

# Regional Lynch Syndrome Multi-Disciplinary Team Meeting SOP v2.3

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## **Document Control**

### **Document Creation**

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### **Document Contents:**

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# Regional Lynch Syndrome Multi-Disciplinary Team Meeting SOP v2.3

## 1. Purpose

This Standard Operating Procedure (SOP) relates to the Lynch syndrome Multi-Disciplinary Team Meeting (MDT) currently held monthly in the South East region.

This SOP aims to deliver

- Step-by-step guidance on how to refer to the MDT.
- Step-by-step guidance on how to run the MDT.
- Step-by-step guidance on post MDT actions.
- Guidance on referral proforma and coordination documentation storage.

## 2. MDT Team Members

### 2.1 MDT Roles and Responsibilities

Those who manage the operations of MDT ensure the meeting is moderated and runs smoothly. The clinical leads will provide recommendations and further care instructions for patient cases the invitees have brought for discussion.

Specific responsibilities for each member are outlined below:

#### **Regional Lynch Syndrome Clinical Nurse Specialist**

- Chair of the MDT meeting.
- Ensure the Regional Lynch Syndrome Coordinator has completed their actions required ahead of the meeting.
- Support with any questions regarding appropriate referrals ahead of the meeting
- Support clinical advice and guidance within the MDT meeting.
- Support the Lynch Syndrome Coordinator to develop the summary report of patient cases, ensuring relevant details are added.
- Facilitate conversations during the meeting, ensuring that each CNS is able to present their patient cases and account for any absences.

#### **Regional Lynch Syndrome Coordinator**

- Delivers invites to all CNS's, Lynch Champions and clinical leads at least 3 months in advance using Microsoft Teams.
- Collate referral proformas received at least 5 working days ahead of the meeting.
- With support from the Regional Lynch Syndrome Clinical Nurse Specialist, collate a summary of the patient cases to discuss ahead of the meeting. When completed, send to the clinical leads in an email no later than 2 working days before the meeting.
- Send the meeting agenda document (appendix 3) containing an abbreviation of referred patients to the MDT members and invitees 2 working days ahead of the meeting.
- Ensure that the meeting runs smoothly, share content on screen to facilitate discussions in the meeting.
- After the meeting, send completed referral proformas to clinical leads lead for MDT outcome, recommendations and comments for each patient, to be returned to the referrer.
- Collates the information captured within the MDT meeting and referral proformas to input within the MDT Tracker excel spreadsheet to measure MDT data (appendix 4).

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## Regional Lynch Syndrome Clinical Lead

- Read through the patient cases sent ahead of the meeting to ensure a broad understanding of the patient's personal history of cancer, family history of cancer and genetic/molecular testing results provided in order to develop further clinical recommendations for each patient.
- Support clinical advice and guidance within the MDT meeting.
- Provide written clinical recommendations within the referral proforma and send back to Coordinator for dissemination.

## MDT Attendees

- Provide information required to complete patient proformas prior to the MDT meeting no later than 5 working days before the meeting.
- At least 1 representative from the referring site are required to be present in the meeting to aid discussions on the patient case. If referrers are not able to attend due to clinical commitments, annual leave etc., they must inform the Regional Clinical Nurse Specialist and MDT Coordinator ahead of the meeting and upon sending referrals to the team.
- If additional participants would like to attend the MDT meeting for learning purposes, a request can be sent to the MDT coordinator by replying to the MS Teams invite email. The request must include name, job title, organisation and email address of attendee. This will be forwarded to the relevant Clinical Lead for approval.
- Support the multi-disciplinary nature of the meeting and provide support to colleagues across organisations.
- The referring clinician is responsible for the tracking and onward management of patients once the MDT outcome document has been released. The Lynch Syndrome MDT is an advice and guidance forum only, and does not assume responsibility for the patient thereafter.

## 2.2 Membership

Clinical representatives from the organisations stated below are welcome to join this meeting, this includes Clinical Nurse Specialists (CNSs) and Lynch Champions from colorectal and gynaecological MDTs in the region.

