

**NBTC's Patient Involvement Working Group (PIWG)**  
**Face to Face Meeting Birmingham New Street, Room 3**

**Friday, 10 June, 10:30 – 15:30**

**Present:**

Charlie Baker (CB) (Chair)	Consultant Anaesthetist, West Midlands
Rebecca Gerrard (RG) (Sec)	National Lead – PBMP Team, NHSBT
Donna Beckford-Smith (DB-S)	Transfusion Practitioner – (South Central region)
Celina Bernstom (CBe)	EA to the NBTC
Kairen Coffey (KC)	Education & Audit Lead – PBM Team, NHSBT
Graham Donald (GD)	Lay rep
Majed Mir (MM)	Web Architect - for Ben McGuinness – Head of Digital Delivery, NHSBT
Biddy Ridler (BR)	Blood Conservation expert
Denise Watson (DW)	Patient Blood Management Practitioner - PBM Team, NHSBT

**Apologies:**

Shubha Allard (SA)	Consultant Haematologist, NHSBT/Barts & The London Hosp TP, West Middlesex Hospital
Monique Chituku (MC)	Marketing, NHSBT
John Kaey (JK)	Lead Transfusion Practitioner, Heart of England Foundation Trust, West Midlands
Jayne Khorsandi (JK)	Head of Strategic Marketing, NHSBT
Neil Phillips (NP)	Chief BMS Blood Transfusion: Western Sussex Hospitals NHSFT
Malcolm Robinson (MR)	Independent Healthcare Sector representative
Ian Stephenson (IS)	Consultant Haematologist, Royal Free Hospital
Mallika Sekhar (MS)	

<b>01/16</b>	<b>Welcome and apologies.</b>
	Ian Stephenson has stepped down from the working group due to his new role outside of the healthcare sector.
	Majed Mir (web architect) was welcomed to the group, he will be reporting to Ben McGuinness
<b>02/16</b>	<b>Minutes from telecon Monday, 15<sup>th</sup> February 2016 and Actions.</b>
	Typos were noted.
<b>03/16</b>	<b>Master Programme</b>
	BR circulated a copy of “All Blood Counts” a comprehensive textbook of Patient Blood Management which she coedited.
	Presentation BR – “Public Knowledge and Perception of Blood: Transfusion and Conservation – The Exeter Experience”. The study was conducted for her Master's degree at the University of Exeter.

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	Aim of study was to ascertain public knowledge and perceptions around blood transfusion, the risks, benefits and whether they thought it was safe and sustainable.
	Concerns are: diminishing donor pool, demand/waste, cost, avoidable errors; clerical error, infections, suppression of immunity.
	UK blood is safe because of altruistic, unpaid donors, rigorous screening and testing. Biggest risk in UK is getting the wrong blood – average of 10 deaths/year, with others affected e.g. kidney failure. Nothing is 100% safe.
	Fragile supply – some components have limited shelf life. This is a world-wide problem, not just UK. Alternatives include intraoperative cell salvage ‘recycling your own blood at surgery, ‘prehabilitation’’. Transfusion should no longer be the default option.
	Why seek public opinion? Part of Better Blood Transfusion 3 was directed to improving patient involvement and this is echoed in many other health initiatives
	NHS, NICE and WHO support people’s involvement in their medical care and should therefore include blood management.
	Very little evidence of any large studies, especially on public opinion outside clinical areas.
	Some publications demonstrated a need for further study on how the public (not just when patients) perceive blood transfusion and conservation.
	Aim of study was to find out what people know or would like to know about blood conservation.
	Study was conducted locally. Test for clarity/user friendliness. Although large numbers of Foundation Trust members, the link was contained in the newsletter so this group was not directly targeted.
	The benefit of receiving a blood transfusion was changed from just a free text question to linear choice. Not all panel members were targeted as Exeter Clinical Research Facility have a policy of only inviting participation four times/year for specific studies such as diabetes.
	Query over sensitive medical problems precluding donation and was low response rate linked to esp. FT members secondary targeting.
	The highest representation was in the 65-74 years age group (36%, 387).
	Over half had known someone who had received blood. Unexpectedly high number (total 186) who had concerns about UK blood – invited to complete text box.
	Six principal and recurring themes emerged. Many varied and occasionally emotional responses. Concerns about safety - ‘contamination’ and logistics of blood donation Reassuringly some did have confidence and one thanked the donors and said ‘keep up the good work’.
	Surprisingly high percentage thought there was not enough blood available for transfusion.
	Concerns about whether NHSBT was going to be privatised e.g. ‘profit before patients’. This mirrors concerns about NHS in general.
	Majority have faith in the blood management system - (950/1082, 88%) not concerned, but 8% (88) did not know.
	Over half of those surveyed would be interested to learn about alternatives to blood transfusion.

