

# QUALITY REVIEW PROCESS: GUIDE FOR STAFF

## HEALTH SERVICES FOR PEOPLE WITH HAEMOGLOBIN DISORDERS

**Version: V3**

**August 2023**

V1	May 2023	N/A
V2	July 2023	Amendments to timetable, presentation guidance and 'how we will review' QS list
V3	August 2023	Minor changes to pre visit process

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## BACKGROUND

- 1 This paper outlines the way in which the Nursing and Urgent Care Directorate team (NUC) within the Midlands and Lancashire Commissioning Support Unit (MLCSU) and UK Forum for Haemoglobin Disorders (UKFHD) peer review programme will be organised. The review process is based on the NUC *'Principles and Approach V1 2023'*.
- 2 The NUC and UKFHD Quality Standards (QS) for Health Services for People with Haemoglobin Disorders and quality review process have been finalised following consultation. Anyone with queries about the Quality Standards or the review process should contact in the first instance:
  - The Nursing and Urgent Care Team at [mlcsu.nuct@nhs.net](mailto:mlcsu.nuct@nhs.net) . The team will direct your query to the most appropriate member of the team.
- 3 Clinical Leads for the programme are: -
  - Dr Emma Drasar - Lead, Adult programme
  - Dr Sara Stuart-Smith- Lead, Adult programme
  - Dr Magbor Akanni - Lead, Adult programme
  - Dr Mark Velangi - Lead, Paediatric Programme
  - Dr Sabhiha Kausar - Lead, Paediatric Programme
  - TBA - Lead, Paediatric Programme

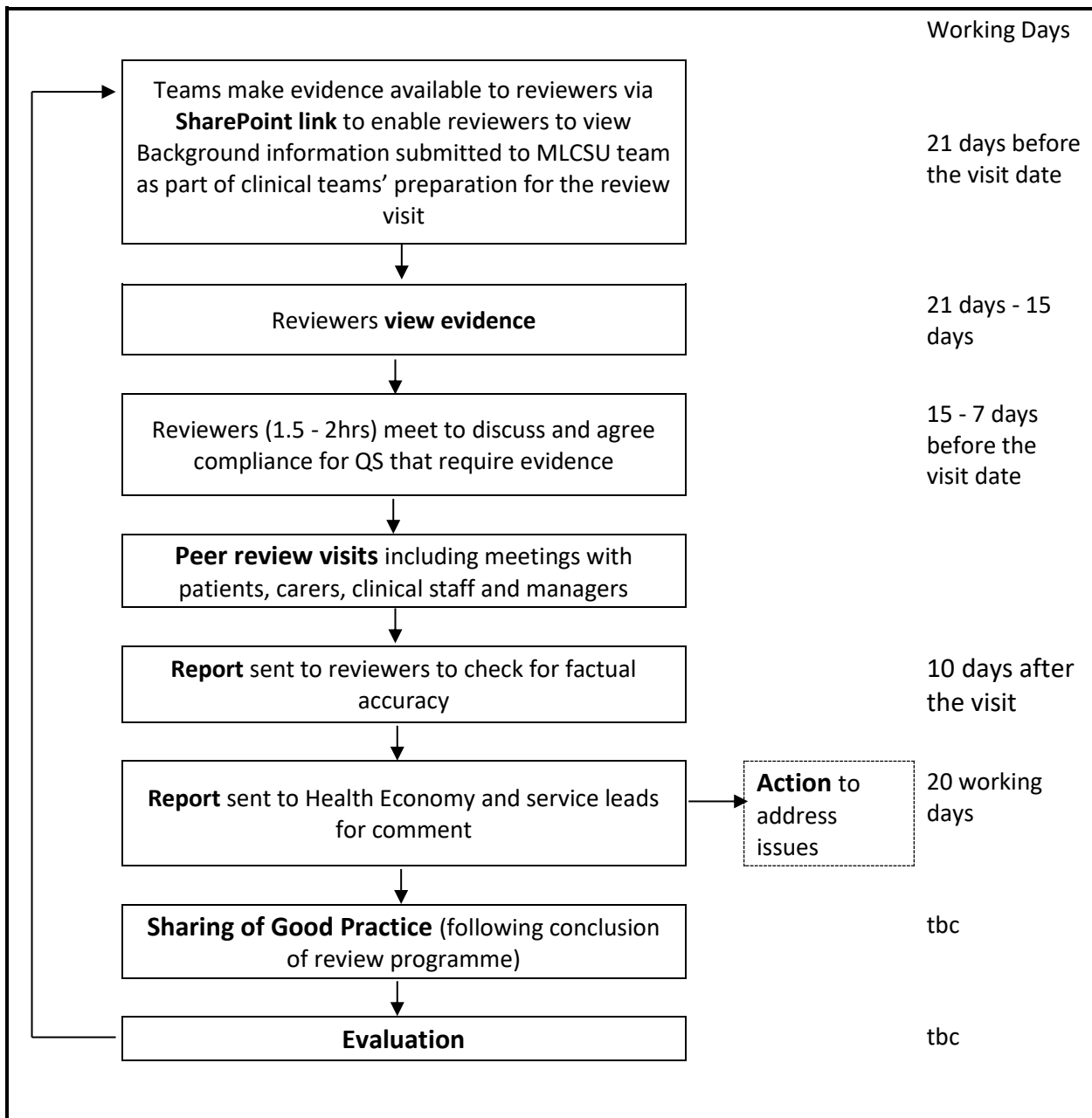
## WHAT BENEFITS ARE EXPECTED FROM THE REVIEW PROGRAMME?

- 4 The aim of Haemoglobin Disorders Peer Review programme is to help organisations to improve the quality of clinical services in a developmental and supportive way. This process does not set out to be an inspection or performance management tool.
- 5 We hope that through the Haemoglobin Disorders Quality Standards and peer review programme:
  - a. Patients and carers will know more about the services they can expect.
  - b. Commissioners will be supported in assessing and meeting the needs of their population, improving health and reducing health inequalities, and will have better service specifications.
  - c. Service providers and commissioners will work together to improve service quality.
  - d. Service providers and commissioners will have external assurance of the quality of local services.
  - e. Reviewers will learn from taking part in review visits.
  - f. Good practice will be shared.
  - g. Service providers and commissioners will have better information they can use as evidence to support regulatory processes.

As part of the integrated Care Boards (ICB) assurance processes, participation in this process will help ICBs to demonstrate that they have appropriate arrangements for quality assurance and quality improvement.

- 6 The benefit that services gain from this process depends hugely on the way in which they approach it. Teams which link the review process with their ongoing work to improve service quality and who see the review visit as useful external quality assurance will find the whole process more constructive. **Appendix 1** gives suggestions on how to get the most from Quality Standards and review visits.

