

**Blood Cancer Alliance**

**Minutes of the meeting held on Tuesday 6<sup>th</sup> August**

**Members present:** Amelia Chong (AC), Anthony Nolan; Orin Lewis (OL), ACLT; Jo Nove (JN), Myeloma UK; Stephen Scowcroft (SS), Lymphoma Action; Angela Smith-Morgan (ASM), Leukaemia UK; Steffi Sutters (SSu), CLL Support; Christopher Walden (CW), Bloodwise; Sophie Wintrich (SW), MDS UK Patient Support Group.

**Dialling In:** Joanne Badger (JB), Leukaemia and Lymphoma NI; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Dave Ryner (DR), CML Support Group.

**Apologies:** Lindsay Bennister (LB), WMUK; Shelagh McKinlay (SM), Myeloma UK.

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

**M & F Health:** James Holloway (JH), Greg Sutherland (GS).

**Janssen:** Laleh Safinia (LS).

No.	Agenda Item	Minutes	Actions
1	Welcome	Introductions made and minutes agreed.	AP to upload May minutes to the BCA website once approval has been attained from Professor Jo Martin who joined the May meeting – <b>Complete</b>
2	Cancer Dashboard Project	JH and GS joined from M & F Health. LS joined from Janssen. SS introduced JH, GS and LS.  JH, GS and LS introduced the project. JM spoke about the progress in the development of the cancer dashboard and highlighted the following:	JH and GS to share presentation with BCA membership once approved by Janssen's internal approval process – <b>ASAP</b>

		<p>The Cancer Dashboard has been developed as a response to recommendations made in the NHS Long Term Plan. The primary aim of the project is to ensure all existing data is grouped together in one place.</p> <p>The project would primarily look at these 8 fields:</p> <ul style="list-style-type: none"> <li>• incidence,</li> <li>• mortality,</li> <li>• prevalence,</li> <li>• route to diagnosis,</li> <li>• time to diagnosis,</li> <li>• waiting times,</li> <li>• survival engagement,</li> <li>• patient engagement.</li> </ul> <p>The project has received a positive response from NHS England and a meeting is being organised to discuss the project.</p> <p>There is a desire to launch the project as soon as possible. Currently the team are working towards a September launch. Following the launch there will be an opportunity to develop the dashboard and input or suggest further data sources on a quarterly basis.</p> <p>Some data within the dashboard still needs to be updated.</p> <p>SS thanked JH and opened the floor for questions.</p> <ul style="list-style-type: none"> <li>• SS asked about how the team had defined blood cancer and whether it would be possible to have a common baseline throughout the data sets. JH</li> </ul>	
--	--	---	--

		<p>suggested that at this stage they will be using the data that is available and more detailed versions can be developed further down the line.</p> <ul style="list-style-type: none"> <li>• KB asked the team to clarify what is meant by various DK definitions. ZPW explained that they relate to specific haematological malignancies.</li> <li>• ZPW explained that not having a consistent definition of blood cancer across all data sets is problematic and there is a need to define what is meant by blood cancer at each stage. JH explained this was not an issue that could be fixed currently, and the main priority is to release the data as soon as possible.</li> <li>• ZPW asked what the waiting times details were based on. JH said they were not based on ICD10 codes and would confirm their basis separately with ZPW.</li> <li>• SW questioned whether there is potential to add new data from different sources. JH clarified they would always be happy to receive new data sources but didn't think any new data could be added ahead of the upcoming launch.</li> <li>• SSu suggested that certain datasets are currently missing. She also explained that she was concerned about the ambiguity around the data which shows how many times a patient has seen a GP before diagnosis is calculated.</li> <li>• SW highlighted that the dashboard should show where the data has originated from. JH reiterated that the</li> </ul>	<p>JH to follow up with ZPW regarding waiting time data - <b>Ongoing</b></p>
--	--	---	--

		<p>immediate priority is to get as much data out there as possible.</p> <ul style="list-style-type: none"> <li>• SSu said there was a need to be aware of errors and gaps in the data but also said she supported the launch. JH explained the dashboard could keep growing as more data becomes available.</li> <li>• KB asked whether NHS England had been consulted on the development of the dashboard. JH explained that they are in communication with NHS England about the project and welcomed BCA member involvement in any future meetings. JH also mentioned the upcoming King’s Fund roundtable in October and encouraged BCA members to attend.</li> <li>• CW questioned whether it is possible to use the data in a league table format. JH explained this would not be possible in all sections but there would be an opportunity in certain sections. LS agreed. CW responded, saying that this could be a good way of holding NHS to account.</li> <li>• CW then asked if it was possible to break the data down by gender and ethnicity. GS said it would be possible in some areas but not all areas and was something that would be worth considering going forward.</li> <li>• SS raised the possibility of the BCA hosting the dashboard on bloodcanceralliance.org. GS confirmed a standalone website had been created but that they are keen for a link to be included on the BCA website.</li> </ul>	<p>JH to update SS re: meeting with NHS England – <b>Ongoing</b></p>
--	--	--	--