All qualifying Trusts within the South East region can attend the MDT. These include:

- a. Guy's and St Thomas' NHS Foundation Trust (GSTT)
- b. Princess Royal University Hospital (PRUH)
- c. King's College Hospital Denmark Hill (DMK)
- d. Lewisham and Greenwich NHS Foundation Trust (LGT)
- e. Ashford and St Peter's Hospitals NHS Foundation Trust (ASPH)
- f. East Sussex Healthcare NHS Trust (ESHT)
- g. Frimley Health NHS Foundation Trust (FHFT)
- h. Royal Surrey NHS Foundation Trust (RSFT)
- i. Surrey and Sussex Healthcare NHS Trust (SASH)
- j. University Hospitals Sussex NHS Foundation Trust (UHSx)
- k. East Kent Hospitals University NHS Foundation Trust - William Harvey Hospital
- l. East Kent Hospitals University NHS Foundation Trust (QEQM)
- m. Maidstone & Tunbridge Wells NHS Trust (MTW)

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- n. Dartford and Gravesham NHS Foundation Trust
- o. Medway NHS Foundation Trust
- p. St George's University Hospitals NHS Foundation Trust (SGUH)

Further trusts within the South West London region are not included within this core list as report to the Royal Marsden MDT, however are welcome to attend this meeting. Further Trusts will also be included in this meeting ad-hoc subject to invitation.

## 3. Procedures

### Ahead of the meeting

#### **Invitation**

The Regional Lynch Syndrome Coordinator will send email invitations to members of the MDT at least 3 months before the meeting, to ensure that clashes with clinical responsibilities are avoided. Contact information for the MDT members can be found in appendix 4.

As per the above, the Regional Lynch Syndrome Coordinator will send the meeting agenda containing an abbreviated list of all the patients referred to the MDT members, including all MDT members and invitees.

#### **Referring a patient to the MDT**

##### Step 1

Clinical Nurse Specialists and Lynch champions will send completed referral proformas, MMR histology reports and family history of cancer documents where required for patients they wish to discuss in the meeting by email no later than 5 working days before to the shared Mailbox [\[insert NHS email\]](#) which is managed by the Regional Lynch Syndrome Coordinator (inbox management processes and procedures are included in Section 8).

If the referral proformas are sent after the 5 days, the patient cases will be brought to the following months meeting. The referral proforma is displayed in Appendix 1. Urgent referrals sent after this period may be considered.

##### Step 2

In order for the clinical leads to receive a full picture of each patient case, a summary of each patient case will be collated by the Regional Lynch Syndrome Coordinator in an Excel spreadsheet format. The Excel spreadsheet format can be found in appendix 2. The Coordinator will send this document to the clinical leads no later than 2 working day before the meeting occurs.

Additionally, the Clinical Nurse Specialists and Lynch Champions who wish to refer patient cases to the MDT are asked to ensure they are in attendance on the day of the meeting so they can provide a brief summary of their patient case within to the MDT members. If attendees cannot attend the meeting due to annual leave, clinical commitments or any other meeting clashes then members will be required to inform the Regional Lynch Syndrome Clinical Nurse Specialist and Regional Lynch Syndrome Coordinator at least 5 working days before the meeting takes place or when the referral email has been sent.

### During the MDT

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Each regional MDT meeting will take place once every month, the duration of each meeting is scheduled for one hour. Meetings will take place online through Microsoft Teams. Further support and guidance outside of the meeting may be given to Regional Clinical Nurse Specialists and Lynch Syndrome Champions by the Clinical Leads.

Patients will be presented in order of referral to the meeting. Case discussions will not have standard times, as require differing support from clinical teams.

Any case that is scheduled for MDT but is not discussed due to time restrictions, will be discussed first at the subsequent MDT meeting the following month.

## **Post MDT**

After the meeting is completed, the Clinical Leads will collate their recommendations for each patient into the patient summary document, collated via an excel spreadsheet (appendix 2). This document will be sent to the MDT Regional Lynch Syndrome Coordinator who will transpose clinical recommendations into the referral proforma and disseminate to the lead referrer through email. It is the responsibility of the referrer to include the MDT outcome to the patient's local records.

The MDT Regional Lynch Syndrome Coordinator will then transfer the relevant information from the MDT outcome onto the SE LS MDT Tracker to record number of cases referred to the MDT to measure the MDT impact in the South East.

## **4. Documentation Storage**

### **4.1 Referral proforma storage**

#### **Need for patient information capture**

Referrers are asked to fill out the Lynch syndrome referral proforma with the appropriate details requested ahead of the meeting in order for Clinical leads to receive an all rounded perspective on the patient case and to provide further care recommendations to the lead referrer. Further information on appropriate patient referral cases can be found in section 6.

#### **Data storage**

Referral proformas received by the Regional Lynch Syndrome Coordinator and the Regional Lynch Syndrome Clinical Nurse Specialist will be collated and stored within the secure shared drive across GSTT and SGUH. Access will be granted through IT for those recipients who require access to referral proforma for storage purposes.

No other method of storing patient information will be undertaken or shared with any other person outside of the MDT meeting in accordance with [Guys and St Thomas' GDPR policy](#) and [St George's University Hospital privacy policy](#). The number of referrals may be collated for data purposes to assess the success of MDTs. Patient personal information will be redacted.

