

**Education Event - *The Patient Experience* - Summary**  
**Wednesday 4 May 2022**  
**Microsoft Teams**

Howard Wakeling RTC Chair	Consultant Anaesthetist	University Hospitals Sussex NHS Trust
Kerry Dowling RTC Deputy Chair	Presenter/ Transfusion Laboratory Manager	Southampton University Hospitals Foundation Trust
Abena	Presenter	
Dr Britannia Volkmer	Presenter	

Welcome	HW welcomed delegates from across the country and introduced the three presenters.
Abena – Sickle Cell Disease Exchange Transfusion Patient	<p>Abena outlined the impact of Sickle Cell Disease on her life. Her experience at different hospitals, and in A&amp;E; managing pain; and the need for medics to listen. Quotes from her presentation included: "my first exchange was nerve racking...I'd never heard of it before and it's not widely spoken about within the Sickle Cell community, not a lot of people know about it..."</p> <p>".. it took a while... but exchange transfusions are definitely working for me"...;</p> <p>"when you go in, you feel tired, after exchange, it's almost like someone's giving you a brand new battery..."</p> <p>"... you're looked after, people are checking on you..."</p> <p>However -</p> <p>"...when you're in pain it's much harder to communicate "</p> <p>"...every Sickle Cell patient should carry a card, I also have my care plan on my phone... this definitely helps, but if the medics don't truly understand Sickle Cell, or they don't understand your treatment plan... that when it's a struggle."</p> <p>".. I say... listen to your patients and check with them – and trust them, there have been many times I don't feel I can trust the doctor... medics need to listen to the patient, they know their care plan, we know what we need..."</p> <p>Useful resources:</p> <p><a href="#">Sickle Cell Society</a></p> <p><a href="#">Patient Information Leaflet</a></p> <p>NHSBT Automated Red Blood Cell Exchange treatment for the prevention of crisis and complications relating to Sickle Cell Disease leaflet</p> <p><a href="https://nhsbtddb.blob.core.windows.net/umbraco-assets-corp/14544/auto-rbcx-sickle-cell-flyer.pdf">https://nhsbtddb.blob.core.windows.net/umbraco-assets-corp/14544/auto-rbcx-sickle-cell-flyer.pdf</a></p> <p><a href="https://www.sicklecellsociety.org/wp-content/uploads/2021/11/No-Ones-Listening-Final.pdf">https://www.sicklecellsociety.org/wp-content/uploads/2021/11/No-Ones-Listening-Final.pdf</a></p> <p><a href="https://edm.parliament.uk/early-day-motion/59617/health-inequalities-for-patients-with-sickle-cell-disease">https://edm.parliament.uk/early-day-motion/59617/health-inequalities-for-patients-with-sickle-cell-disease</a></p> <p>Guidelines:</p> <p>Red cell transfusion in sickle cell disease. Part I: principles and laboratory aspects</p> <p><a href="https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.14346">https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.14346</a></p>

	<p>Red cell transfusion in sickle cell disease Part II: indications for transfusion  <a href="https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.14383">https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.14383</a></p> <p>Position paper on International Collaboration for Transfusion Medicine (ICTM) Guideline ‘Red blood cell specifications for patients with hemoglobinopathies: a systematic review and guideline’ on behalf of the Transfusion Task Force of the British Society of Haematology Guidelines Committee  <a href="https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.16405">https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.16405</a></p> <p>Management of sickle cell disease in pregnancy. A British Society for Haematology Guideline <a href="https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.17671">https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.17671</a></p> <p>NICE Spectra Optia for automatic red blood cell exchange in people with sickle cell disease <a href="https://www.nice.org.uk/guidance/MTG28">https://www.nice.org.uk/guidance/MTG28</a></p> <p>Videos  PBM England YouTube: Setting up and Performing a Manual Exchange Red Cell Exchange in Sickle Cell Disease (Under 40kg)  <a href="https://www.youtube.com/watch?v=e2itKcfXQAE">https://www.youtube.com/watch?v=e2itKcfXQAE</a>  PBM England YouTube: Setting up and Performing a Manual Exchange Red Cell Exchange in Sickle Cell Disease (Over 40kg)  <a href="https://www.youtube.com/watch?v=5QFiLziDxhc">https://www.youtube.com/watch?v=5QFiLziDxhc</a></p>
<p>Kerry Dowling</p>	<p>A pre-recorded video of a Trauma patient was shown, in which he recalls his personal story - a pedestrian in a road accident, with traumatic injuries, his time in A&amp;E, and the care along the way in his recovery.</p> <p>Kerry presented another patient’s story, from his motorbike accident, treatment by the air-ambulance team, through to A&amp;E and final discharge from hospital.</p> <p>Key points</p> <ul style="list-style-type: none"> <li>• Major trauma in the lab is led by protocol – but it’s important to remember that there is a very sick patient at the end of every sample or call and this should be included in lab training and education</li> <li>• Trauma patients are often unaware of transfusion care at the time, but are very grateful for everything the laboratory does in combination with the Trauma multi-disciplinary team</li> <li>• Due to modern trauma care patients are surviving very severe injuries that would previously be unsurvivable</li> <li>• Be aware of Injury Severity Scores – an indication of how severely injured the patient is</li> <li>• Major Trauma patients have a long road to recovery. Care doesn’t end after hospital discharge. Often injuries are life changing</li> </ul>
<p>Dr Britannia Volkmer</p>	<p>Dr Volkmer presented BOOST (Building Optimised Outpatient Services in Transfusion)</p> <p>She outlined the study objectives:</p> <ul style="list-style-type: none"> <li>• To engage in active and open discussion about the patients’ perceptions being presented</li> <li>• To devise, where necessary, any recommendations for practice change</li> </ul>

	<ul style="list-style-type: none"><li>• To consider which recommendations are of priority to address and how this might be done</li></ul> <p>And the following Intervention options were put forward for consideration:</p> <ul style="list-style-type: none"><li>• Staffing capacity review &amp; building shared decision-making culture</li><li>• Provide patients info about safe lab practices and offer visits</li><li>• Review existing space and unit expansion</li><li>• Information leaflets</li></ul> <p>Resource: NICE guidance available at <a href="http://www.nice.org.uk/">www.nice.org.uk /</a> <a href="https://www.nice.org.uk/Guidance/ph6">https://www.nice.org.uk/Guidance/ph6</a></p>
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