		<ul style="list-style-type: none"> <li>ZPW questioned whether all updated versions of the dashboard would need Janssen approval. GS said future updates would not require the same level of sign off.</li> </ul> <p>JH, GS and LS left the meeting.</p>	
3	Secretariat update	<p>KB thanked SM and DR for their comments on the messaging document and confirmed it is now final and would be shared with members.</p> <p>NDM confirmed AP will continue to update the website as needed.</p>	<p>AP to share finalised messaging document with members - <b>16/08/2019</b></p> <p>AP to produce a concise messaging document to be uploaded on the website – <b>Ongoing</b></p>
4	Future funding	<p>SS updated the group on recent conversations with pharmas, explaining there had been a good response to date. Donations to the value of £40,000 have been received from Gilead (£25,000) and Janssen (£15,000). AP have completed full applications for funding from the Astra Zeneca, Pfizer, Takeda and Celgene.</p> <p>The funding received has reached the required level (£35,000) allowing the secretariat to continue for 12 months. SS raised that the industry partners meeting suggestions were included in the funding proposals that had been shared with pharmas.</p> <p>NDM asked about examples of industry partner models. SW highlighted the following examples:</p> <ul style="list-style-type: none"> <li>Haematology cab model</li> <li>Lymphoma cab model</li> </ul> <p>It was agreed that an initial industry partners meeting should take place in January 2020. ZPW agreed that this sounded</p>	<p>AP to investigate and consider relevant models – <b>10/09/2019</b></p>

	<p>reasonable and that we needed to consider the current NICE review.</p> <p>CW asked whether the funding would be used for specific projects. SS said at this stage the funding received so far would specifically be used to cover the cost of running the secretariat.</p> <p>KB suggested the remaining £5,000 currently available could be used to identify data gaps as this is ongoing and relatively low cost. The next priority then depending on the funding received will be the report on access to medicine. This would require £50,000 of additional funding.</p> <p>KB questioned whether it is still the agreed view that the BCA will work with an external partner on this report and whether members are happy for this action to be progressed if further funding is received. BCA members agreed. KB reiterated that if sufficient funds are not received then AP and BCA leadership team will present an alternative activity plan at the next meeting.</p> <p>AC asked whether there is an option to do something lighter touch which fed in with the NICE methods review. KB explained that we should hear back from the four 'warm' pharma leads within the next six weeks and could then come back to the next meeting with other options.</p> <p>OL asked whether the funding is restricted or unrestricted. KB clarified that it is not restricted.</p> <p>CW discussed the recent Chief Executives meeting explaining that it was agreed the BCA should also look for non-pharma</p>	
--	---	--

		<p>funding. SS suggested that at this stage the BCA should concentrate on securing further pharma funding.</p> <p>KB asked whether the Chief Executives had any thoughts about where the new funding base could come from. ASM said thoughts were general and nothing specific had been agreed.</p> <p>AC said similar conversations are taking place in the Cancer Steering Group. Insurance and banks were some of the partners being considered. SS said we will keep broadening views but will look for the 'quick wins' first.</p> <p>SW said the BCA should also reach out to Incyte regarding funding.</p>	<p>SW to contact Incyte on behalf of BCA – <b>16/08/2019</b></p> <p>AP to share pharma spreadsheet with members with monitoring email - <b>Complete</b></p>
5	Parliamentary engagement	<p>MH updated on progress with parliamentarians and shared developments on:</p> <ul style="list-style-type: none"> <li>• Warm leads with Westminster MPs</li> <li>• Organised meetings in devolved administrations</li> </ul> <p>AC fed back on meeting with Anthony Davies in Wales and highlighted the following:</p> <ul style="list-style-type: none"> <li>• Mr Davies strongly recommended the BCA join the Wales Cancer Alliance (WCA).</li> <li>• Anthony Nolan is looking to join the Alliance and would be happy to report back. A further option would be for the BCA as an alliance to join the WCA.</li> </ul> <p>SS said he was happy for Anthony Nolan to represent the BCA in this forum.</p>	<p>AP to follow up on warm leads and share updates with BCA members – <b>04/09/2019</b></p> <p>AC to send through WCA application form and AP to complete form after receiving confirmation BCA can apply – <b>31/08/2019</b></p>