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	The majority were likely to talk to their family about blood and blood conservation.
	Myths e.g. “blood will always be there if I need it”, Risk of infection from AIDS/HIV. Blood is free as donors don't get paid Blood is needed mostly for road accidents and surgery. UK blood goes to EU. UK receives blood from other countries. I can give own blood before an operation.
	Overall both barriers and positives were experienced.
	BR's presentation was discussed and it was confirmed that rarely have the public heard of BBT 1-3.
	Enquiries about artificial blood were received. Questions on blood donation should be passed on to NHSBT. The role of Donor Carers is more 'hands off' these days.
<b>04/16</b>	<b>Information Standard</b>
	<ul style="list-style-type: none"> <li>• DW met with Dan Wills, Assessment and Development Manager, NHS England and discussed gap analysis and forward plan</li> <li>• Working through the standards (6 in total)             <ol style="list-style-type: none"> <li>1. Information Production - you have a defined and documented process for producing high quality information</li> <li>2. Evidence Sources - you only use current, relevant, balanced and trustworthy evidence sources</li> <li>3. User Understanding and Involvement - you understand your users and you user-test your information</li> <li>4. End Product - you double-check your end products</li> <li>5. Feedback - you manage comments/complaints/incidents appropriately</li> <li>6. Review - you review your products and process on a planned and regular basis.</li> </ol> </li> <li>• Need to formalise the process, demonstrating what action was taken and why, what was the outcome and if comments/changes were accepted. If not, need to state why not</li> <li>• Considering combining the processes for new and reviewed into one, rather than two. No changes will be made until DW has attended the 'Process' workshop on Weds 29<sup>th</sup> June which will cover:             <ul style="list-style-type: none"> <li>○ How to write a clear and fluid information production process</li> <li>○ How to document your process and make it accessible</li> <li>○ Meeting the Principle and Requirements of The Information Standard</li> <li>○ Reviewing your production process on a regular basis (creating a review process)</li> <li>○ Using flow charts and appendices.</li> </ul> </li> <li>• Quality Management system (Q-Pulse) will be beneficial in meeting some of the standards</li> </ul>

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	<ul style="list-style-type: none"> <li>• Will be sending out a proforma to the PIWG members, Consultant Haematologists and Virtual TP group to complete so we can demonstrate why we choose certain people to review certain materials:             <ul style="list-style-type: none"> <li>○ Role and number of years in the role</li> <li>○ Experience / knowledge</li> <li>○ Specific interest in transfusion</li> <li>○ Members of any national working groups</li> </ul> </li> <li>• Plan to use the revised PILs to assess what we currently do to meet the standard, identify any gaps and possible solutions</li> <li>• Aiming to achieve the standard by the end of the financial year.</li> </ul>
	Evidence Sources – important to establish a user understanding and that it is a 2 way process. PILs need to be more structured and targeted and involve the public before they become patients. Is it possible to incentivise people especially younger people?
	A virtual Transfusion Practitioner forum was discussed. DW has a workshop to improve processes involving patients on review groups. KC delighted with support from NHS England.
	PIL stock levels being reviewed. It was confirmed that accreditation is reviewed via formal assessment every 3 years and that any changes made need to be submitted to NHS England.
<b>05/16</b>	<b>Consent</b>
	Consent video: <ul style="list-style-type: none"> <li>○ The script of the video is set, request received early May for the image of the front page for the following PILs             <ul style="list-style-type: none"> <li>▪ Will I need a blood transfusion?</li> <li>▪ Will I need a platelet transfusion?</li> <li>▪ Iron in your diet</li> </ul> </li> <li>○ Awaiting an update but Suzy Morton, Consultant Haematologist in Birmingham is on leave until 16<sup>th</sup> June</li> </ul>
	Agreed that issue of consent is a controversial topic.
	CB reiterated the primary areas of blood demand are cardiac, haematology and GI. RG added that consent is made more complicated by the Montgomery ruling with some trusts carrying on in spite of it.
	CB confirmed that consent for transfusion appears to be improving and the recording of reasons for transfusions also seems to be improving. Consent for transfusion in surgery is part of the standard surgical consent form.
	It was agreed that consent forms and PILs should be stored with the prescription charts so they are seen.
	RG was invited to speak at a conference in Turkey. She reported that their patient blood management initiatives are far behind the UK and the expectations of their public with respect to blood transfusions are different. For NBTC in September the aim is to emphasise improvements, what is on the website, what the survey shows. Any improvements please voice.

