

Genetic Counselling Definition

The Association of Genetic Nurses and Counsellors (AGNC) describes Genetic Counsellors to be an internationally recognised group of healthcare professionals who are highly skilled in genomic medicine and counselling skills. According to this definition, 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).

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 duly filled and signed, the genetic counsellor will contact you 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 send them to our team at falak.arshad@junogenetics.com. This information will be used to prepare for your appointment.

At the time of booking the appointment, you will be told the maximum length of the genetic counselling appointment. When necessary, follow up or additional appointments can also be arranged but will be charged at a separate cost.

Please ensure you inform the genetic counsellor if you and/or partner (if relevant) require any support with English reading/writing/listening prior to the session to enable the genetic counsellor to support you. Likewise, 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.

Virtual genetic counselling session(s)

The appointment will be held by virtual electronic means via videoconference, using Microsoft Teams platform. Your appointment will be scheduled with advance notice which will enable you time to download and set up the free Microsoft Teams platform on your electronic device before your appointment. Please take the necessary time to check that you have set up the platform correctly and your microphone and camera are operational. If you would like to access the session in advance to check for any technical issues, please write to the genetic counselling team who will be happy to support you with this. If you experience any issues on or during the appointment, please write to falak.arshad@junogenetics.com who will be happy to support you by providing options to overcome these issues or may offer you the option to conduct the appointment by telephone instead of videoconference or to reschedule the session.

We advise you to attend your genetic counselling appointment in a private and comfortable place where you can freely discuss personal information. If you are unable to identify a safe and private environment for the virtual appointment, please let our team know and we will reschedule your appointment.

If at any point during the session 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 or via the text box in the session who will stop. If you feel unable to write or say verbally, please log out of the session and inform immediately the genetic counsellor by email. If you would like to receive support, please ask the genetic counsellor to telephone you at a time which is convenient for you to attend in order to enable us to provide you the support required. Your safety and security are of utmost importance to us. Therefore, your genetic counsellor will treat you with the utmost respect and dignity, providing you with support and care you need.

We recommend you prepare in advance a hot drink or have access to drinking water during the call.

Please ensure the contact number you provide on this consent form is correct as if any technical issues occur during the appointment this is how the genetic counsellor will contact you to discuss how to proceed. If you have any questions, please do not hesitate to e-mail our genetic counselling team at falak.arshad@junogenetics.com.

In the unlikely event that the genetic counsellor is required to cancel your appointment, you will be informed as soon as possible and provided alternative times/days to reschedule your appointment. We understand the importance of this session and your appointment will be rescheduled to the next available time/day. In case the appointment is not rescheduled, please contact our customer support team on +44 203 743 1944 who will be happy to provide you with an update.

Genetic counselling is only provided to adults above the age of eighteen (18). If individuals under eighteen (18) 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 or due to the presence of other individuals present at the appointment, your genetic counsellor can stop and reschedule your appointment at their sole discretion.

Interpreter service

If you require an interpreter for your appointment, please contact your clinic to support you in arranging this for your scheduled appointment. 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.

Should you require an interpreter, please ask your clinic to inform your genetic counsellor know prior to the session by emailing 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 details prior to the session commencing.

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 identifiable information and the location at which you are joining from.

The genetic counsellor will be ready in the virtual session at the scheduled appointment time to start. If you are unable to attend the appointment within the first fifteen (15) minutes of the start of your appointment, your genetic counsellor will reschedule your appointment. The reschedule of the appointment will be charged separately. In any case, as there are likely to be other sessions following your appointment, the session cannot be extended.

Your 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 happens, you will be provided 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 attending, all attendees are required to be present for the session to start. If you are unsure about whether this applies to you, please liaise with our team, who will be happy to help.

If you need to reschedule or cancel the appointment, please write to our genetic counselling team at: falak.arshad@junogenetics.com at least one (1) day in advance of your scheduled appointment, any requests past this time will incur a cost.

The information discussed during the appointment will be stored confidentially along with any relevant personal and clinical documents/data. Please note, both Juno Genetics' personnel and your clinical team will be able to access to this information. It is important to note that if the genetic counsellor feels that either you are at risk of harm or require urgent medical support, the genetic counsellor is bound by a duty of care to share this information with the appropriate personnel and/or emergency services to ensure you are provided with the necessary medical support as quickly as possible.

Anonymised information may be shared with regulatory, accreditation or professional services for the purpose of reviewing the 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 require more information, please liaise with our team who will be happy to help.

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/professional development 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.

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 authorise the genetic counsellor to share this information? This information may include but is not restricted to collection and exploration of the family medical history.

Yes

No

Declaration

I have read, fully understand and agree with the terms and conditions included in this consent form as stated above and I voluntarily request genetic counselling. My signature below constitutes my acknowledgment that the genetic counselling has been explained to my satisfaction by a qualified health professional.

If several individuals are to receive genetic counselling, this consent form must be filled and signed by both of them.

All fields are compulsory and need to be completed.

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

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

Contact details:

Juno Genetics
Winchester House
Oxford Science Park
Oxford, OX4 4GE
Email: supportuk@junogenetics.com
Telephone: 00442037431944 or 00442037431945