		<p>MH updated on the member Government reshuffle and the new ministers in the DHSC Department. AC then spoke about her past experience of working with Jo Churchill and that the BCA is in a good place to secure a meeting. JL asked about whether the officials in Seema Kennedy's office had remained in place.</p> <p>CW updated group on APPG on Blood Cancer's future plans.</p> <p>CW confirmed the APPG are conducting an inquiry on genomics, with a report to be published next summer. Oral evidence sessions will take place in the Autumn. Terms of reference are being updated now.</p> <p>SS then raised the NICE health technology evaluation methods report and asked whether the group has completed the online survey. SW also asked whether any members were involved in the PIN group. CW affirmed but said the status of the group didn't appear secure. SW argued NICE need to have a much stronger voice.</p> <p>SS asked whether there were any other relevant groups members should be aware of.</p>	<p>AP to draft welcome letters to new ministers when roles confirmed – <b>03/09/2019</b></p> <p>AP to investigate any potential changes in DHSC offices – <b>Ongoing</b></p> <p>CW to share terms of reference with BCA membership - <b>Ongoing</b></p> <p>BCA members to complete online survey if not already completed – <b>31/08/2019</b></p> <p>JL to discuss with SM and feed back to BCA membership – <b>31/08/2019</b></p>
6	BCAM 2019	<p>SS asked members to share what knowledge they have of Janssen's plans for BCAM 2019.</p> <p>SS believed Janssen's focus was the dashboard. Any work during BCAM 2019 would centre on early diagnosis. SS then raised the Connecting the Dots campaign and said Janssen were looking at securing a celebrity ambassador. There was potential for BCA members to be involved through the highlighting of case studies.</p>	<p>AP to share 'Connecting the Dots' presentation – <b>Complete</b></p>



		<p>CW said his understanding was slightly different and that Janssen were looking to link to new symptoms information. AC said Anthony Nolan didn't have case studies and would be taking a very light touch approach. JL said Myeloma UK were in the same position.</p> <p>SW highlighted an email she had received from Janssen asking whether the charity wanted to support the campaign. KB followed up by asking whether all members had received this email.</p> <p>ZPW confirmed he was seeing Mick from Janssen next week and will update members afterwards. He also highlighted that Janssen had produced a microsite for their BCAM 2019 work.</p> <p>SS reminded members of the previously shared draft media posts. KB asked whether the membership would prefer more generic social posts or whether they should focus on early diagnosis for BCAM 2019.</p> <p>MH mentioned he had met with DKMS. KB suggested at this stage we should not share messaging. BCA members agreed. SS highlighted that Leuka is considering joining the BCA.</p>	<p>JL to share email from Janssen and AP to circulate with Friday email – <b>16/08/2019</b></p> <p>ZPW to update after conversations with Janssen – <b>16/08/2019</b></p> <p>AP to re-share previous social media posts and draft new social media posts – <b>16/08/2019</b></p> <p>AP to update DKMS and update membership on conversations with Leuka – <b>Complete</b></p>
7	Devolved nations update	<p>SS mentioned PACS Tier-Two consultation and conversation with SM. It was agreed that on this occasion the BCA would not respond. SS then highlighted the Scottish CPG inquiry and suggested we should contribute as an alliance. KB suggested we could use information from previous consultations.</p> <p>MH highlighted update from JB re Northern Ireland that there is hope a new Executive will be formed shortly.</p>	<p>AP to draft response to the survey and share with members for approval – <b>31/08/2019</b></p> <p>AP to draft letters to relevant Northern Ireland parliamentarians when Executive is re-formed – <b>Ongoing</b></p>

8	AOB and close	<p>SS highlighted a draft letter he had received about CAR-T from a number of academics and asked whether members would support the content.</p> <p>SS raised the recent Patient View report and the Blood Cancer patient groups appendix. SW and ZPW highlighted their scepticism about the questionnaire. SS concluded by saying he had received similar feedback from the other companies involved.</p>	<p>SS to update on next stages when draft letter has been finalised – <b>Ongoing</b></p>
---	---------------	--	--

**Next Meetings**

Date	Agenda
Wednesday 13 <sup>th</sup> November	TBC
Tuesday 11 February	TBC
Tuesday 12 May	TBC