

NBTC's Patient Involvement Working Group (PIWG) Meeting

Friday, 26th June 2015, 10.30 – 15.00
NHSBT West End Donor Centre, Floor 3, Room 3bc

Minutes

Present:

Charlie Baker (CB) (Chair)	Consultant Anaesthetist, University Hospital North Midlands
Rebecca Gerrard (RG) (Sec)	National Lead – Patient Blood Management Practitioner Team, NHSBT
Graham Donald (GD)	Lay rep
Shubha Allard (SA) – Dialled in	Consultant Haematologist, NHSBT/Barts & The London Hosp
Kairen Coffey (KC)	Education & Audit Lead – PBM Team, NHSBT
Neil Phillips (NP)	Head of Strategic Marketing, NHSBT
Ashley Frost (AF) – Dialled in	Digital Transition Manager
Donna Beckford-Smith (DB-S)	Transfusion Practitioner – (South Central region)
Nicola Greaney (NG)	Customer Service Support Coordinator (minutes)

Apologies:

Jayne Khorsandi (JK)	Lead Transfusion Practitioner, Heart of England Foundation Trust, West Midlands.
Mallika Sekhar (MS)	Consultant Haematologist, Blood Transfusion Lead, Royal Free Hospital
Ian Stephenson (IS)	Independent Healthcare Sector representative
Malcolm Robinson (MR)	Chief BMS Blood Transfusion: Western Sussex Hospitals NHS Foundation Trust
Jenny Rodger (JR)	Transfusion Practitioner, Pathology Dept, Wrexham Maelor Hospital
Monique Chituku (MC)	Transfusion Practitioner, West Middlesex Hospital
Biddy Ridler (BR)	Blood Conservation expert
Celina Bernstrom (CBer)	EA to NBTC
Richard Moore (RM)	Design & Production Officer, NHSBT
Emma Whitmore (EW)	Patient Blood Management Practitioner, NHSBT South East

Item		Action for
1.	Welcome and Apologies	
	RG introduced Donna Beckford-Smith to the group. Neil Philips will be attending the meetings from now onwards. Richard Moore will not be attending but to be copied in. Tamsin May to be removed as she has left NHSBT. Action: To update distribution list.	NG and CBer
2.	Minutes, Action Log and Matters Arising From Previous Meeting that are still open and not on the agenda	
	Typos in minutes from 19 th January to be amended: <ul style="list-style-type: none"> change trail' to 'trial' on p2 change 'appropriate usage' to 'inappropriate usage' on p2. 	
	"Choosing Wisely" campaign: Mike Murphy is involved with the RCPATH regarding the Choosing Wisely Campaign. RG has a paper with further information on this and will feedback at the next PIWG meeting. Action: RG to send Choosing Wisely paper around to the group. Action: NG to add the 'Choosing Wisely Campaign' to the next Agenda.	RG NG and CBer

	RCN booklet advising on iron deficiency in adults has now been published. See: http://www.rcn.org.uk/_data/assets/pdf_file/0003/629553/RCNguide_iron_deficiency_WEB.pdf	
	Re patient information on the JPAC website: It has been agreed at the UKBTN meeting that as this is a UK site, there will be some generic patient information on the new Transfusion Practice Toolkit but there will also be links on this site to other sites with patient information on e.g. the blood.co.uk website for information from NHSBT.	
	Re EW fed back on progress with the Informed Consent Action Group (ICAG) pad in the SEC region: Action: EW to feedback on the ICAG pad at the next PIWG meeting.	EW
	RG reviewed and updated the outstanding actions log – see attached.	
3.	Masters programme	
	The group reviewed and discussed Paper C. Noted members may be contacted to help trial packages.	
4.	Patient information on NHSBT's websites	
	<p>RG gave the background to this work: Following a gap analysis on the Western Australia website, it was identified that the patient information on NHSBT sites needed to be improved and a patient information 'App' was suggested: some information such as the PDFs are inaccessible on mobile devices, search engine optimisation was required and the pages and information layout needed to be improved. A business case was put forward to the Digital team in NHSBT Comms.</p> <p>Meanwhile some 'Discovery' work was done on the blood.co.uk site that suggested that donors see themselves as patients and were confused by the 'patient information' on the blood.co.uk site.</p> <p>AF then dialled in to give a brief overview of what Digital Marketing does and also a progress of their current projects which includes doing some 'Discovery' work on the PILs and patient information on the NHSBT websites. This would include a card-sorting exercise and some telephone interviews.</p> <p>The aim of the project is for all patient information to be held in one place, be user friendly and be accessible on mobile devices but for there to be links to this new site from all key NHSBT websites, and this included the blood.co.uk website.</p> <p>The group discussed how this might affect donors/patients who would search for</p>	