**Figure 1 - Review Process Overview**



## WHAT ARE UKFHD QUALITY STANDARDS?

- 7 The Quality Standards for Services were originally developed separately for children and adults' services to support implementation of the 'Standards for the Clinical Care of Children and Adults with Thalassaemia in the UK' (2005, 2nd edition 2008), 'Sickle Cell Diseases in Childhood: Standards and Guidelines for Clinical Care' (2006) and 'Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK' (2008). In 2013, the Quality Standards were combined into a single set of Quality Standards for use in both children's and adult services. Version 4 of the Quality Standards for Health Services for People with Haemoglobin Disorders (2018) included guidance, and comments received during the 2014-2016 peer review programme. Version 5.1 of the Quality Standards have been developed by a sub-group of the UK Forum on Haemoglobin Disorders to reflect the latest service specifications, in particular those for

Haemoglobinopathy Coordinating Centres (HCC) and Specialist Haemoglobinopathy Services (SHT), and the creation of the National Haemoglobinopathy Panel. The Quality Standards have also incorporated the learning from the 2019/20 peer review programme and clinical guidance published since Version 4 was produced.

- 8 Quality Standards, are suitable for use in quality reviews, they are also useful for services to monitor their own progress toward implementation of best practice guidance. Quality Standards are usually measures of structure and process quality. Version 5 of the QS are more outcome-focussed by increasing the emphasis on gathering and reviewing comparable data on patient experience and clinical outcomes. Quality Standards follow the patient and usually include a pathway summary. They reflect the latest national guidance and help to answer the question “if I walk into a service, how I will know that best-practice guidance has been implemented?” Where evidence-based guidance is not available, Quality Standards are based on a consensus of professional and service users’ and carers’ views.
- 9 The standards have followed the same reference structure as previous versions of two letters and three numbers to indicate pathway and service standards and each topic section:

#### Pathway and Service Letters

HC-	Specialist Services for Children and Young People with Haemoglobin Disorders
HA-	Specialist Services for Adults with Haemoglobin Disorders

#### Topic Sections

Each section covers the following topics:

-100	Information and Support for Children, Young People and their Families / Patients and Carers
-200	Staffing
-300	Support Services
-400	Facilities and Equipment
-500	Guidelines and Protocols
-600	Service Organisation and Liaison with Other Services
-700	Governance

- 10 Each Quality Standard reference column includes a box where the shaded area illustrates how compliance will be reviewed. For example:

BI	Background information supplied to review team
Visit	Visiting facilities
MP&S	Meeting service users (children, young people, adults), families, carers and/or staff
CNR	Case notes review or clinical observation. (For CNR for the 2023-25 programme we will be asking for the service to undertake a 10-patient case note audit)
Doc	Documentation should be available. Documentation may be written or be in the form of a website or other social media

- a. **Background Information**  
This means that the information should be included in your background report. A template is available with guidance on completion.
- b. **Visiting Facilities**  
Reviewers will look for information while they are walking around the service. It is really important that you make sure the reviewers see any relevant documentation at this stage; often this is staffing rotas or evidence of training. If they do not see the documentation, then this may affect the final compliance.
- c. **Meeting patients, carers and staff**  
These Quality Standards will be discussed with patients, carers and/or staff (as appropriate). Make sure you tell the reviewers about all the things you are most proud of.
- d. **Case note review/Clinical observation**  
A few of the Quality Standards require reviewers to understand more about what happens in practice. For this programme **we will not be looking** at patient case notes but giving guidance on how we wish to review compliance (see appendix 2). Clinical observation will still take place, undertaken by reviewers during the visit.
- e. **Documentation**  
For this programme reviewers will, where possible look at your evidence via a SharePoint link **before the review visit** and we will discuss the best way to achieve this at the briefing meetings we have with each HCC/SHT. Reviewer feedback from the last programme identified that reviewers wanted more time on the visit day to meet with patients and staff.

The evidence required **before the visit** are mostly policies and guidelines which reviewers need to see. Do provide this in your usual format – although it is helpful if you guide reviewers to the relevant document when you give us access to your evidence. Do use the checklist provided to guide reviewers to relevant documents, for example “relevant information is in section 4.8 of our annual report”.

11 The Quality Standards cover pathways of care and so have the following structure:

a. **Specific Services:**

These are standards for the services on the pathway of care: -

- Specialist Haemoglobinopathy Team (SHT)
- Local Haemoglobinopathy Teams (or Linked Providers) (LHT)

b. **Haemoglobinopathy Coordinating Centres:**

These standards are the responsibility of the Haemoglobinopathy Coordinating Centres (HCC) but, by agreement, the functions may be delegated to another organisation or coordinating group.

12 Further detail of the scope is given in the introduction of the Haemoglobin Disorder Quality Standards. All Quality Standards are available on the UKFHD website: [UKFHD Quality Standards](#) Services.

## QUALITY STANDARDS AND SELF-ASSESSMENT FORMS

- 13 For the visit **we will not** require completion of the excel version of the self-assessment (on the UKFHD website), but a completed background report and for your evidence to be submitted 21 days before the visit. More guidance about the process is included in section on preparation on page 8 and in Appendix 2.
- 14 The excel versions of the self-assessments are available on the UKFHD website <https://haemoglobin.org.uk/> . Organisations may wish to use these as part of their ongoing assessment.

- 15 All Quality Standards are cross-referenced to the British Standards Institution PAS1616:2016 Healthcare – Provision of Clinical Services Specification, Care Quality Commission’s Key Lines of Enquiry (June 2017).
- 16 Self-assessments and peer review visit findings can be used as evidence of ongoing compliance with these Standards.

## BRIEFING ARRANGEMENTS

- 17 The MLCSU NUC team will also arrange an online call with clinical service leads and managers around two to three months before the visit. The purpose of the conference call meeting is to map the services to be reviewed and ensure that everyone is clear about arrangements and responsibilities for the review visit. Trusts will also be asked to identify a link person for the day. See section 35 for further details on the role of the link person.

## QUALITY REVIEW VISITS

- 18 Each service review will consist of:

### **Before the visit**

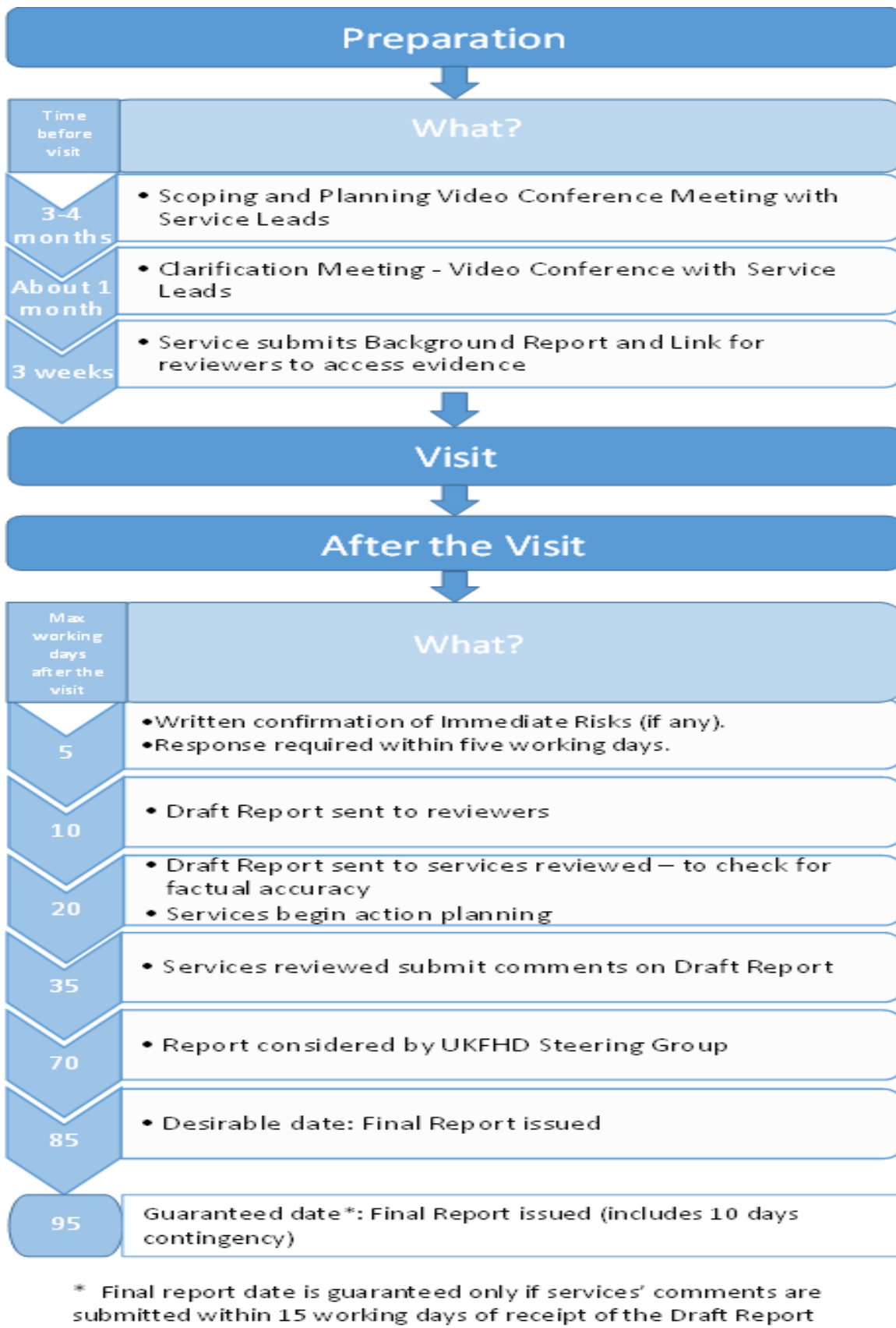
- a. Reviewer preparation and review of evidence (NB. The UKFHD and NUC has worked on ways of minimising the amount of ‘evidence’ which services need to produce.) Please see appendix 2 ‘How we will the review each Quality Standard.

### **On the day of the visit**

- b. Pathway presentation and discussion (see section 27 for more detail)
- c. Clinical observation and case note audit review.
- d. Visit facilities.
- e. Meeting with staff providing the service(s).
- f. Meetings with patients and carers (see section 8 for more detail)
- g. Meeting with lead clinician(s) and manager for each service
- h. Meeting with representatives of local haemoglobinopathy teams (LHT)
- i. Meeting with commissioners and haemoglobinopathy coordinating centre representatives.

Figure 3 on the next page gives an overview of the process for each review visit.

Figure 2 - 'Review at a glance'.





## PREPARATION

- 19 Following the notification of visit letter, NUC will email the leads of the service to agree the date for the review and a pre visit briefing video call will be arranged. During this meeting, we will agree in detail the services to be reviewed and make sure everyone is clear about arrangements and responsibilities for the review visits. While preparing for the review visit, staff will have access to NUC team for advice on the interpretation of the Quality Standards and organisation of the visit.
- 20 At least three weeks before the review visit, services will need to provide NUC with a completed background report on the template provided. The completed background report will be forwarded to the reviewers before the review.
- 21 **Pre-Visit Evidence Review:** Services will need to work with reviewers to make sure they see reasonable evidence of compliance with the Quality Standards. For the 2022 -24 programme, all evidence of compliance should be available for reviewers via a Share Point link **21 days before** the review visit. The MLCSU team will discuss how this process will work as part of the briefing sessions with participating teams.
- 22 The amount of work in preparing evidence for reviewers should be kept to a minimum. **Appendix 2** gives guidance on the presentation of this evidence and how we will review each of the Quality Standards and this will be covered in the briefing session for service leads.
- 23 **Case Records/Notes/Care Plans:** Some Quality Standards published in V5.1 require reviewers (NHS employees only) to look at case notes or electronic records in order to determine compliance. **For the 2023-25 programme, we will not** be requesting to view case notes or patient care plans, but request some information as part of your background report.

## VISIT

- 24 Review visits will usually start at 9.15 and will finish by 5.30 or 6pm. A detailed timetable for each visit will be produced after the pre-visit conference call and, in general clinical staff will meet the visiting team between 10.15am and 3.30 pm.

For each service, the review visit will consist of:

- a. Reviewer preparation and review of evidence (NB. See **Appendix 2** about minimising 'evidence' services need to produce).
  - b. Pathway presentation and discussion (see section 27 for more detail)
  - c. Clinical observation and/or case note review.
  - d. Visit facilities.
  - e. Meetings with:
    - (i) Patients' and carers' representatives (see section 28 for more detail)
    - (ii) Staff providing the service.
    - (iii) Lead clinician/s and manager for the service
    - (iv) Service management and governance
  - f. Reviewers draw conclusions.
  - g. Feedback (if paediatric and adult services are on separate sites staff would come together for conclusions. The service team based on the other site would need to travel for conclusions)
- 25 **People to meet the visiting team:** The visit timetable will identify who should meet the visiting team. People should only attend one meeting during the review visit. In some cases, this is a general heading and **it will be for each service to decide who are the most appropriate people to invite and allocate to one meeting only.** Please make sure that people attending these meetings are briefed beforehand on the purpose of the review and the Quality Standards which are being considered and that you know who is

likely to attend. If there is a large number of people attending let us know so that we can arrange to split the meeting into appropriate groups. **Appendix 5** gives a short paragraph you may wish to circulate to individuals attending these meetings. If in doubt, please ask NUC team and we will advise. Sometimes people are not available for the 'slot' identified on the timetable. We can be flexible within the 10.30am to 3.30 pm period, so long as the reviewers are not supposed to be elsewhere. It is important that there is communication with NUC team about any changes to the timetable. Flexibility outside this time period is more difficult and **must** be discussed with NUC.

26 Please also let the ward and department staff know that reviewers will want to talk to them when visiting clinical areas.

27 **Presentations:** The timetable includes a presentation. It is acknowledged that some information will have been requested as part of your background report, however the purpose of the presentation is to orientate the visiting team to the pathway and service(s) they are reviewing. Presentations should be a maximum of 20 minutes and should cover:

Presentation Structure	Prompts
HCCs	About the HCC, processes for business meetings and development and management of guidelines
SHT (including SHTs with an HCC function)	Brief outline of the SHT, including pathways and constituent LHTs
Staffing	Overview of staffing.
Patient Involvement	Engagement and involvement in local decision-making. Feedback
Highlight	What is working well? Good Practice Issues/challenges You may wish to comment on any gaps/issues with meeting the previsit evidence requirements. Changes since the last peer review visit.

Please make copies of the presentation available to reviewers.