The Regional Lynch Syndrome Coordinator will store the referral proformas onto their secure personal drive on their work computers.

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## Data sharing

Access to basic patient information will be displayed to all MDT members during the meeting for purposes of collaborative working and sharing ideas on possible patient outcomes. However, any sharing of patient information outside of the meeting, including the referral proforma will not be permitted with anyone other than the Regional Lynch Syndrome Clinical Lead, Regional Lynch Syndrome Clinical Nurse Specialist and the lead CNS who has referred the patient to the MDT meeting.

## Data disposal

Patient information may be stored and contained up to 8-10 years will be disposed of as per the [GSTT GDPR policy](#) and [SGUH privacy policy](#) after patient data is no longer required.

## 4.2 MDT coordination storage

Documentation required for the coordination of the meetings, including the SE LS MDT Meeting Agenda, SE LS MDT Tracker and MDT summary lynch cases spreadsheet are also contained and stored within the shared drive across GSTT and SGUH.

## 5. Qualifying patient cases

The following guidance is intended for referrers to gain an understanding of the types of cases they can bring forward to the MDT meeting for further guidance from MDT Clinical Leads. We hope this guidance will not hinder referrers from sending referrals for further discussions on potential Lynch syndrome cases to the MDT meeting.

### Appropriate patient referrals

All patients who have undergone germline testing should be discussed in the MDT regardless of their result (positive, negative, variant of unknown significance).

Clinical Nurse Specialists (CNS) will provide care and support to patients who have a diagnosis of colorectal and endometrial cancers along the cancer treatment pathway. There will be instances when further questions around the future management of patients with a possible Lynch syndrome diagnosis may need to be discussed at the MDT meeting.

Questions around future care management could include:

- Patients who lack capacity or are unable to consent for further testing;
- Future patient management advice requiring support from Clinical Leads;
- Any further Lynch syndrome related questions.

### Inappropriate patient referrals

The MDT encourages discussions around any Lynch syndrome related matters. Patients with non-Lynch related cancers or family history suggesting cancer predisposition other than Lynch Syndrome should be referred to Genetics.

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## 6. Advice to referrers

### Training and development

All members of MDT are advised to undertake training/education for continuous support of Lynch Syndrome discussions. It is suggested that training should be undertaken by Clinical Nurse Specialists in order to further develop their understandings of Lynch syndrome and the appropriate cases to refer to the MDT.

Click on below links to access Colorectal & Endometrial specific training:

Colorectal cancer MDT: [Link to training](#); [Link to supporting documents](#)

Gynaecological cancer MDT: [Link to training](#); [Link to supporting documents](#)

### Referral proforma expectations

As per the referral proforma shown in appendix 1, it is important to input the relevant details to present to the MDT members as this will allow the Clinical Leads gain an overarching understanding of the patient case and will facilitate further conversations and recommendations from the meeting. The following outlines key details required under each heading within the referral proforma.

#### ***Patient Background:***

- This includes an overview of the patient clinical details that the referrer believes are relevant for the MDT Clinical Leads to gain an overview of the patient situation.

#### ***Patient demographics:***

- Age and ethnicity will be captured to support the ongoing review of equity of access to testing.

#### ***Personal History of Cancer / Polyps (endoscopic and surgical history):***

- This information will allow for the MDT Clinical Leads to gain an understanding of whether Lynch syndrome may be present from the personal history of cancer.

#### ***Date of cancer diagnosis***

- Patients with a diagnosis of colorectal and endometrial cancers as well as any other cancer diagnosis should be mentioned in order to gain an understanding of the patients link to Lynch.

#### ***Family History/Pedigree (attach if possible):***

- This will allow the Clinical Leads to understand whether known relatives have had history of cancer which could indicate a presence of Lynch syndrome.

#### ***Genetic/Molecular testing results:***

- MMR immunohistochemistry or MSI result
- BRAF test result and/or if MLH1 methylation promoter test result.
- R210 test results/ germline testing result/ predictive genetic testing for Lynch syndrome.
- Please include lab reports with the referral proforma when sending to Coordinator ahead of the MDT meeting.

#### ***Date of R210 result***

- If known by the referrer, requested or ongoing, this will allow the team to analyse the time from cancer diagnosis to Lynch diagnosis.

