

**Blood Cancer Alliance**

**Minutes of the meeting held via Webex on Tuesday 12<sup>th</sup> May 2020**

**Members present:** Amelia Chong (AC), Anthony Nolan; Dawn Farrar (DF), Leukaemia UK; Orin Lewis (OL), ACLT; Shelagh McKinlay (SM), Myeloma UK; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Stephen Scowcroft (SSc), Lymphoma Action; Steffi Sutters (SSu), CLL Support Group; Christopher Walden (CW), Blood Cancer UK; Sophie Wintrich (SW), MDS UK Patient Support Group.

**Guest Speaker:** Leela Barham (LB), Independent Health Expert.

**Apologies:** Joanne Badger (JB), Leukaemia and Lymphoma NI; Lindsey Bennister (LB), WMUK; Julie Child (JC), Race Against Blood Cancer; Alan Miller (AM), DKMS UK; Dave Ryner (DR), CML Support Group; Angela Smith-Morgan (ASM), Leukaemia UK.

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

No.	Agenda Item	Minutes	Actions
1	Welcome	Introductions made and minutes agreed. ZPW thanked SSc for his past year as chair of the BCA	AP to upload February minutes to the website - <b>Complete</b>
2	Secretariat update	MH explained progress since the last meeting had focused on: <ul style="list-style-type: none"> <li>• Liaising with LB on the Access to Drugs Report</li> <li>• Securing additional funding from partners</li> <li>• Hosting and running the Industry Partners Forum</li> <li>• Drafting new political audit and planning engagement strategy</li> <li>• Drafting submission to Health and Social Care Select Committee inquiry into Delivering Core NHS and Care Services During the Pandemic and Beyond</li> <li>• Focusing on core activities such as reporting on developments and providing updates</li> </ul>	

