

Medical Genetics (All Ages) Quality Dashboard 2019/20



Indicator Reference Number	Domain	Theme	Measure	Rationale	Name of Indicator/Description	Numerator	Denominator	Period Type	Frequency	Data Source Numerator	Data Source Denominator	Target	Interpretation Guidance	Notes	Reporting Periods			
															Q1	Q2	Q3	Q4
GEN02a	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical Process	Multi Disciplinary Clinics (MDC) - with patients in attendance - clinical genetics clinics		Proportion of clinical genetic clinics that are part of a MDC (not MDT)	Number of clinical genetic clinics that are part of a MDC (not MDT)	Total number of genetic clinics	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Neutral	It is good practice to have MDC for some conditions that affect multiple body systems where a patient otherwise would need to have appointments to see different specialist clinicians. Agree that we need to establish baselines to determine a measurement range that would indicate that services are performing well against this indicator. Only include clinics led, organised and commissioned by the commissioners of clinical genetics (do not include clinics organised by other specialties but attended by staff from clinical genetics). This will include NSCAG clinics.	Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20
GEN02b	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical Process	Multi Disciplinary Clinics (MDC) - with patients in attendance - where clinic has been organised by other specialties but attended by staff from clinical genetics		Rate of attendances by clinical genetics to clinics organised by other specialties	Number of clinics organised by other specialties but attended by staff from clinical genetics	Number of WTE clinical geneticists and genetic counsellors (excluding trainees)	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Neutral	Include clinics organised by other specialties but attended by staff from clinical genetics.	Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20
GEN03	Domain 3: Helping people to recover from episodes of ill health or following injury	Clinical Process	Clinical audits		Proportion of clinical audits completed and action plans put in place (the number and type of audits need to be agreed)	Number of clinical audits completed and action plans put in place (from the agreed list of audits)	Number of clinical audits that the clinical genetics department was expected to participate in	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	The number and type of clinical audits that services are expected to participate in will need to be agreed with the CGS/Lead Clinicians on an annual basis to establish how many audits they are expected to participate in.	N/A	N/A	N/A	Apr 19 - Mar 20
GEN05	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Clinical Process	Educational sessions provided by clinical genetics to other specialties to support genetics in mainstream medicine		Rate of educational sessions provided by clinical genetics to other specialties	Number of educational sessions provided by clinical genetics to other specialties	Number of WTE clinical geneticists and genetic counsellors (excluding trainees)	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Higher is better	An educational session is a formal post graduate education session lasting an hour (excludes undergraduate teaching).	Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20
GEN06	Domain 4: Ensuring that people have a positive experience of care	Clinical Outcome	Patient experience		Rate of written complaints about the genetics department	Number of written complaints about the genetics department received during period	Total number of patient contacts (appointments including telephone contacts that replace a face-to-face appointment) in period	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Lower is better		Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20
GEN07a	Domain 4: Ensuring that people have a positive experience of care	Clinical Outcome	Patient experience		Has a patient survey been undertaken within the last year?	Yes / No	N/A	Annual	Annual	Provider submitted data			Higher is better		N/A	N/A	N/A	Apr 19 - Mar 20
GEN07b	Domain 4: Ensuring that people have a positive experience of care	Clinical Outcome	Good patient experience		Have the results of the annual survey been communicated to commissioners and the CRG?	Yes / No	N/A	Annual	Annual	Provider submitted data			Higher is better		N/A	N/A	N/A	Apr 19 - Mar 20

