Shared Care Working Group

Tuesday 4th February – Teams Meeting

Chair:
Kate Maynard (KM)

Attendance:

Name	Role	Organisation
Kate Maynard (KM)	Senior Transfusion Practitioner	Croydon Health Services NHS Trust
Nella Pignatelli (NP)	London's RTC Administrator	NHSBT
Sam Alimam (SA)	Haematologist	UCLH and NHSBT
Sibel Bafker (SB)	Senior Biomedical Scientist	East Sussex NHS Trust
Emily Carpenter (EC)	Transfusion Practitioner	King's College Hospital
Luke Dowey (LD)	Transfusion Practitioner	Clatterbridge Hospital
James F (JAF)	Senior Epic Application Analyst	Cambridge University Hospital
Michaela Gaspar (MG)	Transfusion Nurse	Royal Brompton Hospital
Julie Jackson (JJ)	Transfusion Practitioner	James Paget University Hospitals NHS Foundation Trust
Jane Iatrou (JI)	Transfusion Practitioner	Whiston Hospital
Vathsala Juhan (VJ)	Transfusion Practitioner	Queen Elizabeth The Queen Mother Hospital
Katarina Kacinova (KK)	Blood Bank Manager	University Hospitals of Derby and Burton
Matt Hazell (MH)	Consultant Clinical Scientist	NHSBT
Heli McAleese (HM)	Transfusion Practitioner	Bart's Health NHS Trust
Nikki Swarbrick (NS)	Laboratory Incident Specialist	SHOT Team
Peter Baker (PB)	Transfusion Service Manager	University Hospitals of Liverpool Group
Stephanie Cairns (SC)	Clinical Systems Developer	NHSBT
Victoria Tuckley (VT)	Laboratory Specialist	SHOT
Victoria Waddoups (VW)	Transfusion Practitioner	Rotherham NHS Foundation Trust
Jay Faulkner (JF)	Transfusion Practitioner	Leeds Teaching Hospitals NHS Trust
Louise Sherliker (LS)	Programme Director of Transfusion Transformation	NHSBT

Apologies: Vince Michael (VM)
Special Mentions: Sue Hill (SH), Ming Tama (MT)

Minute Secretary: Nella Pignatelli (NHSBT).
Please contact nella.pignatelli@nhsbt.nhs.uk for any amendments.

Meeting summary:

The National Shared Care Working Group discussed various initiatives and challenges related to transfusion care. Key points included the need for a shared care record, with examples from Clatterbridge's automated alert system and the importance of clear communications between hospitals. LS highlighted the national Transfusion Transformation strategy, emphasising digital interoperability and the shared care record. The group explored potential solutions, such as integrating special requirements into EPRs and leveraging NHS apps. They agreed to focus on internal communication processes and develop a toolkit of best practices to improve shared care within hospitals. The meeting focused on improving sample referral for the Hemoglobinopathy Geno Project, which faces a lag in some hospital trusts. MH emphasised the urgency due to expiring government funding, stressing the need to utilise it to avoid negative implications for the NHS. The team agree to disseminate this information through various forums.

-- Meeting Starts --

1. Welcomes & Introductions:

KM started the meeting by asking the group to introduce themselves.

2. Review of minutes from last meeting – 23rd September 2024

The group read through last meeting's minutes. No amendments needed and the draft was accepted.

3. Review of Actions from last meeting – 23rd September 2024

No.	Action	By Whom	Status update
1	Establish if an information governance specialist can join the group, Suggested that NHSBT rep would be helpful as knowledgeable about national processes.	ST	Unable to find a governance specialist yet.

2	Suggested changes made to scoping document and to send round for comments.	KM	Scoping document sent around for comments and then was submitted.
3	To present shared care form at lab managers group	HM, KP and SW	No capacity to present shared care in the November meeting. KM will try and present it in the next meeting in February.
4	To share form with clinical colleagues to ascertain usability	ALL	Ongoing
5	Contact NHSBT Q and AS authors to suggest that this may be better hosted via H and S website.	KM	KM submitted it but has yet to hear anything back.
6	Share terms of reference for comments, all to feed back.	KM	Done
7	Find a patient or clinical nurse specialist representative	ALL	Ongoing.