3	Access to Drugs Treatment Report	<p>ZPW welcomed LB to the meeting.</p> <p>LB introduced herself to the meeting explaining her background as a health economist and expert.</p> <p>KB moved to discuss LB's current work programme, mentioning the completed literature review and draft interim report and work in progress report. KB explained the next stage of the research process will involve contacting stakeholders for interviews; those stakeholders without external COVID responsibilities will be prioritised first.</p> <p>KB added the COVID-19 outbreak has caused a delay in sending invitations to stakeholders. KB added a number of requests had been shared with stakeholders and that the letters had been sensitively drafted, but that the timeline had been impacted.</p> <p>LB expanded on the present outlook; informing the meeting that due to the outbreak of COVID-19 a decision had been reached not to directly follow up with invitees who failed to respond. LB said she was also now considering expanding the current suggested list of interviewees and asked for further feedback from members. LB explained that the initial plan focused on interviewing two members from each stakeholder group, but this may now be harder to achieve KB reaffirmed all approaches were being constantly assessed</p> <p>KB then raised the topic of patient surveys and indicated members should not feel pressurised on sharing the survey given the current climate. KB suggested it will be beneficial to receive feedback from members. KB concluded by outlining the current proposed timetable; setting out the plan to sign off</p>	<p>Members to feedback on suggested interviewee list - <b>Ongoing</b></p>
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		<p>the end report at the August quarterly meeting with a finalised draft ready in July.</p> <p>KB opened the floor to questions from members:</p> <ul style="list-style-type: none"> <li>• CW asked if any of the stakeholders had been contacted yet. LB confirmed that to date eight invites had been shared but that she did not want to overrepresent one group and was very happy to receive any additional names.</li> <li>• CW followed up by asking if there was a contingency plan should we not receive the requisite number of responses from stakeholders. KB suggested the BCA will be consistently reviewing the evidence base and that if a low proportion of responses were received, a decision will be made on whether to publish the report. LB added she was confident the report can be completed, arguing the current research already included significant new information and a stronger evidence base than previous literature. KB suggested there might be a possibility of holding off some work until next year.</li> <li>• AC questioned the current inclusion of non-submission information in the interim report and whether further evidence was needed about non-submissions; concluding she is happy to share further data if useful. KB believed this would be highly beneficial. SM confirmed she can provide more information on non-submissions and suggested adding Peter Clark to the list of interviewees. LB responded she was very happy to add Peter Clark to the list but was unclear whether he would be able to take part.</li> </ul>	
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		<p>KB progressed the conversation to discuss the appropriate timeline for the patient engagement section of the research:</p> <ul style="list-style-type: none"> <li>• SSc raised that a lot of surveys are being shared with blood cancer patients about the impact of COVID and that he recommended continuing with the proposed timelines. LB suggested a possible solution can be limiting the survey to 10 questions; focusing specifically on access to treatments. SSc followed up by asking whether questions relating to COVID-19 can be filtered out? LB answered there needed to be a discussion about the goals of the survey and suggested sharing her current draft survey with members. KB argued that given the current context, more people might be likely to reply.</li> <li>• OL asked whether the questionnaire considered gender and ethnicity, highlighting the current research on COVID-19 and BAME patients. LB believed it might be hard to achieve this whilst keeping the survey compliant with GDPR and limited to 10 questions.</li> <li>• ZPW challenged LB on the questions likely to be asked around access to treatments and drugs. LB explained it was her intention to link the questions to the medicines a GP can recommend and that more detailed questions will expand the length of the survey. ZPW added he was happy to look at draft questionnaire but was worried we will be missing an opportunity if we didn't ask questions about particular issues that patients had faced. LB suggested it might be beneficial to have a separate and longer discussion around questions.</li> <li>• SW suggested a physician wouldn't recommend a medicine that wasn't available. LB said she was</li> </ul>	<p>Members to share further information about non-submissions – <b>Ongoing</b></p> <p>LB and ZPW to organise separate conversation to discuss survey questions – <b>Ongoing</b></p>
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		<p>content to discuss the exact wording of the questions. SW added the majority of patients rely on the information they receive from their GP. SSu retorted that a number of patients from the CLL community are very aware of all the medicines that are available. SW believed these questions might be more relevant to some cancer groups compared to others.</p> <p>KB concluded it will be useful for member groups to share evidence of their experiences of challenges to treatments. LB supported this approach. KB added the next stage is for LB to share the draft survey. KB also explained it is still the intention to use this report for campaigning and that the BCA leadership is looking at an Autumn/Early Winter timeframe. An idea being considered is launching the event in Parliament. KB asked for the thoughts from members about this plan:</p> <ul style="list-style-type: none"> <li>• AC shared that in co-ordination with the APPG, Anthony Nolan (AN) had been considering digital options for launch events and are looking to see if this was a viable option going forward.</li> <li>• ZPW asked about any potential refunds for cancelled events. MH responded that the House of Lords is committed to providing full refunds and was confident the House of Commons will have a similar policy.</li> <li>• SSc argued given the uncertainty around COVID-19 an online event might be more effective. SSu raised concerns about shielding and whether members or patients will be able to attend. KB acknowledged this point and agreed that holding an event in parliament whilst shielding is ongoing would be inappropriate and that the BCA will look at other options.</li> </ul>	<p>Members to share evidence about challenges to treatments – <b>Ongoing</b></p> <p>LB to share draft survey with members – <b>Ongoing</b></p> <p>AP to explore alternative options for report launch- <b>29/5</b></p>
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		<p>ZPW moved the conversation onto the methods review and the involvement of members in the process:</p> <ul style="list-style-type: none"> <li>• CW said Blood Cancer UK (BCUK) is relying on the work of the BCA and for members to provide relevant updates. SSc concurred with this position.</li> <li>• SM revealed the modifiers task and finish group appeared to be behind others and that she did not have a lot to report back and concluded she was engaging with the process but was unclear about its current aims.</li> <li>• ZPW shared his account from the General Decision-Making Task and Finish Group; revealing he had received limited insight from the other groups and that his view was to support the BCA position.</li> </ul> <p>ZPW concluded the question and answer session and asked for any further thoughts. SSc said he would be supportive of not extending the timeline further. ZPW concurred.</p> <p>LB left the meeting.</p>	
4	Impact of COVID-19	<p>ZPW introduced the next section and questioned how members are reacting to the COVID-19 outbreak.</p> <ul style="list-style-type: none"> <li>• ZPW shared that Leukaemia Care (LC) had been focusing on addressing the questions they are receiving from patients and had been running a series of webinars. A series of tailored surveys had also been produced and shared with members. He added they had furloughed a few hospital members of staff.</li> <li>• CW added that BCUK's work which fixated on early diagnosis, emotional support and APPG on genomics, is on hold. CW also revealed BCUK is now thinking</li> </ul>	

