

**Blood Cancer Alliance**

**Minutes of the meeting held on Tuesday 11<sup>th</sup> February 2020**

**Members present:** Joanne Badger (JB), Leukaemia and Lymphoma NI; Julie Child (JC), Race Against Blood Cancer; Amelia Chong (AC), Anthony Nolan; Dawn Farrar (DF), Leukaemia UK; Caitlin Farrow (CF), Anthony Nolan; Alan Miller (AM), DKMS UK; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Dave Ryner (DR), CML Support Group; Stephen Scowcroft (SSc), Lymphoma Action; Angela Smith-Morgan (ASM), Leukaemia UK; Christopher Walden (CW), Bloodwise.

**Dialling In:** Daniel Cairns (DC), Myeloma UK.

**Guest Speaker:** Greg Judge (GJ), Anthony Nolan.

**Apologies:** Lindsey Bennister (LB), WMUK; Ira Laketic-Ljubojevic (ILL), Myeloma UK; Orin Lewis (OL), ACLT; Steffi Sutters (SS), CLL Support Group; Sophie Wintrich (SW), MDS UK Patient Support Group.

**Atlas Partners Secretariat (AP):** Katie Begg (KB), Bethan Phillips (BP), Mike Hough (MH).

No.	Agenda Item	Minutes	Actions
1	Welcome	<p>Introductions made and minutes agreed.</p> <p>New Memorandum of Understanding agreed and signed.</p>	<p>AP to upload November minutes to the website - <b>Complete.</b></p>
2	Secretariat update	<p>MH explained progress since last meeting had focused on:</p> <ul style="list-style-type: none"> <li>• Organising the Industry Partners Forum</li> <li>• Co-ordinating the appointment of a new research partner</li> <li>• Securing support from pharmas</li> <li>• Drafting letter to new Northern Ireland health minister</li> <li>• Sharing drafted parliamentary written questions with Angela Burns AM</li> </ul>	

		<ul style="list-style-type: none"> <li>• Confirming application of new member; Race Against Blood Cancer</li> </ul>	
3	Members update	<p>SS invited members to set out their priorities for the year:</p> <ul style="list-style-type: none"> <li>• DR outlined CML Support will be focusing on access to treatments – usual clinical questions and treatments.</li> <li>• ZPW said Leukaemia Care will be concentrating on the access to treatment and NICE methods review and the resulting implications.</li> <li>• AM indicated DKMS will be focused on NICE methods review, looking at building a strategy around BAME engagement and that they are on schedule for their 10 millionth donor this year.</li> <li>• ASM said Leukaemia UK will have an internal focus following the merger and deciding on the role going forward for the charity.</li> <li>• JB confirmed Leukaemia and Lymphoma Northern Ireland will be focusing on a new research package they have given to Queen’s University Belfast, supporting the NI Cancer Strategy and engaging with the new Northern Ireland Assembly.</li> <li>• CF suggested Anthony Nolan was looking specifically at equality of process and how we talk about blood cancer and stem cell transplantation.</li> <li>• CW established Bloodwise will be looking at early diagnosis and ongoing research in regard to rapid diagnostic services and CPES.</li> </ul> <p>DF entered and introduced herself.</p> <p>SS outlined that Lymphoma Action policy priorities are aligned to the three key BCA priorities.</p>	<p>AM to update on timeline for 10 millionth donor - <b>Ongoing.</b></p>