	<p>leaflets on the Blood website and whether the hits for this website would decrease because of it. It was agreed that further discussions need to take place between this group and Digital Marketing</p> <p>Digital explained to the group that they are currently unsure where the patient information and the PILs will be located moving forwards.</p> <p>NP gave an overview of the number of 'hits on the blood.co.uk website to the group. In the last month there were 407,000 hits on the website however a lot of them were users searching for blood donor sessions. Digital reiterated that all websites need to be user driven.</p> <p>The group confirmed that they were happy to be involved in the Discovery work as required.</p>	
5.	Transfusion information on other key websites	
	<p>RG provided an update on the work being done by her team to link with relevant patient organisations and ensure they have a named contact in the PBM team, up to date information on transfusion on their websites and links to NHSBT pages.</p> <p>7 of the 20 organisations contacted have so far have completed this and work is ongoing.</p>	
6.	Patient Consent	
	<p>1. Update following NCA</p> <p>SA explained that there are two NBTC groups currently involved in taking forward the recommendations from the NCA on patient information and consent: the PIWG and the Education Group. There are also some KPIs on patient information and consent in the PBM Strategy and Workplan.</p> <p>Action: RG and SA to collate a table showing progress with the recommendations in the NCA audit report.</p> <p>Once this is completed, to send to John Grant-Casey.</p> <p>Action: NG to put 'NCA Audit and progress with recommendations' on the next PIWG agenda.</p> <p>2. Feedback from RTCs on hospitals that have successfully implemented recommendations from SaBTO on consent:</p> <p>RG gave an overview: 9 examples have been submitted. The group suggested that the hospitals be contacted and asked if their examples can be put on the internet and shared with others.</p> <p>Action: RG to contact hospitals that have shared their examples of good practice on consent and ask if it can be put on the internet for others to review.</p> <p>Action: Produce a template 'consent' form for blood transfusion, using information from the examples provided, for hospitals to use.</p> <p>3. New consent law:</p> <p>RG highlighted key changes as illustrated in the publication paper F.</p> <p>CB explained that the change to consent was sent round to all consultants in his Trust.</p> <p>NHSBT's Clinical Governance department within NHSBT are currently reviewing</p>	<p>RG and SA</p> <p>NG and CBer</p> <p>RG</p> <p>RG and CB</p>

	<p>this new legislation and undertaking an impact analysis. RG suggested that the wording on the websites and in the PILs may need to be changed.</p> <p>Action: RG to feedback to NICE that the new law on consent must be taken into account and recommend that the wording should be strengthened in the draft transfusion guidelines.</p>	RG
7.	PBM Strategy – For Information	
	<p>RG confirmed that the Strategy has now been presented to 2 internal senior team meetings and suggested changes have been made to strengthen the introduction and the financial section. They have also been asked to consider and include what else could be achieved if additional funding was provided.</p> <p>The PBM Teams are currently working towards the objectives within the strategy. Feedback on any aspects of the PBM Strategy was still welcomed as it will not be presented to the Executive team until September now.</p>	
8.	Patient information leaflets	
	<p>EW is currently off work so was unable to give an update.</p> <p>RG explained that the PBM Team will be reviewing all PILs this financial year and to see if the pictures and context are still fit for purpose. The ‘Will I need a Blood Transfusion’ leaflet was low on stock so this has been reordered for 3-4 months worth of stock until EW returns.</p> <p>On a monthly basis, RG receives a stock report showing what has been order monthly, the stock level for each resource and what needs reviewing.</p> <p>Action: RG to provide an update on issues of PILs at the next meeting.</p> <p>Suggestion for Bone Marrow Transplant Card</p> <p>EW is gathering information to bring to the next PIWG Meeting.</p> <p>Independent Certification/Review of PILS</p> <p>KC presented some work she has recently done re gaining independent certification of all of the PILs. She proposed exploring the ‘Crystal Mark’ from the ‘Plain English Campaign’ and the ‘Information Standard’ from NHS England. NHS England no longer charges for gaining certification.</p> <p>After a discussion it was agreed that KC would do further work with NHS England and update the group at the next meeting.</p> <p>Action: KC to undertake further work with NHS England and ‘The Information Standard’ and feedback progress at next meeting.</p> <p>A short discussion took place around post transfusion advice for patients and DB-S has recently produced some information for her Trust. RG stated that although there is not a PIL for this, the team have previously produced an editable word document that DB-S might also find useful.</p> <p>Action: RG to send DB-S the word document for Patients after receiving a Blood Transfusion.</p>	<p>RG</p> <p>EW</p> <p>KC</p> <p>RG</p>