Further comments on action No. 4:

KM asked the group if anyone had received feedback after sharing the form with their clinical colleagues.

JF mentioned that she shared it with her consultant, who provided feedback.

KM will forward this feedback to HM for review.

HM also shared the form with her clinical team, who were enthusiastic about it and did not find any issues so far.

→ **ACTION:** KM informed the group that she plans to present the form to the Lab Managers Group, hoping they will introduce it at the next NBTC meeting for review.

HM emphasised the importance of ensuring the form is suitable for use before proceeding further.

PB noted that the form had been discussed regionally, and while he did not receive many comments, the overall response was positive. He added that the form needs national branding or endorsement.

This idea was presented in the UK Forum by KM and the group is happy for this to be implemented UK wide.

→ **ACTION:** PB suggested briefing RTC leads in advance of their meetings so they can review it and comment on it rather than it just being dropped as an agenda item.

4. Shared care within hospitals: Clatterbridge Cancer Centre

Introduction to Clatterbridge Practices

LD was the first to share to the team about practices being done at Clatterbridge. Clatterbridge covers quite a large area including North Wales, Liverpool and Isle of Man. There are a lot of haematology patients who have special requirements – such as Hodgkin Lymphoma patients and stem cell transplant patients. The original method of noting down when patients have transfusion reactions was confusing and unclear, so LD and his team built a special indicator resembling a flag which goes by the patient's name and instead of having multiple special requirements alerts, they are now grouped together. This helped staff a lot as they did not have to scroll and search for original notes from potentially years ago that state the patient needs – let's say - irradiated blood.

Monthly Reporting and Insights

The Business Intelligence Team at the trust has been diligently working to extract data from the system to generate a monthly report on the usage of the special indicator, including details on its frequency and user demographics. LD monitored the report generation process and discovered that the Lymphoma team excelled at recording special requirements for their patients. The transplant team used it sporadically, while the Myeloid team had inconsistent usage. This insight enabled LD to concentrate his efforts on promoting the special indicator in underutilized areas, leading to its increased adoption over time.

Daily Alerts and Laboratory Coordination

The reports were then automated to be sent at 9 am each morning, accompanied by an alert to inform LD and his team of any new special indicators added in the past 24 hours, allowing LD to verify their accuracy. Since Clatterbridge sends all blood samples and transfusion requests to Liverpool community laboratories, the six transfusion managers and deputy managers there also receive these daily alerts and update their LIMS accordingly. The goal is to ensure that if blood products are requested incorrectly (e.g., clinical staff do not specify the need for irradiated blood), the laboratory will be alerted by the special indicator, ensuring the patient receives the correct blood products.

Communication with Referring Hospitals

LD also forwards the special indicators to referring hospitals, enabling them to update their LIMS. Some hospitals prefer to be notified via telephone rather than email about special requirements, as staff can update their LIMS immediately whilst on the phone whereas emails can sometimes be overlooked. LD acknowledges the challenge of remembering each hospital's preferred communication method. He suggested that

having a standardised shared care form for the country would streamline this process and minimise potential errors. LD also noted that a system relying solely on him could be problematic, especially during his annual leave.

Q&A/Discussion:

- NS raised concerns about the reliability of the information and asked if LD needed to, could he contact the person who entered the data.

- LD explained that he has instructed consultants, registrars, and clinical nurse specialists to add the special indicator when consenting a patient, which then alerts the laboratory. Additionally, if LD reviews a patient's notes and finds no clear reason for the indicator, he contacts the staff member directly to verify if it was added by mistake.

- PB expressed that he thinks specialist units may struggle with the increase in workload from this process and that it may be more useful in a district general hospital.
  → **ACTION**: KM added that this could be something to bring up at in the next Lab Managers meeting.

- VT commended LD for his efforts thus far and inquired about how he navigated information governance and obtained permission to share information across different areas.

- VT also asked if this had received approval.

- LD explained that he had consulted with the trust's information governance lead, who was satisfied with the automated alerts being sent to Liverpool and Aintree, as these locations are directly involved in patient care and issuing blood products to our patients. The information governance lead confirmed that the information was shared securely via NHS emails and solely for the purpose of providing patient care.