28 **Involving - Patients and Carers Representatives**

The timetable will include a meeting with representatives of patients and carers. We suggest that Trust staff **do not** attend this meeting to enable patients and carers to speak freely about the service. This meeting will cover all the standards in the '100s' sections of the Quality Standards. Reviewers will have seen some evidence earlier in the visit but will be interested in exploring these issues. The reviewers will also ask patients and carers about their general experience of using the services being reviewed and the process for user and carer feedback and involvement. **Appendix 5** gives a short paragraph you may wish to circulate to patients and carers attending these meetings. Services should make every effort to get patient views from patients with both sickle cell and thalassaemia with an open invitation to patients to meet the review team, possibly with places on a 'first come, first served' basis. If patients with sickle cell disease and thalassaemia are attending to meet the visiting team, then separate meetings should be held.

29 **Questionnaires**

Services may wish to use a questionnaire in advance of the visit to gather feedback from patients and carers. A response rate of at least 10% is recommended for patient surveys undertaken in advance of review visits.

30 **Feedback**

Initial feedback is given at the end of each 'module' of the visit. The written report and compliance will include more detail and may differ from the initial feedback because further information has become available.

## ORGANISING THE VISIT

- 31 **Booking Rooms:** A base room for the visiting team at each location will need to be booked. **The base room should not be used for other meetings.** Other rooms will be needed for the meetings shown on the timetable. The visiting team will be flexible and specific rooms may not be needed for small meetings.
- 32 **Car parking:** If it is possible to arrange car parking for reviewers this makes their day much less stressful. This is especially useful if reviewers are travelling to other sites during the day.
- 33 **Refreshments:** Refreshments for the visiting team will be needed including plenty of tea/coffee on arrival and then during the day, water or juice throughout, some biscuits or fruit throughout the day and lunch. Refreshments do not need to be elaborate. Ideally refreshments are provided in the reviewers' base room.
- 34 **DBS Checks:** NHS employees are DBS checked as part of their employment arrangements. Patient and carer reviewers will have been DBS checked by either their nominating organisation or by the NUC.
- 35 **Guides and Link person:** It is requested that each Trust to be visited identifies a 'link' person for the day. This person will be responsible for meeting and greeting people arriving for meetings and taking them to their meetings. In addition, it is asked that they also take responsibility for managing refreshments for reviewers and dealing with any queries to/from the visiting team.

Sometimes the leads for the service may act as guides for their reviewers as this gives more opportunity for discussion. A health service employed person or NUC person must always accompany user and carer reviewers whilst they are visiting clinical areas. If necessary, an NHS member of the reviewing team will accompany user and carer reviewers during the meeting with patients and carers so that local patients and carers can speak freely about local services.

- 36 **Expenses:** The MLCSU does not fund expenses of any staff or patients and carers who come to meet the visiting team. Some Trusts have a policy for User and Carer Involvement which covers these arrangements.

## VISIT REPORTS

- 37 Visit reports will identify compliance and issues related to the achievement of the Quality Standards. Issues will be categorised as:
- **Achievements** made by the service reviewed.
  - **Good practice** which should be shared with other organisations.
  - **Immediate risks** to clinical safety and clinical outcomes.
  - **Concerns** – related to the Quality Standards or prerequisites for their achievement. Some concerns may be categorised as 'serious'.
  - **Further consideration** – areas which may benefit from further attention by the service.
- The review team will draw its conclusions from multiple sources and the reports will not identify individuals' comments.
- 38 If a potential immediate risk is identified, the procedure outlined in the NUCT '*Principles and Approach*' (**Appendix 3**) will be followed.
- 39 Draft reports of quality reviews will be sent to reviewers and to the health economy concerned to check for factual accuracy. Draft reports will normally be sent to reviewers within 10 working days (WD) and to the service concerned within 20 working days of the visit. Health Economies will normally be given 15 working days to comment on factual accuracy. We are not expecting to receive any further information from Trusts at this stage unless specifically requested in order to clarify a point within the report.

- 40 Haemoglobinopathy Coordinating Centres Quality Standards will be reviewed during the HCC/SHT visit.
- 41 Reports of quality reviews will be agreed by the UKFHD Steering Group and then disseminated to the health economy concerned. Health economies will be advised to place the report in the public domain and handle any associated publicity through their normal mechanism. After allowing a reasonable time for this, reports, as for previous programmes will be placed on the UKFHD website.
- 42 Health economies have the right to appeal on the factual accuracy of all reports. Appeals will be considered by a minimum of three members of the UKFHD Board and senior member of the NUCT (at least one patient member, one clinician and one other).
- 43 When all visits are completed for the review programme an overview report will be produced and a good practice sharing event organised.
- 44 An evaluation of all work and visit programmes will also be undertaken.

## ACTION FOLLOWING VISITS

- 45 Most of the issues identified by quality reviews can be resolved by services' own governance arrangements. Many can be tackled by using appropriate service improvement approaches. Some require commissioner input. Individual organisations, working with their lead commissioner, are responsible for taking action and monitoring this through their usual governance mechanism. Action planning should start as soon as possible after the review and should link closely with the services' ongoing management and governance arrangements. The lead commissioner for the service concerned is responsible for ensuring action plans are in place, monitoring their implementation and working with provider organisation on any issues that cannot be resolved internally. NUCT is not responsible for agreement of action plans or for monitoring implementation. NUCT will advise on action plans and may provide support for reviewing progress.

## VISITING TEAM

- 46 The review team will be varied and depend on the number and configuration of services to be reviewed and any travelling involved. Most reviewers will be needed for only one day. Some, especially those reviewing all services will be required for the whole review. The review team composition in the main, will consist of the following disciplines: -
- Lead for children's services
  - Lead for adult services
  - Two service users or carers, ideally one representing patients with sickle cell disease and one for those with thalassaemia
  - Consultant haematologist (adult services)
  - Consultant paediatrician/paediatric haematologist (paediatric services)
  - Specialist nurse (paediatric services)
  - Specialist nurse (adult services)
  - Senior manager/ HCC operational manager
  - Commissioner

Role	Adult Service	Paediatric Service	Joint Adult and Paediatric Service
Consultant Paediatrician / Paediatric Haematologist		√	√
Consultant Haematologist	√		√

Specialist nurse (Paediatric)		√	√
Specialist nurse	√		√
Commissioner/senior manager	√	√	√
Patient/service user	√		√
Carer	√	√	√

- 47 All providers and commissioners of services being reviewed are invited to nominate reviewers for the roles in the review teams (**see Appendix 3**). Being a reviewer is an excellent way to learn about other services and bring back the learning. Evaluations consistently show that over 80% of reviewers use the experience to improve their own services. Reviewer training and being a reviewer is continuing professional development (CPD) for NHS staff. Experience of previous reviews is that potential reviewers who identify late in the programme that they wish to become involved are disappointed because the training and reviewing opportunities are then limited.
- 48 NHS staff who act as reviewers will be able to claim for car mileage and rail travel incurred to and from review visits. NUCT can arrange rail travel for reviewers.
- 49 NUCT will always arrange any overnight accommodation (including evening meal) if required. In line with NHS Shared Business Services financial standing instructions. The accommodation costs cover breakfast. Subsistence covers food and drink costs when these are not provided with your accommodation or during the visit. A guideline for these costs is: up to £5 for breakfast (where leaving the house before 7am), £5 for lunch and £15 for an evening meal, with the maximum claim per 24-hour period being up to £25. Claims from reviewers for overnight accommodation will not be reimbursed.
- 50 Parking costs will be met for the duration of the meetings or reviews, but not excess parking penalties, charges, or fines. Parking costs must be evidenced with a receipt.
- 51 NUCT does not pay for reviewer's time and other subsistence as reviewers should claim from their employing organisation in return for the Continuing Professional Development and development and learning gained by all who take part.
- 52 Service user and carer reviewer nominations have been requested through relevant voluntary organisations and provider and ICB Patient Involvement Leads. User and carer reviewers will need to comply with the reviewer person specification (including having been DBS checked by NUCT, see **Appendix 3**) and sign a confidentiality agreement before participating in a review visit. All reviewers will be required to undertake half a day of reviewer training.
- 53 Service Users and Carers who act as reviewers will be reimbursed for any travel via public transport or car mileage and subsistence costs in accordance with NHS England/ MLCSU financial standing instructions. NUC staff will liaise with service users and carers before the visit and arrange hotel accommodation and travel tickets in advance if required.
- 54 Reviewers will be booked for visits based on their availability. Reviewers will have at least six weeks' notice of a review visit. Certificates of attendance at training and reviews will be issued for inclusion in CPD portfolios.