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GEN08	Domain 4: Ensuring that people have a positive experience of care	Clinical Process	Patients waiting excessively for pre-natal (PN) genetic test results where the patient is seen in the clinical genetics department		Proportion of patients receiving test result within 5 working days after the clinic receives the laboratory report for PN genetic test results	Of all patients seen in clinical genetics who had prenatal diagnosis during the period, the number who received their prenatal genetic test result within 5 working days of the clinic receiving the laboratory report	Number of patients seen in clinical genetics who had prenatal diagnosis during period.	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Higher is better	In clinical genetics (unless patient choice has opted to receive results in the post) in most cases, the results should be communicated back to the family members face-to-face and more likely for PN test results this is done over the phone by a consultant geneticist or genetic counsellor. This is because unlike other biochemical and pathology blood tests, genetic test results have lots of implications either way for family members and this all needs to be explained. Good practice would advocate seeing or consultant calling patients to give them results. We suggest that this could be measured by reviewing patient appointments attended or phone calls made to explained(receive) genetic test results. There would need to be in place the ability to code clinical records for appointments attended or phone calls made to receive genetic test results.	Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20	
GEN09	Domain 4: Ensuring that people have a positive experience of care	Clinical Outcome	Do Not Attends (DNA) as defined in the Data Dictionary (http://www.datadictionary.nhs.uk/)		Proportion of appointments that are not attended	Number of DNAs within period	Total number of appointments booked during period within clinical genetics (311 treatment function). This can be taken as the total number recorded on PAS including DNAs	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Lower is better			Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20
GEN10	Domain 4: Ensuring that people have a positive experience of care	Clinical Process	Patients counselled without a referral		Rate of patients counselled without a referral	Number of patients counselled without a referral during period	Total number of patients attending appointments during period	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Lower is better	Trends need to be monitored		Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20
GEN11a	Domain 4: Ensuring that people have a positive experience of care	Clinical Process	Patients co-counselled by a genetic counsellor and doctor working together		Rate of patients co-counselled by a genetic counsellor and doctor during period	The number of clinic appointments where a genetic counsellor co-counsels with a doctor (excluding MDC co-counselling activity)	Total number of clinical genetics appointments of all types during period (appointments including telephone contacts that replace a face-to-face appointment)	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Neutral	Ideally this would be an average of rates measured per patient but it's recognised that at present it is unlikely that trusts would be able to measure this.		Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20
GEN11b	Domain 4: Ensuring that people have a positive experience of care	Clinical Process	Patients counselled independently by a genetic counsellor		Rate of appointments counselled independently by a genetic counsellor during period	The number of independent genetic counsellor clinic appointments (excluding planned pre-clinic appointments preparing for a doctor's appointment)	Total number of clinical genetics appointments of all types during period (appointments including telephone contacts that replace a face-to-face appointment)	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Neutral	Ideally this would be an average of rates measured per patient but it's recognised that at present it is unlikely that trusts would be able to measure this.		Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20
GEN11c	Domain 4: Ensuring that people have a positive experience of care	Clinical Process	Patient appointments held in preparation for a doctor's appointment		Rate of genetic counsellor clinic appointments held in preparation for a doctor's appointment	The number of genetic counsellor clinic appointments held in preparation for a subsequent doctor's appointment	Total number of clinical genetics appointments of all types during period (appointments including telephone contacts that replace a face-to-face appointment)	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Neutral	Ideally this would be an average of rates measured per patient but it's recognised that at present it is unlikely that trusts would be able to measure this.		Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20
GEN12a	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Clinical Outcome	Serious untoward incidents regarding patient care		Number of serious incidents involving patient care	Number of serious incidents (Sis) involving patient care	N/A	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Lower is better			Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20
GEN12b	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Clinical Outcome	Serious untoward incidents regarding lab tests		Rate of serious incidents involving lab tests	Number of serious incidents involving lab tests	Number of lab tests during period	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Lower is better			Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20

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GEN13	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Clinical Process	External Quality Assurance		Episodes of poor performance in EQA schemes the laboratory participates in	Episodes of poor performance notified to the laboratory by UKNEQAS, EMQN or another EQA service provider	Number of EQA schemes participated in	Annual	Annual	Provider submitted data	Provider submitted data		Lower is better	It is mandatory that all labs participate in at least one EQA scheme. The EQA schemes are test specific by condition and therefore we would expect the specific schemes to vary by lab as different labs across the country provide different tests for different conditions.	N/A	N/A	N/A	Apr 19 - Mar 20
GEN14	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Clinical Process	Activity audits (laboratory)		Proportion of audits participated in by the genetics laboratory (ACGS activity audit and ACGS workforce audit for both Molecular and Cytogenetics tests). Four audits per year	Number of audits (from the agreed list of audits) that genetics laboratory participates in	Number of audits that the genetics laboratories should be participating in	Annual	Annual	Provider submitted data	Provider submitted data		Higher is better	As per Clinical Molecular Genetics Society/Association for Clinical Cytogenetics and UKGTN audits requested. To include workforce audit.	N/A	N/A	N/A	Apr 19 - Mar 20
GEN15	Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm	Clinical Process	Non-Adherence to UKGTN Testing Criteria (laboratory) as per UK GTN website.		Proportion of test requests from clinical genetics that did not comply to UKGTN testing criteria where TC apply	Number of tests requested by clinical genetics from specified list that did not comply with UKGTN testing criteria	Number of tests requested from specified list.	Quarterly	Quarterly	Provider submitted data	Provider submitted data		Lower is better	All UKGTN testing criteria are available from the UKGTN website. The 3 tests for which adherence to UKGTN testing criteria are: 1) Silver Russell Syndrome, 2) Kabuki syndrome, 3) MEN2.	Apr 19 - Jun 19	Jul 19 - Sep 19	Oct 19 - Dec 19	Jan 20 - Mar 20

Data collection has been approved by the Review of Central Returns - ROCR
ROCR/OR/2230/001MAND