- VT asked LD if there are any talks about getting information automatically sent from the EPR to the LIMS in LD's trust.

- LD responded that there was a talk previously about having a digital link where information could go digitally but because it is not an in-house laboratory and the fact that it is a different laboratory with a different system, we are disconnected in that way.

- LD is optimistic that this will be something they will work towards in the future.

- SA complimented LD's work and asked if his organisation is looking at upgrading at any level, as it is currently too heavily dependent on one individual.

- LD informed the group that his organisation is looking at getting a new EPR.

5. Transfusion Transformation

Guest speaker: LS

LS introduced herself as the Program Director for Transfusion 2024 at NHS BT. KM invited LS to discuss the shared care record as part of the strategic work being done.

Discussion on Shared Care Record

- Transfusion 2024 has a limited timeframe, and a new strategy called Transfusion Transformation has been developed.
- Three strategic themes have emerged from the new strategy, focusing on digital interoperability.
- Recommendations around digital integration and interoperability include the shared care record.

Transfusion 2024 and Transformation Strategy

- The new strategy aims to incorporate work not completed in the broader transfusion strategic plan.
- Digital interoperability is a core focus, with many involved in working groups around this theme.

Digital Interoperability and Recommendations

- Recommendations for digital integration include the shared care record.
- Discussions with EC and KM have led to scoping out requirements for the shared care record.
- Collaboration with NHS England is ongoing to finalise and sign off on recommendations.

Infected Blood Inquiry and Subgroup 7F

- The Infected Blood Inquiry reported in May last year, with recommendations focusing on digital and safety requirements for blood transfusion.
- Subgroup 7F, led by SH and MT, is working on scoping out requirements.
- Recommendations from Transfusion Transformation will be incorporated into the Infected Blood Inquiry 7F group.

Next Steps and Funding

- Work with key people leading digital transformation at NIHR.
- Form a clear vision of the current state and challenges in the pathology and transfusion pathway.
- Map out the digital transfusion pathway comprehensively.
- Prioritize projects and seek funding to support the work.
- Discussions are ongoing to support the shared care record for transfusion.

Conclusion:

- The shared care record for transfusion is a priority but will take time to implement.
- Funding requests have been made, and outcomes are awaited to move forward.

Q&A/Discussion:

- KM thanked LS for her input and asked if there were any specific questions from the group.

- KM Inquired about the platform for the shared care record, questioning if it would be on the NHS spine or if it was too early to determine.

- LS Responded that it is too early to determine the platform and mentioned various development potentials and processes, including the federated data platform in NHSE.

- LS highlighted the importance of automating processes to reduce errors, particularly transcription errors and emphasised that the shared care record is a priority and not sidelined, but the exact approach is still being figured out.

- NS raised a question about the group's direction and purpose, considering parallel work being done elsewhere and asked about the plan for the group and the implementation of the electronic shared care form.

- LS acknowledged the group's expertise and the importance of including them in the ongoing work and mentioned that it is still early in the process and could not provide a definitive answer at the moment.

- LS emphasised the need to bring the group into the conversation and ensure the right people are involved and expressed a vision for setting up a defined project with clear actions and funding as part of a digital program.

- KM Highlighted the challenge of interfacing different EPR systems with LIMS and then with each other.

- LS Agreed that shared care involves significant challenges and emphasised the need to keep these challenges on the horizon and address them through digital mapping.

- LS Stressed the importance of moving towards standardisation of systems and mentioned the need to clearly define requirements and ensure all attributes are included in the systems.

- LS also highlighted the importance of being part of broader conversations to stay aware of developments and avoid working in isolated pockets and suggested tapping into larger groups to ensure comprehensive integration and standardisation.

6. Discussion around shared care

- KM shared to the group an overview of Shared Care.

- EC found the visual representation of shared care on one slide very useful, as it clearly shows the complexity involved due to the many elements. She suggests expanding on the involvement of multiple tertiary hospitals, which adds another layer of complexity.