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## 7. Useful Resources

Link to [Patient information resources - RM Partners](#)

Link to [Patient information resources – Royal Marsden](#)

## 8. Shared Regional Lynch Syndrome MDT Mailbox

### Rationale

At the inception of the Regional Lynch Syndrome MDT patient cases were received by individual mailboxes of the Regional Lynch Syndrome Project Team. This is no longer tenable as increase in referrals are being seen and the support team for the MDT has grown. In order to manage the MDT referrals more efficiently each month, a secure shared Mailbox for the MDT meeting is required. This will be a nhs.net mailbox.

### Ownership & Management

The Regional Lynch Syndrome MDT shared mailbox is managed by the Regional Lynch Syndrome Expert Network Coordinator. The mailbox will be monitored on a daily basis with a structured filing system to ensure appropriate management of referral information. On the occasion that this member of staff is unavailable the mailbox will be monitored by the Project Manager.

### Purpose

The mailbox will only be used for the following purposes:

- Receipt of patient referral proformas and associated clinical details
- Communication with referring teams
- Communication of MDT outcomes with referring teams
- Coordination of the Regional Lynch Syndrome MDT
- Escalation of clinically urgent escalations and queries for note to clinical leads

### Lifecycle

During 2024-25 this mailbox will be managed by the Lynch Syndrome Regional Project Team, as aforementioned. Funding is being sought to extend the contract for this project team, including those who manage this function.

In the eventuality that funding will not be ascertained this mailbox will be closed. The responsibility for closing this mailbox will be held by the South East Genomic Medicine Service Alliance (SE GMSA) team, hosted by Guy's and St Thomas' NHS Foundation Trust. This will be communicated by the SE GMSA to all members of the Regional Lynch Syndrome MDT.

Temporary support for this mailbox can be provided by alternate members of the SE GMSA or the South East Thames Clinical Genetics Service if there is a period of significant disruption to the project team, disabling their ability to manage and oversee this mailbox.



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## 9. Appendices

### Appendix 1.

MDT Referral Proforma

#### Lynch Cancer Case MDT– Referral Proforma

**Patient Name:** Jane Doe

**Hospital/NHS number:** 000 000 000

**DOB:** 01/01/01, 23y

**Ethnicity:** White/British

**Patient Background:**

**Personal History of Cancer / Polyps (endoscopic and surgical history):**

**Date of cancer diagnosis:**

**Cancer treatment stage:**

**Family History/Pedigree (attach if possible):**

**Genetic/Molecular testing results:**

**Date of R210 result:**

**Name of referrer:**

**Referring Hospital:**

**Email of referrer:**

**Question for MDT:**

What will be the future management plan for Jane Doe?

**Date of MDT:**

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**MDT Attendees:**

**MDT outcome:**



SE LS MDM referral  
blank.docx

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## Appendix 2:

Summary of LS patient cases excel format

Lynch syndrome MDT case discussion							
Patient details	Referrer	Clinical details	Histology	Discussion	Management Plan	Comments	
<i>Patient name</i> <i>DOB and age</i> <i>NHS number</i> <i>Hospital number</i>	CNS name CNS contact email Referring Hospital	<i>Cancer diagnosis</i> <i>Date of cancer Diagnosis</i> <i>Patient past medical history (PMH)</i> <i>Family history/pedigree</i>	<i>Genetic molecular testing results -</i> <i>MMR, BRAF, Methylation and genetic</i> <i>test results.</i> <i>Date of R210 result.</i>	<i>Questions and for the</i> <i>MDT</i>	<i>MDT outcome and recommendations for</i> <i>further patient care</i>	<i>Any applicable further</i> <i>comments from clinical</i> <i>leads or MDT members</i>	
Patient 2							
Patient 3							



MDM lynch cases  
blank spreadsheet.x

## Appendix 3:

SE LS MDT Meeting Agenda:



Lynch Cancer Case  
MDT agenda BLANK.

## Appendix 4:

SE LS MDT Tracker:



MDT tracker v.2.xlsx

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## Appendix 5:

MDT members contact information

Role	Name	Contact email
Regional Lynch Syndrome Clinical Nurse Specialist	Aela Limbu	<a href="mailto:Aela.Limbu@gstt.nhs.uk">Aela.Limbu@gstt.nhs.uk</a>
Regional Lynch Syndrome Coordinator	Monika Sommerrey	<a href="mailto:Monika.Sommerrey@gstt.nhs.uk">Monika.Sommerrey@gstt.nhs.uk</a>
Regional Lynch Syndrome Clinical Lead	Adam Shaw Dimitra Repana	<a href="mailto:Adam.Shaw@gstt.nhs.uk">Adam.Shaw@gstt.nhs.uk</a> <a href="mailto:Dimitra.Repana@stgeorges.nhs.uk">Dimitra.Repana@stgeorges.nhs.uk</a>