## APPENDIX 1 GETTING THE MOST OF THE REVIEW PROGRAMME

The benefit that a service gets from a review visit depends a lot on the approach it takes. Services which see the visit as externally imposed and use language such as “we are doing this for peer review” will get little sustained change. Services which say, “this is part of our ongoing work to improve our care” and “the review visit will give us useful external quality assurance” will find the whole process more constructive. It may be useful to remind staff that the programme of review visits was agreed by Health Economies with the aim of improving quality.

‘CALIPSO’ Suggestions for getting the most out of the process:

<b>C</b>	<b>Communicate</b>	Make sure everyone knows that the visit is happening, including all staff in the services being reviewed, diagnostic departments, medical secretaries, senior managers, governance and communications teams and public and patient involvement groups. Keep on communicating about the arrangements. Continue the communication after the visit so everyone knows about the findings and the actions that are planned.
<b>A</b>	<b>Approach</b>	Keep emphasising that this is not a separate exercise but links with existing internal quality improvement and governance processes. Make sure that it does link with these processes. All services on a ‘quality improvement journey’; the review visit is just one point on this journey.
<b>L</b>	<b>Leadership</b>	You will need to identify lead/s for each of the services being reviewed. The service lead may identify others to support them in this work by taking a leadership role. These people will need to provide real leadership in communicating with staff, preparing for and organising the visit and continuing the quality improvement work afterwards.
<b>I</b>	<b>Involve</b>	Preparing for the quality review visit can be a very good opportunity to involve a wide range of staff. Sometimes a member of staff takes the lead and puts together a beautiful ‘evidence folder’ which no-one else is allowed to touch in case they ‘mess it up’. These folders are likely to end up on a shelf with little impact on the services provided.
<b>P</b>	<b>Prepare</b>	Preparing for the review visit has three distinct parts: A - Ensuring the service meets the Quality Standards: This work should have a lasting impact on the quality of care and patient experience. You may want to use the self-assessment form to monitor progress. You may also choose to do a practice review internally using staff who have been trained as reviewers. B - Demonstrating to the visiting team that you are meeting the Quality Standards: This work should be kept to a minimum. <b>Appendix 2</b> provides guidance on the presentation of evidence which aims to make this as easy as possible. C - Organising the visit: This will be additional work for someone. Unfortunately, you cannot have the benefits of the review process without the focus of the visit.
<b>S</b>	<b>Support</b>	We aim to make the reviews as supportive and developmental as possible but being reviewed is always a stressful experience. Supporting the leads and the person with overall responsibility for organising the visit can turn the experience into a positive team-building exercise.
<b>O</b>	<b>Onward</b>	The quality review visit is one point on your quality improvement journey. It is not an end in itself. A ‘good visit’ is when the visiting team confirms the service’s own views of its strength and mean for improvement. Continuing is work and addressing any issues identified through the visit are essential to building lasting improvement.

## ORGANISING THE VISIT

**Booking Rooms:** A base room for the visiting team at each location will need to be booked. **The base room should not be used for other meetings.** Other rooms will be needed for the meetings shown on the timetable. The visiting team will be flexible and specific rooms may not be needed for small meetings.

**Car parking:** If it is possible to arrange car parking for reviewers this makes their day much less stressful. This is especially useful if reviewers are travelling to other sites during the day.

**Refreshments:** Refreshments for the visiting team will be needed including plenty of tea/coffee on arrival and then during the day, water or juice throughout, some biscuits or fruit throughout the day and lunch. Refreshments do not need to be elaborate. Ideally refreshments are provided in the reviewers' base room.

**DBS Checks:** NHS employees are DBS checked as part of their employment arrangements. Patient and carer reviewers will have been DBS checked by either their nominating organisation or by the NUCT.

**Guides:** It is helpful to have a few guides who can take people to relevant meetings. Often the leads for the service will act as guides for their reviewers as this gives more opportunity for discussion. A health service employed person or NUCT person must always accompany user and carer reviewers whilst they are visiting clinical areas. If necessary, an NHS member of the reviewing team will accompany user and carer reviewers during the meeting with patients and carers so that local patients and carers can speak freely about local services.

**Expenses:** NUCT does not fund expenses of any staff or patients and carers who come to meet the visiting team. Some Trusts have a policy for User and Carer Involvement which covers these arrangements.

## INVOLVING PATIENT AND CARER REPRESENTATIVES

The timetable will include a meeting with representatives of patients and carers:

- a. For example, patient or service user groups, patient support groups or public and patient involvement leads. If no relevant groups are identified, then the service lead should invite some individual patients and carers who have used the service recently.
- b. We suggest that Trust staff **do not** attend this meeting to enable patients and carers to speak freely about the service.
- c. This meeting will cover all the standards in the '100s' sections of the Quality Standards. Reviewers will have seen some evidence earlier in the visit but will be interested in exploring these issues. If carers would like to meet reviewers separately from patients then this should be discussed with NUC. The reviewers will also ask patients and carers about their general experience of using the services being reviewed and the process for user and carer feedback and involvement. **Appendix 5** gives a short paragraph you may wish to circulate to patients and carers attending these meetings.

