

Blood Cancer Alliance

Minutes of the meeting held on Wednesday 13th November 2019

Members present: Joanne Badger (JB), Leukaemia and Lymphoma NI; Amelia Chong (AC), Anthony Nolan; Nigel Gordon (NG), DKMS; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Stephen Scowcroft (SSc), Lymphoma Action; Christopher Walden (CW), Bloodwise.

Dialling In: Shelagh McKinlay (SM), Myeloma UK; Steffi Stutters (SSt), CLL Support.

Apologies: Lindsay Bennister (LB), WMUK; Orin Lewis (OL), ACLT; Dave Ryner (DR), CML Support Group; Angela Smith-Morgan (ASM), Leukaemia UK; Sophie Wintrich (SW), MDS UK Patient Support Group.

Atlas Partners Secretariat (AP): Katie Begg (KB), Nina Doehmel-Macdonald (NDM), Bethan Phillips (BP), Mike Hough (MH).

No.	Agenda Item	Minutes	Actions
1	Welcome	Introductions made and minutes agreed.	AP to upload August minutes to the website once approval has been attained from James Holloway, Greg Sutherland and Laleh Safinia who joined previous meeting – 22/11
2	Secretariat update	<p>NDM and MH explained progress since the last meeting had focused on:</p> <ul style="list-style-type: none"> • Completing pharma applications and securing funding • Organising meetings with parliamentarians and drafting written questions • Applying to join the Wales Cancer Alliance • Producing response to the Scottish CPG Cancer Survey • Arranging meetings with DKMS re: becoming a member of the BCA. 	

3	Future funding	<p>SS updated the group on recent conversations with pharmas, explaining the BCA had secured funding from Gilead (£25,000), Janssen (£15,000) and Takeda (£15,000) to date.</p> <p>SS also raised explained the remaining warm leads and opened up the floor to questions:</p> <ul style="list-style-type: none"> • AC asked whether the BCA had a current financial projection. NDM responded that the BCA year ran from August 31st to September 1st and that the BCA has a rolling budget. • CW recommended adding a new colour for warm leads in the pharma spreadsheet and asked how the funding process could be more straightforward in the future. SS believed that going forward the funding process would be easier as pharmas were more aware of the BCA. <p>NG joined meeting.</p>	<p>AP to send updated pharma spreadsheet to members – complete</p> <p>AP to update pharma spreadsheet to highlight warm leads - complete</p>
4	BCA activity	<p>KB updated the group on the current BCA workplan, introduced the Industry Partners proposal and reiterated that the aim was to send the document to partners as soon as possible. The proposal would be accompanied by a Save The Date invite for the first meeting.</p> <p>KB thanked members for feedback and asked if there were any new comments:</p> <ul style="list-style-type: none"> • SSt raised concerns over the 7 minute limit for partner presentation and suggested this should be extended to 10 minutes. KB agreed to amend the document. • AC suggested it was important to communicate that partners would have no control over BCA activities. KB confirmed presentations would only be informative and 	<p>AP to update proposal to reflect new presentation length limit – 15/11</p>

