

NBTC's Patient Involvement Working Group (PIWG)
Telephone Conference

Friday, 09 June 2017

Present:

Charlie Baker (CB) (Chair)	Consultant Anaesthetist, University Hospital North Midlands
Donna Beckford-Smith (DB-S)	Transfusion Practitioner – (South Central region)
Celina Bernstrom (CBe)	EA to the NBTC
Monique Chituku (MC)	TP, West Middlesex Hospital
Kairen Coffey (KC)	Education & Audit Lead – PBM Team, NHSBT
Graham Donald (GD)	Lay representative
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
Lindsay Duffin (LD)	Transfusion Nurse Specialist Nuffield Group
Kath Hearnshaw	Lay representative
John Keay (JK)	Marketing, NHSBT
Raheela Khalid (RK)	Deputy Pathology Manager
Jayne Khorsandi (JKh)	Lead Transfusion Practitioner, Heart of England Foundation Trust, West Midlands
Malcolm Robinson (MR)	Chief BMS Blood Transfusion: Western Sussex Hospitals NHSFT
Mallika Sekhar (MS)	Consultant Haematologist, Royal Free Hospital

01/17	Minutes (paper A), outstanding action log (paper B) and matters arising from meeting 03.04.17
	<u>Minutes:</u>
	KC confirmed that Louise Sherliker is no longer required to attend these meetings and should be removed from the distribution list. Action: CBe
	Kath Hearnshaw has not been in touch and it was said that CBe should follow up calendar invites that are not responded to. Action: CBe
	Minutes were agreed as a true record.
	<u>Action Log:</u>
	It might be useful to invite people to the forthcoming NBTC meeting on 18 September 2017 to report on success stories and challenges experienced. It would be ideal to have ICAG pads available for the NBTC. GD added those with good practice do not need to use it. It is more important to know about those hospitals that have bad practice or those that are interested in improving. It should be seen as an optional resource. TPs are ambassadors for promoting the use of the ICAG pads. GD to follow up and find out who is using and what the feedback is. Action: GD.
	KC confirmed that there is now budget for the development of the ICAG pad. There have been no budgetary cuts. KC to arrange teleconference and proceed with the printing of ICAG pads to take to the Consent Workshop at the NBTC ON 18 September 2017. Action: KC.

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	BR's Master's Programme can now be removed from the Action Log. Action: CBe
02/17	Information Standard
	<ul style="list-style-type: none"> • Quality mark that proves: <ul style="list-style-type: none"> – A rigorous assessment – Information is: <ul style="list-style-type: none"> – Clear – Accurate – Up to date
	DW provided a comprehensive presentation explaining that the Information Standard is a quality mark that proves: 1) A rigorous assessment and 2) Information is clear, accurate and up-to-date. We are working towards a standard over the next 15 months or so and a gap analysis will soon be completed before sending to NHS England.
	PILs are one way of communicating with patients but other mediums are available such as videos and smartphone applications.
	There are 6 standards/requirements to meet.
	<ul style="list-style-type: none"> ○ Information Production ○ Evidence Sources ○ User understanding and involvement ○ End Product ○ Feedback ○ Review
	Discussions on how to produce a PIL. Who has requested it and then it needs to be brought to the PIWG who will then decide who will lead.
	Biographies will be needed and anyone who reviews PILs will be required to fill in a Declaration of Interest form. Reviewers should review one or two at a time, not more.
	A structured template was suggested and must avoid too much unnecessary jargon. Any updates should be referenced from the evidence source. KC confirmed that there is a standard to identify levels of evidence.
	DW confirmed that the process has gone through a plain English process. Discussion over the translation into other languages but this has previously been explored and the expense was too high.
	DB-S asked what resources are available for those with learning difficulties such as induction loops. Hospitals usually have interpreters available to facilitate a greater understanding.
	NHS England's Accessible Information Standard https://www.england.nhs.uk/ourwork/accessibleinfo/ that explains the legal requirement

