

Medical Genetics Quality Dashboard 2018/19



| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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. | | | | Apr 18 - Mar 19 |
| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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 | | | | | Apr 18 - Mar 19 |
| 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 | | | | | Apr 18 - Mar 19 |
| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |

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| 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/data_dictionary/attributes/a/ari/attended_or_did_not_attend_de.asp?shownav=1) | | 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |
| 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. | | | | Apr 18 - Mar 19 |
| 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. | | | | Apr 18 - Mar 19 |

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| 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 18 - Jun 18 | Jul 18 - Sep 18 | Oct 18 - Dec 18 | Jan 19 - Mar 19 |

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