		<p>about how to conduct remote APPG sessions and was concentrating on their support lines and responding to questions from patients about shielding and Government communications. CW concluded by highlighted ongoing work with BCUK CEO Gemma Peters on securing financial support from the Government but that the process was shrouded in uncertainty. CW added that a few members of staff had been voluntarily furloughed due to childcare issues.</p> <ul style="list-style-type: none"> <li>• SSc asked about the work of One Cancer Voice. CW responded that NHS England is now leading on the process but that it did take up a lot of his time at the start of the pandemic</li> <li>• AC said her work at AN was entirely focusing on COVID-19 and that she had been participating in weekly calls with NHS England. AN have conducted a patient survey and is actively looking at their plans for the future and how to communicate with stakeholders.</li> <li>• CW asked whether it was AC's understanding that the level of stem cell transplants will return to normality by the end of March 2021. AC explained she believed we were now past the emergency stage and are in the recovery stage. AC added 20% of the workforce has been furloughed. AC then concluded by arguing a lot of decisions are now being taken by NHS regional teams.</li> <li>• SM said at Myeloma UK the team is now about 80% COVID focused, but that the NICE review is still viewed as critical. SM added they've had two rounds of furloughing staff. SM thanked CW for his work on One Cancer Voice, adding this had been very helpful and that Myeloma UK had also been part of the NHS England calls and iso concentrating on the following tasks:</li> </ul>	
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		<ul style="list-style-type: none"> <li>○ Filling out CRUX intelligence tracker.</li> <li>○ Weekly calls with Myeloma specialists.</li> <li>○ Producing a patient survey on how people with myeloma desire to be treated in light of COVID and the impact on care.</li> <li>○ Actively thinking about the next stages for patients who are shielding.</li> </ul> <p>SM concluded by asking whether there was a messaging angle BCA can develop in regards to shielding.</p> <ul style="list-style-type: none"> <li>• AC added that if any members had any questions on stem cell transplants that they could email her and agreed with SM that messaging around shielding might be an area for the BCA to look at.</li> <li>• SSu revealed that from a CLL perspective, 20% of its membership had not received shielding letters; which is creating many issues. SSu added she was working with ZPW on questionnaires. CW asked if SSu had seen the latest letter from Peter Johnson. SSu confirmed she had seen the letter, but that it was all too late.</li> <li>• ZPW raised that Peter Johnson’s letter specifically mentioned MDS patients. SW said she will take a look at the letter; adding that MDS UK is receiving a lot of calls about shielding. SW confirmed that prior to the lockdown MDS UK was able to send out a newsletter including a range of advice and guidelines. MDS UK had also been conducting the following exercises:             <ul style="list-style-type: none"> <li>○ Writing guidelines with MDS experts.</li> <li>○ Participating in international webinars through MDS alliance.</li> <li>○ Taking part in the NHS England calls.</li> </ul> </li> </ul>	<p>Members to email AC re: any questions about stem cell transplants – <b>Ongoing</b></p>
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		<p>○ Looking into producing a survey.</p> <p>ZPW then confirmed that he had sent the letter.</p> <ul style="list-style-type: none"> <li>• OL reiterated that all at ACLT had been furloughed apart from him, but that the start of pandemic coincided with the release of the newsletter. ACLT is now trying to reassure patients in light of the new findings on BAME individuals and COVID-19 and is frustrated by the lack of clarity from Government.</li> <li>• DF said Leukaemia UK (LUK) has limited patient support and initially had been unable to cope with the bombardment of calls. DF also thanked CW for his work on One Patient Voice and added LUK was trying to share as much information as possible and is keeping in touch with clinicians.</li> <li>• SSc said that from a Lymphoma Action perspective the situation was similar. He questioned whether the BCA can do more to look at issues around COVID-19 and the BAME community. OL concurred and said there were questions and queried whether a question could be put to Government. AC said she was happy to share a link from a new research paper which showed haematological patients are more at risk from COVID-19 and looked at the difference between different communities. SSu added she has some interesting reports and could share details. OL said the more information that could be shared the better.</li> </ul> <p>KB concurred about the importance of looking into the topic, especially the psychological impact of shielding on BAME blood cancer patients and suggested the BCA can draft a letter. SW believed a line needed to be added about the</p>	<p>ZPW to share letter with SW – <b>Complete</b></p> <p>AC to share link from research paper - <b>Ongoing</b></p>
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		<p>ongoing confusion caused by the new advice. KB believed this tied into the issue of clarity and could be included in the letter. SW added that to her knowledge GPs are following NHS England advice and that MDS patients had not been placed on the official shielding list. SSu concurred; saying she had heard that some patients had not received shielding letters and are being called back into work.</p> <p>The meeting broke for a short comfort break.</p>	<p>AP to draft letter and share with members <b>Complete</b></p>
5	Funding update	<p>ZPW introduced next session.</p> <p>BP provided a funding update, confirming that since the last meeting the BCA had received funding from:</p> <ul style="list-style-type: none"> <li>• Incyte</li> <li>• Takeda</li> <li>• Celgene</li> </ul> <p>BP added that to date the BCA had raised £147,000 from 10 industry partners, sharing a graph highlighting current expenditure and outlay. BP confirmed the BCA is drafting a new letter that would be shared with partners asking about Year Three funding following a request from Janssen who indicated they will be willing to support the BCA.</p> <p>ZPW explained the rationale in asking for more funding and that the Year 2 surplus covered forecasted spend. ZPW added Gilead had also expressed a desire to support the BCA. SSc added that some of the funding is agreed on a pro-rata basis and that it was important to keep the conversation ongoing. SM asked about the graph being discussed. BP said she will share after the meeting.</p>	<p>AP to share graph from the presentation <b>Complete</b></p>