9.	Harvey's Gang	
	<p>MR was absent from the meeting however an update was provided by RG. There is an article on Harvey's Gang in this month's edition of NHS Blood and Transplant Matters as well as an article in this month's edition of BBTS Bloodlines. There will be a poster presentation at BBTS/ISBT Excel in London on Monday 29th June 2015</p> <p>NHSBT have been shortlisted (1:5) for the NHS "Kate Granger 2015 (Team) Award" which will be part of a National NHS event in Manchester in November. RG is still waiting to hear back from HEE regarding an application to gain funding to roll this initiative out.</p>	
10.	Plans for National Pathology Week	
	<p>SA discussed RCPATH's National Pathology Week that takes place 2nd – 8th November 2015. The background for this project is as follows;</p> <p>The Royal College of Pathologists organises a National Pathology Week initiative in November each year which aims to celebrate pathology and the important contribution pathologists make to healthcare, through a programme of events aimed at people of all ages. Throughout the week, pathologists and laboratory scientists, both nationally and internationally, will be running a variety of events to improve public awareness and understanding of the science behind the cure. This year the theme is "Unlocking the key to your health.</p> <p>NHSBT and the PIWG have been involved in National Pathology Week initiatives in the past and this year will focus on sickle cell disease (SCD) and blood transfusion.</p> <p>A project Group has been created that is made up of representatives from NHSBT (Clinical, Donor, OWD and Communications teams), Hospitals (trainees, Haemoglobinopathy Consultant, Specialist Haemoglobinopathy Nurse), Patients and representatives from the Sickle Cell Society.</p>	
11.	PIWG Workplan	
	<p>Most of the workplan had previously been discussed as part of the meeting.</p> <p>GD is involved in James Lind Alliance which starts September.</p>	
12.	NICE guidance out for consultation	
	<p>The NICE Guidelines were discussed in item 6.</p>	

13.	Penrose Enquiry	
	<p>RG highlighted the key points from the Penrose Enquiry report that can be located on the following link http://www.penroseinquiry.org.uk/.</p> <p>The document is 1,800 pages long and the enquiry cost £11 million. It covers the story of Hepatitis C in Scotland and will have implications for blood safety in the future.</p> <p>A piece of work has been completed in NHSBT to review the governance procedures and policies in place to try and prevent this sort of thing happening again.</p>	
14.	AOBs	
	<p>RG – NPSA SPN 14 and transfusion competencies</p> <p>On behalf of the NBTC, Lynne Mannion is leading a group of Transfusion Practitioners to review and update the standards related to the competencies.</p> <p>NBTC Chair, Jonathan Wallis, has contacted NHS England to ask if the new standards could be located on their website and has been put in touch with their Patient Safety Groups to take this forward. It has been suggested that a key member of the NBTC should sit on one of these seven groups.</p> <p>Membership</p> <p>It was also agreed by the group that DB-S was a valuable asset to the group and she was invited to become a permanent member – she agreed.</p> <p>Action: Add DB-S to the circulation list.</p>	NG and CBer
15.	Date of next meeting	
	<p>Action: NG to change the current telecon booked from 16th October to 14th October, 14.00 – 16.00.</p>	NG and CBer