Privacy Policy for further information.

7. Consent for feedback

The genetic counselling service may contact patient(s) to gather information regarding their experience. Would you be happy to be contacted after the session for feedback using a feedback questionnaire?-

- Yes
 No

8. 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

9. ONCE READ AND UNDERSTOOD THE ABOVE, I/WE DECLARE THAT:

I/WE have read and agree to the terms included in this consent form at stated above and I voluntarily request genetic counselling.

10. PATIENT/S INFORMATION (This form must be signed by all patients due to receive genetic counselling. Please complete all fields.)

PATIENT 1	PATIENT 2
Full Name of PATIENT 1	Full Name of PATIENT 2
Date of birth PATIENT 1 (DD/MM/YYYY)	Date of birth PATIENT 2 (DD/MM/YYYY)
Address PATIENT 1	Address PATIENT 2 (<input type="checkbox"/> Same address as PATIENT 1)
Patient's e-mail address	Partner's e-mail address
Patient's telephone number	Partner's telephone number
Signature PATIENT 1	Signature PATIENT 2
Date	Date