## APPENDIX 2 GUIDANCE ON PRESENTATION OF EVIDENCE AND HOW WE WILL REVIEW THE QUALITY STANDARDS

- 1 The UKFHD Health Services for People with Haemoglobin Disorders Quality Standards expect certain guidelines and protocols to be in place. In several places, the Quality Standards are explicit that written guidelines/protocols should be available. This is because only when the guidelines or protocols are written down can we be sure that everyone understands what is intended – and adherence can be audited. Some staff will say “we all know what to do - and we all do the same thing. It’s a waste of time writing it down”. Most staff will be aware that this attitude may conceal significant variation in practice. The aim of national guidance and the Quality Standards is to reduce variation by raising standards to the best. The places in the Quality Standards where written guidelines/protocols are expected was carefully considered during their development. The Quality Standards have been agreed and the expectation for written guidelines therefore will not change (until the Quality Standards are reviewed).
- 2 The way in which each service structures their guidelines and protocols is for the service to decide and should not be determined by the Quality Standard. Do not feel that you must have a separate protocol for each Quality Standard. You may have one protocol that covers several Quality Standards – or several protocols to show compliance with a single standard. Do not forget the expectation that clinical guidelines and local protocols should have been agreed through your usual clinical governance arrangements and should conform to reasonable document and version control standards.
- 3 The Quality Standards expect only that guidelines and protocols are in place. It is not realistic for services to present evidence of audit of implementation of all guidelines and protocols. During the visit reviewers will, however, be considering whether practice generally reflects the service’s guidelines/protocols and whether staff are aware of their existence. Reviewers may decide that a service is non-compliant with a particular Quality Standard even if a written protocol is presented if, for example, a) there is no indication that the protocol has been approved/agreed, b) staff are not aware of its existence and/or c) the protocol is not being implemented.
- 4 The service staff and the visiting team need to work together to ensure that the visiting team is shown evidence of compliance with all the Quality Standards. We are keen to reduce the amount of preparation for teams and maximise the time reviewers have to understand your service and whether the quality standard is met. Some Quality Standards require reviewers to see facilities; for others they need to see written evidence and for others they will talk to staff or service users and carers. Please only provide documentary evidence in your allocated SharePoint folder for those Quality Standards that require evidence to be submitted .
- 5 **The demonstration of compliance has been amended since the publication of Version 5.1 of the Quality Standards.** Where possible the UKFHD Steering Group has reduced the amount of evidence that will need to be made accessible to the reviewers.
- 6 The table below shows ‘at a glance’ how each Quality Standard will be reviewed, whether the information is required in your background report, as evidence or will be reviewed on the visit day. A fuller document which contains the list of Quality Standards, where written evidence is to be made accessible to reviewers before the visit. You can access the full set of the Quality Standards from the [UKFHD website](#).
- 7 Background Report: There is a specific template that you will need complete. This template will be made available when we meet with the leads at the briefing and planning session.
- 8 Presentation of evidence via your SharePoint folder should align to the number structure in the table below to help navigate reviewers through your evidence. For example, all evidence with a 100\* prefix should be filed in a folder, then 200\*\*, 300\* etc. This will be covered in more detail during the briefing sessions for those people who have responsibility for organising the visit. Access to your evidence should also be made available to the reviewers 21 days before the visit.



- 9 Your background report will need to be sent to [MLCSU.nuct@nhs.net](mailto:MLCSU.nuct@nhs.net) and your evidence accessible to reviewers **21 days before the visit**. We will agree the date that your background report and access to your online evidence with the leads as part of your briefing and planning session.

#### How we will review each of the Quality Standards

V5 Ref - Adults	V5 Ref - Children & Young People	Short Title	Include in your Background Report	Evidence to be made accessible to reviewers before the visit	Review on visit day
HA-101	HC-101	<b>Haemoglobin Disorder Service Information</b>			Review at visit
HA-102	HC-102	<b>Information about Haemoglobin Disorders</b>			Review at visit
HA-103	HC-103	<b>Care Plan</b>		Copy of template used	Reviewers will ask in meetings with patients and staff
HA-104	HC-104	<b>What to Do in an Emergency?</b>			Reviewers will ask in meetings with patients and staff
HA-105	HC-105	<b>Information for Primary Health Care Team</b>			Reviewers will ask in meetings with patients
-	HC-106	<b>Information about Transcranial Doppler Ultrasound</b>		Copy of SOP or leaflet	
-	HC-107	<b>School or College Care Plan</b>			Reviewers will ask in meetings with patients and staff
HA-194	HC-194	<b>Environment and Facilities</b>			Review at visit
HA-195	HC-195	<b>Transition to Adult Services</b>		Service Operational Policy covering transition	Reviewers will ask in meetings with patients and staff
HA-197	HC-197	<b>Gathering Views from Adults Children, Young People and Families</b>	X		
HA-198	HC-198	<b>Network-wide Involvement of Adults Children, Young People and Families</b>	x		Reviewers will ask in meetings with patients and staff
HA-199	HC-199	<b>Involving Adults, Children, Young People and Families</b>	x		Reviewers will ask in meetings with patients and staff
HA-201	HC-201	<b>Lead Consultant</b>	x		
HA-202	HC-202	<b>Lead Nurse</b>	x		
-	HC-203	<b>Lead for Transcranial Doppler Ultrasound</b>	x		

V5 Ref - Adults	V5 Ref - Children & Young People	Short Title	Include in your Background Report	Evidence to be made accessible to reviewers before the visit	Review on visit day
HA-204	HC-204	<b>Medical Staffing and Competences: Clinics and Regular Reviews</b>	x		
HA-205	HC-205	<b>Medical Staffing and Competences: Unscheduled Care</b>	x		Reviewers will ask in meetings with staff
HA-206	HC-206	<b>Doctors in Training</b>	x		Reviewers will ask in meetings with staff
HA-207	HC-207	<b>Nurse Staffing and Competences</b>	x	Competence Framework (if covers all disciplines only make one copy available)	Reviewers will ask in meetings with staff about staff roles and competences.
HA-208	HC-208	<b>Psychology Staffing and Competences</b>	x		Reviewers will ask in meetings with staff about staff roles and competences.
-	HC-209	<b>Transcranial Doppler Ultrasound Competences</b>		Annual review report	
HA-299	HC-299	<b>Administrative, Clerical and Data Collection Support</b>	x		
HA-301	HC-301	<b>Support Services</b>	x		
HA-302	HC-302	<b>Specialist Support</b>	x		
HA-303	HC-303	<b>Laboratory Services</b>			Reviewers will ask in meetings with staff
HA-304	HC-304	<b>Urgent Care – Staff Competences</b>	x	Competence framework or training plan and audit of on management of acute pain	
HA-501	HC-501	<b>Transition Guidelines</b>	x	Guidelines	
HA-502	HC-502	<b>New Patient and Annual Review Guidelines</b>	x	Guidelines	
HA-503	HC-503	<b>Clinical Guidelines: LHT Management and Referral</b>	x	Guidelines	
-	HC-504	<b>Transcranial Doppler Ultrasound Standard Operating Procedure</b>	x	Guidelines	

V5 Ref - Adults	V5 Ref - Children & Young People	Short Title	Include in your Background Report	Evidence to be made accessible to reviewers before the visit	Review on visit day
HA-505	HC-505	<b>Transfusion Guidelines</b>	x	Guidelines	
HA-506	HC-506	<b>Chelation Therapy</b>	x	Guidelines	
HA-507	HC-507	<b>Hydroxycarbamide and Other Disease Modifying Therapies</b>	x	Guidelines	
HA-508	HC-508	<b>Non-Transfusion Dependent Thalassaemia (nTDT)</b>	x	Guidelines	
HA-509	HC-509	<b>Clinical Guidelines: Acute Complications</b>	x	Guidelines	
HA-510	HC-510	<b>Clinical Guidelines: Chronic Complications</b>	x	Guidelines	
HA-511	HC-511	<b>Anaesthesia and Surgery</b>	x	Guidelines	
HA-512	-	<b>Fertility and Pregnancy</b>	x	Guidelines	
HA-599	HC-599	<b>Clinical Guideline Availability</b>			Review at visit
HA-601	HC-601	<b>Service Organisation</b>		Organisational policy	Review at visit
HA-602	HC-602	<b>HCC Service Organisation</b>		HCC service organisation policy	
HA-603	HC-603	<b>Shared Care Agreement with LHTs</b>			Review at visit - SLA with LHTs
HA-604	HC-604	<b>Local Multidisciplinary Meetings</b>			Review at visit schedule of the meetings and attendance records
HA-605	HC-605	<b>HCC Multidisciplinary Discussion</b>			Review at visit the attendance register
HA-606	HC-606	<b>Service Level Agreement with Community Services (if applicable)</b>		Service Level Agreement with Community Services	
HA-607	HC-607	<b>HCC Business Meeting Attendance</b>			Review at visit the attendance register
-	HC-608	<b>Neonatal Screening Programme Review Meetings</b>		Evidence that reviews meetings have taken place	
HA-609	HC-609	<b>NHS Blood and Transplant Liaison</b>			Review at visit HCC MDT business meeting