- VT appreciates the concept and visual representation but highlights several problem points from a SHOTperspective. These include issues with updating the LIMS, communication breakdowns between labs and clinical teams, and steps being skipped in the process. She notes that the complexity of the system often leads to these issues and suggests adding more problem points, such as updating the EPR and ensuring clinical teams are informed.

- KM mentioned the challenge of labs identifying special requirements, such as needing HLA matched samples, and how this impacts clinical decisions.

- VT discussed examples like IGA deficient patients having reactions and the importance of communicating test results, including extended phenotyping.

- VW highlighted issues with how delays are reported and recorded, particularly when EPR systems don't communicate effectively, leading to patient deterioration.

- NS noted that delays can occur when labs have the information in the EPR but don't know how to proceed, or when they lack necessary resources and fail to inform clinicians about alternatives.

- The group agreed that there is a need to improve communication channels between labs and clinical teams to ensure timely updates and decisions and address issues with EPR systems to prevent delays and ensure accurate reporting and recording of special requirements and reactions.

- KM asked the group if there were any other projects they would like to start or any concerns or issues they would like to raise.

- JF pointed out that the main issue in her hospital is the absence of alerts for special requirements, despite having alerts for conditions like bleomycin patients. She noted concerns about alert overload.

- JF stressed the importance of highlighting special requirements, particularly for patients who might be on a surgical ward instead of a haematology ward due to other health issues. The critical challenge is ensuring that all relevant staff are aware of these requirements.

- VT emphasised the importance of the patient within all this, stating that in her hospital patients often inform staff about their requirements.

- NS agreed and suggested that the NHS app, which contains extensive information on a patient’s health conditions, appointments, and medications, could be used to highlight special requirements.

- NS added on that they have been discussing the possibility of adding antibody cards or letters to EPIC MyChart to avoid the issues with physical cards. We've consulted with NHSBT and received approval to use the same letter. Now, it's just a matter of implementing it.

- KM responded, stating that including shared care results on the NHS app might simplify the process. Some letters do appear, depending on the document type. The EPR system influences what gets onto the app, while MyChart follows a different process.

- NS discussed the use of patient alerts to inform blood orders. Alerts pull information automatically but require prior knowledge to be effective. Alerts can be added from clinical areas, providing additional information.

- MG emphasised the importance of having shared care forms accessible through the NHS app for better communication between hospitals, especially for non-cardiac issues.

- KM suggested focusing on improving internal communication processes and possibly creating a toolkit of best practices. Pharmacy-generated lists of new monoclonal therapies were mentioned as a useful example.

- NS proposed presentations on good practices, highlighting the use of pharmacy lists and closing gaps using EPIC.

- LD raised concerns about the frequency of pharmacy-generated lists, suggesting real-time or daily updates to avoid missing critical information.

- NS shared a past practice of using a chart for special requirements, suggesting it could be adapted locally and made into a Word document for flexibility.

- VT mentioned plans to release a lab chapter addressing delays due to lack of information, with editable documents for hospital adaptation.

- NS suggested that participants email her and KM with good examples of practice to compile and share.

- VT mentioned capturing positive cases and good learning events, particularly around major haemorrhage communication.
- KM proposed focusing on internal communication processes and creating a toolkit of best practices.

- NS and LD discussed the importance of real-time updates for pharmacy-generated lists to avoid missing critical information.

- HM highlighted the importance of continuing sample referrals for hemoglobinopathy genotyping due to government funding.

- The next meeting is tentatively scheduled for early May, with dates to be confirmed.
  → **ACTION:** Nella will send out a poll to determine the date for the next meeting

- Participants were thanked for their contributions.

7. Actions

No.	Action	By Whom	Status update
1	Establish if an information governance specialist can join the group, suggested that NHSBT rep would be helpful as knowledgeable about national processes.	ST	
2	To present the shared care form at the Lab Managers Group Meeting in February, hoping they will introduce it at the next NBTC meeting for review.	KM	
3	To share form with clinical colleagues to ascertain usability.	ALL	
4	Find a patient or clinical nurse specialist representative.	ALL	
5	Briefing RTC leads in advance of their meetings on the shared care form so they can review it and comment on it.	?	
6	Send out a poll to determine the date for the next meeting.	NP	

-- Meeting ends --