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	for all NHS providers.
	The importance of asking family and friends as well as Patient Representatives was noted.
	Need to look at end product and decide whether the objectives have been achieved.
	Discussions around reviews of the Information Standard took place and they should be constantly reviewed, self-certified annually with a formal review date at 2-3 years. Any comments throughout the year should be logged on QPULSE. Everyone agreed this is a good idea and needs to be actioned.
	Importance of training was highlighted so everyone is aware of the process. The review feedback should carry a strict deadline.
	Any comments on the Flow Chart are to be sent to DW by Friday, 23 June. Action: All
03/17	Consent
	Consent video https://youtu.be/sWIEON8Z9U0
	The YouTube video was discussed and it was noted that the previous comments have not resulted in the video being updated – the microwave for defrosting FFP was still pictured.
	<u>Consent workshop – 1.5 hours, Monday, 18 September 2017.</u>
	<ol style="list-style-type: none"> 1. BR – to talk about collective patient experiences and her master's research. 2. GD to discuss negative patient experience and what could be done differently. 3. Loretta to give positive patient experience on blood transfusion concerning her son. 4. DB-S to talk about how they have taken the guidelines and put them into practice. 5. Liz Tatem (South East Coast region) and ICAG Pad 6. Suzy Morton and her video and processes of its production.
	The group really wanted to promote the message of patient empowerment and the importance of putting the patient in the middle.
	The PIWG do not claim to be experts on Consent and will invite guest speakers.
	CBa will open the session and talk about SABtO, legalities - where we are up to with Consent but not Montgomery as KP has asked NHSBT solicitor, Ruth Clarke to do this and CBa will work with her prior to the meeting to avoid gaps and overlaps.
	Liz Tatem (South East Coast region) has been approached to ascertain her availability to attend the meeting and illustrate successes and challenges concerning the ICAG Pad and how they are really trying to promote areas of good practice in the hope of shared learning.
	Use Consent Video produced by Suzy Morton. KC to invite her and if she present her

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	video and talk about how she put it together.
	DB-S added that if Suzy Morton was invited she needs guidance about what we want her to talk about; is the Audit Tool working or not, what Consent means in clinical areas.
	DB-S to find out if we can use the poster presented to SHOT for this workshop. Action: DB-S.
	GD suggested Patient Experience to be valuable and offered to articulate his mother's experience as a case study.
	MC expressed concerns over language – “Top up” was not appropriate for instance.
	Montgomery issues could be explored if a slide explaining what Montgomery is.
	BR suggested a list of questions; “What am I consenting to...”. BR to talk about collective patient experiences and her Masters research.
	MC said transfusion via a surgical pathway is dealt with better whereas anaemia patients on wards do not have the luxury of time to discuss. The pros and cons of transfusion are not explored.
	GD added his daughter had minor elective surgery and he was satisfied with the explanations they received. Bedside manner is so important. Important to note negative patient experiences too. GD to present on this to ascertain how we can improve in the future.
	DB-S asked CBe for a formal invitation to attend Consent workshop to present to her line manager. CBe to contact Jonathan Wallis for PIWG to participate and share best practice. Action: CBe (or can I circulate the e-mail from Kate Pendry that I circulated during the meeting to those present? Please advise, thanks)
	DB-S to present at the workshop about how they have taken the guidelines and put them into practice.
	Tools/props were discussed. ICAG Pad (via Liz Tatem), H&S website, PILs and a display.
	Invite patients to convey personal experience. “Loretta” had been previously fearful of transfusion and did not have faith in the process but when she realised that her son's health depended on it she happily accepted. Concerns over approaching her when her son had since passed away.
	DW to present an overview of resources.
	Would expect to receive feedback and ideas for the next patient information campaign.
04/17	PILs
	3 left to review. Received positive feedback. Had two requests from Trusts who want links to the Hospital and Sciences website – not direct to a PIL.
	CBa asked how many leaflets have a low pick up rate and is this being monitored. KC said sickle cell has a low uptake and could be discontinued.
	The aim would be to always keep PILs as a free resource. DB-S added that is we start charging for PILs hospitals will try and produce their own in-house and this is not ideal, margins for error are high. Everyone agreed.
05/17	PIWG Workplan
	DW gave overview and asked for ideas on how to influence the website. A need for an IT/Comms person to be present was highlighted.

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	Discussion around NHS Choices. GD wants to know as a tax payer and a patient who is making decisions. CBa to raise at NCG meeting as NHS England will have a presence. Action: CBa
	KC has been working with Royal Colleges, RCN and RCM to raise transfusion awareness. It is about influencing the importance of transfusion education.
	Harvey's Gang initiative is growing.
	KC – remove item 4 – PIWG. Action: CBe
	DW to ascertain how many boxes of resources would need to be delivered to the venue the day before. DW to liaise with CBe on this. Action: DW/CBe.
06/17	PPID Survey
	This was cascaded to TLMs with a closing date of 23 June. CBa to present results to NBTC on 18 September 2017.
07/17	AOB
	BR mentioned a book by Ian McEwan called "Children's Act" containing reference to Paul Stevenson's chapter on blood conservation and Paul will be credited.
08/17	Date of next meeting
	CBe to arrange and circulate.

- END -