V5 Ref - Adults	V5 Ref - Children & Young People	Short Title	Include in your Background Report	Evidence to be made accessible to reviewers before the visit	Review on visit day
					attendance for compliance
HA-701	HC-701	<b>National Haemoglobinopathy Registry</b>		Annual Report	
HA-702	HC-702	<b>HCC Business Meetings</b>		Attendance list, dates of meetings held for the previous two years	
HA-703	HC-703	<b>HCC Annual Programme of Work</b>	x		
-	HC-704	<b>Transcranial Doppler (TCD) Monitoring Report</b>	x	HCC report detailing quality assurance process and results	
HA-705	HC-705	<b>Other Audits</b>	x		
HA-706	HC-706	<b>HCC Audits</b>	x		
HA-707	HC-707	<b>Research</b>	x		
HA-797	HC-797	<b>Review of Patient Experience and Clinical Outcomes</b>		HCC annual report/ Business meeting	
HA-798	HC-798	<b>Review and Learning</b>			Review at visit
HA-799	HC-799	<b>Document Control</b>			Review at visit

## APPENDIX 3 BEING A REVIEWER

### REVIEWER PERSON SPECIFICATION

For the composition of the review team please see section 46.

The generic specification for reviewers:

- Are aware of, and committed to implementation of, the Quality Standards for the service they will be reviewing.
- Have good communication and inter-personal skills including:
  - Ability to listen and understand the views of others.
  - Ability to probe and search for evidence on which to base conclusions.
  - Ability to observe and draw conclusions from observation.
  - Tact and diplomacy at all times, including when faced with difficult issues.
  - Ability to work as a member of a team, respecting the contributions of others.
- Have the ability to prepare well and accurately record findings.
- Have the ability to analyse issues, evaluate information and draw conclusions from evidence received.
- Have the ability to commit to and work as an equal member of the review team.

Professional reviewers will normally have at least two years' experience working in the role they will be undertaking during the visit or in a similar role.

### BEING A REVIEWER

The willing cooperation of reviewers is essential to the success of the review programme. Previous evaluations have shown that reviewers gain a great deal from the experience and are able to improve their own services as a result. Reviewers also usually find the visits a very enjoyable experience. The potential benefits include:

- Learning about how other services are organised.
- Sharing good practice with colleagues from other areas.
- Helping colleagues to improve the care they are able to offer.
- Preparing for your own peer review visit.
- Time spent reviewing other services also contributes towards continuing professional development (CPD) and can be included in a CPD portfolio.

#### Commitment

Training	0.5 day
Pre visit preparation and meeting	4hrs (flexible)
Per visit	1 or 2 days
Checking reports (per visit)	2hrs (flexible)

## NUC SERVICE USER AND CARER REVIEWER PERSON SPECIFICATION

Specification	Essential Skills
<p><b>Experience</b></p> <p>Have recent knowledge and understanding of the particular service/care pathway being reviewed.</p> <p><b>Knowledge, understanding</b></p> <p>Have some knowledge and understanding of how the NHS works.</p> <p><b>Aptitude</b></p> <p>Would like to help NHS organisations improve their services.</p> <p><b>In addition, nominees for peer review should be:</b></p> <ul style="list-style-type: none"> <li>• Able to commit to and be available for any briefing sessions, reviewer training and undertake at least one quality review visit. (Minimum of 2 ½ days).</li> <li>• Have the ability to commit to and work as an equal member of the review team.</li> <li>• Willing and able to support (buddy) new service user or carer team members as individuals become experienced.</li> </ul>	<p><b>Good Listener and Communicator</b></p> <ul style="list-style-type: none"> <li>• Can contribute to discussions.</li> <li>• Ability and confidence to present own viewpoint clearly and concisely in meetings and working with other team members.</li> <li>• Ability to listen to others' viewpoint without interruption.</li> <li>• Ability to understand and utilise others' contribution.</li> <li>• Tactful in communication and awareness to others' verbal / nonverbal reactions.</li> </ul> <p><b>Good at working in teams</b></p> <ul style="list-style-type: none"> <li>• Ability and confidence to ask for advice, guidance and the views of other team members where necessary.</li> <li>• Ability to demonstrate respect for others' points of view.</li> <li>• Able to adapt own approach/style to suit situation during the review day – between the different sessions of the day (the morning preparation, the review, and report writing sessions)</li> <li>• Able to demonstrate an ability to work within a team.</li> <li>• Ability and confidence to raise any concerns with the review team and ask for help if needed.</li> </ul> <p><b>Ability to prepare for review</b></p> <ul style="list-style-type: none"> <li>• Able to assimilate relatively large amounts of information both at the review and in preparation prior to the review.</li> <li>• Ability and confidence to ask probing questions sensitively during the review day.</li> <li>• Able to use the evidence available to base judgements at the review to ask questions and contribute to the writing of the report.</li> <li>• Ability to maintain and project enthusiasm during the review day</li> </ul>

All service users and carers should comply with the requirements of the person specification. The NUC generic person specification should be used as a basis and may be amended as necessary by the relevant programme Steering Group.

All service users and carers must agree to the NUC confidentiality agreement prior to starting their involvement with NUC. NUC will only use as reviewers service users and carers who have been vetted (DBS checked) and we will give more details about how this can be undertaken.

A member of NUC staff will speak to all service users and carers prior to them starting any involvement with NUC activities.

### NOMINATING REVIEWERS

Services may nominate staff and users and carers of their services to be reviewers. A 'call for reviewers' has been sent to your service leads and to the UKTS and Sickle Cell Society. If you are unable to access nomination form, then please email [mlcsu.nuct@nhs.net](mailto:mlcsu.nuct@nhs.net) and we will send this to you.

Each application must come with confirmation of support from the employing organisation that the nominee meets the person specification.