		<p>recommended setting aside time at the end of the meetings where BCA members could discuss agreed actions without the partners present.</p> <ul style="list-style-type: none"> • SSc hoped the meetings would offer an incentive for other partners to support the BCA. • SM questioned whether all partners would be in the room for all presentations. SSc clarified that they would. • SM indicated she was uncomfortable with two sets of minutes being produced, believing there should only be one set of minutes. SM suggested as a potential solution; there could be one set of publicly available minutes and a further confidential note if needed. • CW asked if the industry partners meeting was an idea from pharma. SS responded this was a BCA idea. <p>KB progressed the conversation to the research tender document and emphasised the planned report would look into access to medicines and treatments for people with blood cancer. KB asked if there was any feedback:</p> <ul style="list-style-type: none"> • SSc thanked CW for leading on the document and said he was keen to progress the process. KB said she was hopeful potential bidders could provide further guidance on the timeline. • AC recommended asking potential partners to deliver an interim report coinciding with the NICE review. KB agreed and said the document would now reflect this. • AC added that within the report there should be an outline of expected deliverables. KB said she expected the report to include recommendations the BCA could unite behind. 	<p>AP to update Industry Partners Proposal to reflect conversation on minutes – 15/11</p> <p>AP to amend Research Tender document to include note on producing interim report – 15/11</p>
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		<p>as more money became available the BCA could commission individual reports on the devolved nations.</p> <ul style="list-style-type: none"> • ZPW intimated the answer depended on the nature of the report. KB said it was her view that this should be a 'state of play' report. • AC asked whether we could tighten up the research tender document. KB argued we could amend the document to ensure the sole focus was on Government. <p>SSc highlighted the other BCA priorities and plans around CPES data. ZPW recapped the suggestion involved taking existing data, looking at different cuts and then comparing with other data sets. The purpose of the research would be to highlight how the system isn't working for blood cancer patients.</p> <p>KB believed it was important that any future work showcased the difference between blood cancer and other types of cancer. This could be packaged up through cuts of CPES data and use of the Blood Cancer Dashboard. A future BCA project could focus on 'Unmet Needs', and pull together all existing data. This could form the next priority in 2020/21 following the policy report. JB believed having long term priorities could be beneficial in conversations with partners.</p> <p>SM advanced the conversation to the Scottish Parliament's Health and Sport inquiry into the supply and demand of medicines and suggested the inquiry offered a chance to build on the BCA's engagement in Scotland.</p> <p>SM asked whether members agreed the BCA should submit to the inquiry. There was widespread agreement the BCA should produce a submission. SM requested that members feedback</p>	<p>AP to produce new document outlining future priorities if further support is received - ongoing</p> <p>Members to send relevant information to SM re: supply and demand of medicines inquiry – 15/11</p>
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		<p>comments by the end of the week, given the impending deadline.</p> <p>SSt followed by raising a recent King's Fund roundtable. SSc confirmed he had represented the BCA but no written summary had yet been provided. SS added a phone call was now planned on the 19th November to decide the next steps.</p> <p>SSt left the meeting.</p>	<p>SS to feedback on agreed actions from King's Fund roundtable after phone call – 19/11</p>
5	BCAM 2019	<p>SSc introduced the next session on BCAM 2019 and asked for comments from members:</p> <ul style="list-style-type: none"> • CW expressed frustration that due to limited communication with Janssen, Bloodwise had ended up in the same place as last year. • AC added that due to the nature of the campaign this year, Anthony Nolan felt they couldn't support it. • NG discussed DKMS activities during BCAM 2019 and how they had focused on supporting campaigner Peter McCleave. The campaign was successful and led to the registry of around 30,000 new donors to the registry and £25,000 in donations. <p>KB concluded that in future the BCA did not have to rely on Janssen and could devise their own ideas.</p>	<p>Members to provide feedback to Janssen about need for better coordination - ongoing</p>
6	Parliamentary engagement	<p>SSc updated on his meeting with Angela Burns AM. He explained the meeting had been productive and that Ms Burns is willing to support the BCA.</p> <p>NG fed back on his meeting with Jim Shannon. He confirmed Jim is fully on board with BCA priorities and is prepared to engage through written questions and by writing to the Minister.</p>	<p>AP to follow up with Angela Burns AM office – 29/11</p> <p>AP to reconnect with Jim Shannon after General Election – 17/12</p>

		<p>Since the last meeting, SM updated she had met with Miles Briggs MSP, Alex Cole-Hamilton MSP, David Stewart MSP and Brian Whittle MSP. SM added the parliamentarians were willing to submit drafted written questions.</p> <p>AC provided feedback from the Wales Cancer Alliance meeting on 26th September. The meeting featured a presentation from Dr Briggs highlighting CAR-T announcements. Going forward, the key output would originate from a sub-group which is focusing on developing a consensus around a future cancer plan. The meeting with the Minister had also now been moved to Monday 16th December. AC confirmed she could no longer attend.</p> <p>MH raised the current political environment and future engagement. KB suggested holding off further engagement until after a new Queen's Speech in January.</p> <p>CW updated the group about the Blood Cancer APPG and confirmed the inquiry into genomics had been postponed. CW added conversations were ongoing about a new chair if Henry Smith is not re-elected in the General Election. Colleen Fletcher was suggested as a possible alternative.</p>	<p>SM to draft written questions for parliamentarians to submit - ongoing</p> <p>Members to update if they can attend the meeting with the Minister – 10/12</p> <p>AP to produce updated political audit after the General Election – February 2020</p>
7	Devolved nations update	<p>JB explained that due to the current political situation in Northern Ireland there had been limited progress in many areas and that they were no further forward with Cancer Drugs Fund.</p> <p>SM briefly updated that the Scottish Cancer strategy was being updated. SM added a new fast track process in regards to the ultra-orphan pathway was progressing.</p>	<p>SM to send through minutes from latest PINS meeting - complete</p>
8	AOB and close	<p>SS asked about the BSH annual scientific meeting in 2020 and whether there was a desire to have a BCA presence at the</p>	

	<p>meeting. ZPW suggested BSH might not be charging for individual charities and that Leukaemia Care would be happy to help if needed.</p> <p>ZPW highlighted that Leukaemia Care had been selected by The Daily Telegraph for their Christmas appeal and asked whether this could be an opportunity to share BCA messaging.</p> <p>SSc raised the One Cancer Voice manifesto and the mentions of blood cancer and added he had been invited by Takeda to attend The Economist's War on Cancer event. He asked whether any other members would be willing to attend, given he is not able to attend.</p> <p>MH highlighted an upcoming Gilead roundtable on the NICE methodology review on 15th January, and explained that all members are invited to attend.</p> <p>AC concluded by asking if anyone was responding to NHS commercial framework consultation for medicines. ZPW and SM suggested they were.</p>	<p>AP to look into securing a stand - ongoing</p> <p>AP to discuss publication of relevant messaging in Telegraph – 01/12.</p> <p>Members to discuss using their social media channels to show support for manifesto - complete.</p> <p>Members to update AP on whether they would like to attend roundtable - ongoing</p>
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Next Meetings

Date	Agenda
Tuesday 11 February	TBC
Tuesday 12 May	TBC