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	Update re: H&S website:
	Cost of ICAG pad discussed. KC to calculate and feedback to the group.
	<ul style="list-style-type: none"> <li>o New additions include Consent for Transfusion template (Word)</li> <li>o Patient consent for blood transfusion (PPT)</li> </ul>
	<b><u>Action KC</u></b>
<b>06/16</b>	<b>PILs</b>
	<ul style="list-style-type: none"> <li>• All leaflets have been transferred to the new Hub with minimal disruption. Received one or two emails from users which have been forwarded to Carol Chester and addressed re: accessing the new website: <a href="https://hospital.nhsbtleaflets.co.uk">https://hospital.nhsbtleaflets.co.uk</a></li> <li>• Revised PILs now effective as of 1<sup>st</sup> June, 2016 and in stock: <ul style="list-style-type: none"> <li>o Will I need a blood transfusion?</li> <li>o Will I need a platelet transfusion?</li> <li>o Will my baby need a blood transfusion?</li> <li>o Will my child need a plasma transfusion?</li> <li>o Information for patients needing irradiated blood</li> </ul> </li> <li>• New PILs uploaded onto the Hospitals and Science website and awaiting approval for the NHS Choices website.</li> <li>• Note: New PILs are no longer available in translated languages, English only</li> <li>• Revised PIL at the printers, will be effective as of 1<sup>st</sup> July, 2016 <ul style="list-style-type: none"> <li>o FFP and Cryoprecipitate</li> </ul> </li> <li>• Under review: <ul style="list-style-type: none"> <li>o Will your child need a blood transfusion? (Pack)</li> <li>o Anaemia leaflet</li> <li>o Protecting women and babies with anti-D immunoglobulin</li> <li>o Patient Blood Management</li> <li>o Iron in your diet</li> </ul> </li> <li>• Plan to review all PILs again once The Information Standard is achieved.</li> </ul>
	These are on the corporate site for now but where they sit permanently needs to be decided.
	MM confirmed hits are being received, 15,000 hits this year making it the 4 <sup>th</sup> highest hit website overall.
	To make changes to the design of the website is costly and the need for changes would need to be justified.
	RG changed wording regarding risk upon advice from solicitors around the Montgomery ruling on consent.
	Discussions took place on risks. It was agreed impossible to list every possible risk.
	Mobile phone application options were discussed. A PBM App is to be piloted imminently and available via the App store. MM to look at possibility of PILs being included on App.
	Some PILS are due for updates and there was a steer not to increase them but to

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	improve what we have.
<b>07/16</b>	<b>PIWG Work plan</b>
	Membership discussions took place. Either MM or Ben McGuinness to be present.
	CBe to circulate TORs to the group in advance of the NBTC meeting Monday, 19 <sup>th</sup> September 2016.
	RG confirmed that all PILs are meant to be on NHS Choices and reviewed regularly.
	DW to circulate PIWG Work plan draft to the group.
	<b><u>Action: DW / CBe</u></b>
<b>08/16</b>	<b>AOB</b>
	The need for more lay representatives and succession planning was raised again. BR mentioned a group in her Trust that is very proactive and that it would be possible to tap into this via data managers if of interest. Meetings are more usually by telephone rather than face to face. RG to send list to KC.
	<b><u>Action RG</u></b>
	The School Sciences conference was a success and will be held again next year.
	<u>Harvey's Gang update:</u>
	2016 Chief Scientific Officer award for patient and Public Participation
	9 Trusts LIVE Harvey's Gang tours; 11 coming soon (including Great Ormond Street) plus at least 2 overseas. (and Australia to come too)
	Paperwork to register Harvey's Gang as a Charity has been submitted. We are also working very closely with Monkey Wellbeing and will be developing a Film and a book; Monkey joins Harvey's Gang (expand their Monkey needs a blood Test) and Monkey needs a Transfusion.
	RG – thanked Emma and wished her well having finished with NHSBT. CB extended thanks to RG for running the group and everyone wished her well in her new role.
<b>09/16</b>	<b>Date of next telecons/meetings</b>
	<u>Telecon:</u>
	Monday, 3 <sup>rd</sup> October 2016, 13:00 – 15:00

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	<u>Telecon:</u>
	Monday, 23 <sup>rd</sup> January 2017, 13:00 – 15:00
	<u>Face to Face – Birmingham</u>
	June Date TBC
	<u>Action: CBe</u>

**- END -**