## APPENDIX 4 CHECKLIST FOR SERVICES BEING REVIEWED

Action		When
<b>Identify service leads</b>	Decide who from each service will coordinate preparation for the visit.	Immediately
<b>Communicate</b>	Make sure everyone knows that the visit is happening, including all staff in the services being reviewed, medical secretaries, senior managers, governance and communications teams and public and patient involvement groups.	Immediately
<b>Agree date</b>	Following confirmation of the visit date, please inform all teams being reviewed of the date.	ASAP
<b>Agree who will need access to the SharePoint folder</b>	You will need to agree and let the MLCSU team know who will be able to upload evidence to your allocated SharePoint folder. Once we have these name(s), then permissions will be granted	ASAP
<b>Book Rooms</b>	After the briefing meeting, please book a base room for reviewers at each agreed location. The base room should not be used for other meetings.	ASAP
	Other rooms will be needed for the meetings shown on the timetable. The visiting team will be flexible and specific rooms may not be needed for small meetings.	ASAP
<b>Plan with teams</b>	Decide who will meet with the visiting team, which meeting is most appropriate and let them know. Background report and all evidence is needed three weeks before the visit date. As described in <b>Appendix 1</b> , services will get the most from the visit if they are involved early on in the preparation for it.	Ongoing throughout the preparation period <b>(see Appendix 1)</b>
<b>Book Refreshments</b>	Please make sure there is plenty of tea, coffee and water and some fruit/biscuits available throughout the day. Please book lunch.	In accordance with organisational policy
<b>Timetable</b>	Discuss the timetable with all staff and make sure everyone knows when they are needed.	Following briefing session
<b>Submit information to MLCSU</b>	Each visit: <ul style="list-style-type: none"> <li>• Background report</li> <li>• Confirmation that evidence has been uploaded to the SharePoint folder</li> <li>• Directions including car parking advice</li> <li>• Name and location of base room</li> <li>• Background report</li> <li>• Emergency contact</li> <li>• Self-assessment if requested.</li> </ul>	<b>Three weeks before the visit.</b> <i><b>This information is required to send to reviewers in advance of the visit for review and for reviewers group discussion before the visit</b></i>

Action		When
<b>Remind</b>	A week before the visit it is helpful to confirm arrangements, including: <ul style="list-style-type: none"> <li>• Who is doing the presentation</li> <li>• Guides</li> <li>• Who is expected at each meeting</li> <li>• Who is expected to come to the feedback sessions</li> </ul>	One week before the visit
<b>Initial feedback</b>	It is often helpful to communicate a high-level summary of the feedback, to clinical teams	Day after the visit
<b>Comments</b>	When you receive the draft report, please circulate to all clinical teams and coordinate their responses	20 WD after the visit at the latest.
<b>Action Plan</b>	Action planning should start straight after the visit, at the latest, when you review the draft report. Do coordinate with other mechanisms – rather than having a separate ‘peer review’ plan.	Start as soon as draft report received
<b>Comms</b>	Service leads will be sent a copy of the report that goes to the Steering Group. This will go also to your Communications Team so that they can a) check if there are any particularly sensitive issues where it may be helpful to make minor changes to the wording and b) plan communications about the report.	When final draft report received



## APPENDIX 5 BRIEFING INDIVIDUALS AND SERVICES WHO WILL MEET THE VISITING TEAM

The following short paragraphs may be helpful to send to individuals or patient groups who have been invited to meet the visiting team or reviewers.

### **Patients' and Carers' Representatives:**

A review of our services is taking place as part of a drive to improve care for people with *[insert programme]*. The review is looking particularly at pathways of care for people [with **xxxx** or who use **xxxx**]. A team of patients, carers and healthcare professionals will look at the care offered here, identify things we do well and areas where we could improve. We have the opportunity to visit other services and learn from their experiences as well.

The visiting team would like to meet with patients and carers [either with **xxxx** or who use **xxxx**]. The meeting will last about an hour. The reviewers will ask you about your general experience of care, how you access services and the process for user and carer feedback. They will ask about information and support that is available for you, how care is planned and monitored, and arrangements for 'self-care'. Reviewers will have seen some information earlier in the visit but will be interested in exploring these issues with you in the meeting. The review team will draw its conclusions from multiple sources and the reports will not identify individuals' comments.

The purpose of this meeting is to gather feedback. More information about the Quality Standards being reviewed is attached. ***[Please attach the 100s section of the Quality Standards if you think this would be helpful to the patients and carers you have invited.]***

Thank you very much for agreeing to come to this meeting. The review will help us to improve the care we offer, and your ideas and suggestions may help people in other areas as well.

## APPENDIX 6 ILLUSTRATIVE TIMETABLES FOR ADULT, PAEDIATRIC AND JOINT ADULT AND PAEDIATRIC VISITS

Illustrative timetable for a review of either an adult or paediatric service

UKFHD Haemoglobin Disorders Quality Review Programme				
XX XXXX 2023/24/25				
XXXXX Hospital				
Illustrative timetable for single site but different teams caring for adults and children				
Reviewers:				
9.00	Reviewers arrive and welcome		9.00	
9.15	Trust presentation		9.15	
9.45	Meet with members of the MDT including community (1hr) (Quality Standards review)		9.45	
11.00	Walk Pathway Visit Emergency Admission areas (A&E, Direct admissions area if different) and Wards	Visit Day Unit Visit Outpatients (paediatrics only)	11.00	
12.00	Patient and carer meeting - Sickle Cell Disease (1hr)	Video conference with LHTs	HCC Business meeting	12.00
13.00	Reviewers Lunch (allocation to afternoon meetings)		13.00	
13.30	Patient and carer meeting - Thalassaemia	Meet Lead Consultant Lead Manager and Lead nurse	13.30	
14.30	Meeting with Divisional Leads (Nursing, Ops and Finance)	Meet commissioners	14.30	
15.00	Draw conclusions		15.00	
16.00	Meet CEO or nominated deputy		16.00	
17.15	Feedback to team		17.15	
17.30	Depart		17.30	

Illustrative timetable for a review of a joint adult and paediatric service cared for by separate teams

UKFHD Haemoglobin Disorders Quality Review Programme						
XX XXXX 2023/24/25						
XXXXX Hospital						
Illustrative timetable for single site but different teams caring for adults and children						
Reviewers:			Reviewers:			
9.00	Reviewers arrive and welcome				9.00	
	<b>ADULT SERVICES</b>		<b>PAEDIATRIC SERVICES</b>			
9.15	Trust presentation		Trust presentation		9.15	
9.45	Meet with members of the MDT including community (1hr) (Quality Standards review)		Meet with members of the MDT including community (1hr) (Quality Standards review)		9.45	
11.00	Walk Pathway Visit Emergency Admission areas (A&E, Direct admissions area if different) and Wards	Visit day unit	Walk Pathway Visit Emergency Admission areas (A&E, Direct admissions area if different) and Wards	Visit Day Unit Visit Outpatients (paediatrics only)	11.00	
12.00	Patient and carer meeting - Sickle Cell Disease (1hr)	Video conference with LHTs (may be joint if teams are joint)	HCC Business meeting	Video conference with LHTs (may be joint if teams are joint)	Patient and carer meeting - Sickle Cell Disease (1hr)	12.00
13.00	Reviewers Lunch (allocation to afternoon meetings)				13.00	
13.30	Patient and carer meeting - Thalassaemia	Meet Lead Consultant Lead Manager and Lead nurse	Meet Lead Consultant Lead Manager and Lead nurse	Patient and carer meeting - Thalassaemia	13.30	
14.30	Meeting with Divisional Leads (Nursing, Ops and Finance)	Meet commissioners (Joint meeting)		Meeting with Divisional Leads (Nursing, Ops and Finance)	14.30	
15.00	Draw conclusions		Draw conclusions		15.00	
16.00	Meet CEO or nominated deputy (Joint meeting)				16.00	
16.15					16.15	
17.15	Feedback to team		Feedback to team		17.15	
17.30	Depart		Depart		17.30	