		<p>DC joined the call.</p> <ul style="list-style-type: none"> <li>• DC spoke of Myeloma UK's plans for the year which concentrate on the heavy access workload and working on Rapid Diagnostic Services and with NICE on methods process review.</li> </ul>	
4	Future funding	<p>BP updated the group on recent conversations with pharma's and the latest funding figures, outlining that since the last meeting BCA had secured funding commitments from Incyte (£15,000), Sanofi (£15,000) and Kyowa Kirin (£7,500).</p> <p>KB explained the current BCA priorities were as follows:</p> <ul style="list-style-type: none"> <li>• Producing a policy report on barriers to access to new medicines and treatments for blood cancer patients</li> <li>• Launching a policy campaign based on access to treatment policy report evidence and calls to action</li> <li>• Unmet needs in blood cancer project</li> </ul> <p>KB asked for feedback and whether members were still happy with the priorities.</p> <ul style="list-style-type: none"> <li>• AC asked whether the report will be live before BCAM and if BCA was looking at producing some high-level messaging for BCAM 2020. KB replied the BCA leadership was having an ongoing conversation about BCAM and that September might be a good month to launch a campaign. SS confirmed report will be completed by September.</li> <li>• DR questioned if the report will feature the NICE methods review. KB verified the research project</li> </ul>	<p>BCA leadership and secretariat to discuss plans for how to divide up BCA funds between three priority areas - <b>Ongoing</b>.</p>

		<p>includes an interim report which will help form BCA's response to the review.</p> <ul style="list-style-type: none"> <li>• CW raised concerns about BCAM plans and activities in previous years. KB also spoke about problems the secretariat had experienced in co-ordinating with Janssen.</li> <li>• KB then discussed the possible unmet needs project and how this would need to identify data gaps and could lend itself to a project.</li> <li>• AC questioned the current status of the Blood Cancer dashboard. ZPW and SS believed it was being actively updated. KB mentioned we could discuss it further at Industry Partners Forum.</li> </ul>	<p>AP to draft a brief on unmet needs reflecting conversation in quarterly meeting - <b>Ongoing</b>.</p>
5	<p>Discussion on research partner</p>	<p>KB confirmed the appointment of Leela Barham (LB) as the BCA's research partner. KB introduced a couple of questions for members from LB. Firstly, whether BCA members would be happy to send recommendations of key materials for literature review. KB opened the floor to remarks.</p> <ul style="list-style-type: none"> <li>• DR highlighted several suggestions including documents from BPAS, NICE and IQVIA.</li> <li>• SS queried whether a summary from LB's proposal and approach could be shared with members. KB answered that Leela will be focusing on desk-based research, external stakeholder interviews and interviews with the BCA as well as ad-hoc opportunities to engage.</li> </ul> <p>KB moved to ask on behalf of LB whether members would be happy to join and share an online survey of patients and if so what kind of materials will be needed:</p>	<p>DR to send through some links for reading materials – <b>Complete</b>.</p> <p>AP to share overview of Leela's preferred approach and ways of working – <b>21/2</b>.</p>

		<ul style="list-style-type: none"> <li>• AC indicated it would be helpful to know the timeline and that there may be questions about GDPR. KB agreed and suggested this needed to be considered.</li> <li>• AC believed the survey should be clear on intended participants and suggested the best responses would come from their patient email list. CF argued a one pager could be produced.</li> <li>• ASM asked for a rough timeline on the online survey project. KB said it would likely be completed by the end of April.</li> <li>• KB asked about ongoing member research. DC highlighted Myeloma UK had recently completed a survey on access and would be happy to share results when analysed.</li> <li>• CW questioned the current timeline for the completed research report. KB replied the report will be ready by the summer but there is flexibility.</li> <li>• DC asked whether the report would focus just on England or on the whole of the UK. KB reiterated the report will look at the whole of UK.</li> </ul> <p>KB moved the conversation to the NICE methods review and whether members had any early insights:</p> <ul style="list-style-type: none"> <li>• DR argued the review had changed a lot since initial launch and that there are going to be several challenges. The key tension is the drive towards alignment and that suggested big changes are likely to be frustrated. ZPW concurred with this prognosis and questioned whether NICE had the authority to implement the changes.</li> </ul>	<p>AP to confirm timeline for project – <b>Ongoing.</b></p> <p>AP to share information for patient survey- <b>Ongoing.</b></p>
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		<p>JC entered the meeting.</p> <ul style="list-style-type: none"> <li>• DR returned to problems of the appraisal programme. ZPW highlighted the current conversations happening within NICE.</li> <li>• It was raised that NICE is trying to protect its independence within the scope of the review. But also that NICE does not have power to make any substantial changes as it cannot change VPAS – only the DoH can do that.</li> <li>• CW asked about Cancer Drugs Fund (CDF). DR suggested that based on the Conservative Party manifesto, there could be significant changes and a dilution of the CDF within the new Innovative Medicines Fund. This is of particular concern given that over 50% of CDF drugs are blood cancer drugs.</li> <li>• KB asked whether drugs can transfer from CDF funding to being routinely commissioned by NHS England. ZPW confirmed medicines are funded through CDF on an interim basis before being reappraised by NICE and if approved, moved to baseline commissioning. DR also raised previous pressures with NHS England drugs budget and that it will be cost that is a barrier to this.</li> <li>• KB questioned whether the NICE methods review will deal with the future of the CDF. DR indicated the review will have to deal with the CDF.</li> <li>• AC suggested it will be beneficial to have a little more clarity on CDF's future and could maybe use this as an opportunity to ask some parliamentary questions. CW shared that Bloodwise had tabled some PQs through Clive Betts MP.</li> <li>• ZPW later queried what we will do with the interim report. KB indicated that we could go public with the</li> </ul>	
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		<p>findings if we feel it is necessary – via press or Parliamentary questions.</p> <p>MH introduced JC.</p> <ul style="list-style-type: none"> <li>• DR asked whether the research report should include Brexit.</li> <li>• ZPW said from his experience there is an ongoing conflict between NICE and the Task and Finish groups.</li> </ul> <p>KB asked members if there were any areas NICE isn't looking at:</p> <ul style="list-style-type: none"> <li>• SS raised the narrowing of the Task and Finish groups.</li> <li>• ZPW believed that the review on HST needs to be prioritised.</li> </ul> <p>JC introduced herself and the work of Race Against Blood Cancer.</p> <p>The meeting broke for a short comfort break.</p>	
6	Industry Partners Forum	<p>MH updated on the Industry Partners Forum and plans for the day. KB reiterated the day is designed to be informative.</p> <p>DC confirmed there will be an attendee from Myeloma UK, AM confirmed there will be an attendee from DKMS UK, ZPW confirmed his attendance as did CW.</p> <p>AC asked whether there will be time to debrief at the end of the day. ZPW suggested a debrief call after the meeting.</p>	<p>AP to send through agenda for meeting – <b>Complete.</b></p> <p>AP to send through list of attendees – <b>9/3</b></p> <p>AP to organise pre-briefing phone call and post-meeting call - <b>Ongoing.</b></p>
7	Parliamentary engagement	<p>MH explained that over the next month, the secretariat will be focusing on producing an updated political audit and</p>	

		<p>highlighted that since the last meeting, the following activities have been completed:</p> <ul style="list-style-type: none"> <li>• Drafted new written questions for Angela Burns AM.</li> <li>• Drafted and sent new letter to Northern Ireland Health Minister.</li> <li>• Conducted ongoing conversations with Jim Shannon's office.</li> </ul> <p>AC raised that Anthony Nolan were in discussions with Mark Tami MP about an adjournment debate.</p> <p>CW confirmed the APPG on Blood Cancer had been relaunched and that there was a new timeline for the inquiry on genomics. He questioned whether the BCA would submit to the inquiry. KB asked for volunteers to draft a response. CW confirmed he will come back with possible suggestion.</p> <p>CW highlighted that the membership of the APPG had stayed the same and that Jason McCartney MP had attended the AGM. AC also confirmed the APPG for Stem Cell Transplantation had been re-established and discussions were ongoing about an upcoming evidence session on equity of access.</p>	<p>CW to share information on APPG report – <b>Complete.</b></p> <p>AP to share information with Friday monitoring email – <b>Complete.</b></p> <p>AP to add Jason McCartney MP to political audit - <b>Ongoing</b></p>
9	Devolved nations update	<p>AC initiated proceedings by raising the Wales Cancer Alliance and their meeting with Vaughan Gething AM. The major priority is securing a new Cancer Plan.</p> <p>DC highlighted there had been developments into the following areas in Scotland:</p> <ul style="list-style-type: none"> <li>• Inquiry into supply and demand of medicines in Scotland.</li> </ul>	



		<ul style="list-style-type: none"> <li>• The new ultra-orphan pathway.</li> <li>• The finalising of the Scottish Cancer Coalition’s plans for the coming years.</li> </ul> <p>JB fed back on progress in Northern Ireland:</p> <ul style="list-style-type: none"> <li>• There is a huge backlog of work in Northern Ireland meaning it is hard to secure a meeting.</li> <li>• There is currently no mention of blood cancer within the cancer strategy.</li> </ul> <p>DR asked about a Brexit deal and its impact on Northern Ireland. JB believed it will remain the same as mainland UK.</p> <p>AC then asked what is the best way to stay on top of the developments. JB said she will send a link to the mailing list.</p>	<p>DC to share relevant information from inquiries for MH to distribute to the members – <b>Ongoing.</b></p> <p>JB to share link to mailing list with AC – <b>Ongoing.</b></p>
10	AOB and Close	<p>BP confirmed AP will be designing and making fliers for BSH event which will be shared with members. ZPW suggested fliers could be sent to their office. SS raised the charity village and how it is now free for charities to have a presence.</p> <p>DR asked whether the BCA is going to put a response into the NICE review and that this represented a chance to differentiate the BCA. SS affirmed the BCA will.</p> <p>SS introduced the discussion around Google Ads and welcomed GJ. GJ updated on the current situation mentioning:</p> <ul style="list-style-type: none"> <li>• There has been an increase in unregulated clinics due to a loophole in the current regulations. The FDA was putting pressure on Google to cease these promotions.</li> </ul>	<p>AP to share leaflets with members when completed – <b>Ongoing.</b></p>

		<ul style="list-style-type: none"><li>• Google had then developed a policy which inadvertently banned all mentions of stem cells in advertising.</li></ul> <p>GJ concluded that a letter from the BCA could be a useful next step and that different digital teams had been communicating. KB suggested that although this could not presently be a secretariat priority, BCA materials could be shared.</p> <p>ZPW asked whether there was a plan to do anything on social media. GJ said this was definitely an option.</p> <p>AC then raised a recent meeting between Anthony Nolan and Professor Peter Johnson (new National Cancer Director) and highlighted that the discussions had focused on the following:</p> <ul style="list-style-type: none"><li>• The importance of early diagnosis and investing in research.</li><li>• Professor Sir Mike Richard's review of children cancer services.</li><li>• How NHS England can work with relevant stakeholders.</li><li>• The current targets and their potential impact on the ground.</li></ul> <p>DR asked whether the cancer strategy was discussed. AC said there had been no formal wrap up and that the Long Term Plan is the only thing being discussed. CW said this was also consistent with his conversations.</p> <p>SS concluded by confirming this was his last meeting as chair and highlighted some achievements from the last year including:</p> <ul style="list-style-type: none"><li>• Securing new funding and partners.</li></ul>	<p>AP to share necessary resources with GK – <b>Complete.</b></p> <p>AP to share summary highlighting achievements from the last year – <b>Ongoing.</b></p>
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		<ul style="list-style-type: none"> <li>• Working on the Blood Cancer dashboard.</li> <li>• Increased engagement with parliamentarians.</li> <li>• Expanding the reach of members.</li> </ul> <p>KB, MH, ZPW all thanked Stephen and ZPW confirmed Stephen would still be involved in the BCA leadership team going forward.</p> <p>The meeting concluded.</p>	
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**Next Meetings**

Date	Agenda
Tuesday 12 May	TBC