		ZPW then concluded the session.	
6	Further projects – unmet needs report	<p>ZPW introduced the next session looking at the unmet needs report highlighting that following previous discussions CW had produced a draft tender document looking at the unmet needs of blood cancer patients.</p> <p>CW suggested that the draft brief concentrated on a number of issues including:</p> <ul style="list-style-type: none"> <li>• Diagnosis</li> <li>• Treatment</li> <li>• Ongoing support</li> </ul> <p>CW said he hoped the brief would facilitate a conversation on patients experience and how blood cancer patients faced different experiences to others. CW suggested that further data needed to be added. KB responded that within the blood cancer community there are knowns, large number of known unknowns and unknown unknowns and challenges that needed to be raised. CW agreed it will be beneficial to provide greater information.</p> <p>ZPW believed the report should be about creating a robust evidence type; reinforcing the lack of data that existed in regards to blood cancer patients. KB added she believed there are many areas that had existing gaps and that the draft report could focus on these gaps. ZPW agreed and said the logical next step would be for the document to be shared and for BCA members to feedback on the draft and what was necessary.</p>	<p>AP to share draft report of Unmet Needs – <b>Complete</b></p> <p>Members to feedback on draft report- <b>Ongoing</b></p>
7	CEO group of BCA	ZPW moved to the next agenda item; raising the ongoing BCA CEO group; feeding back that they were working on the following areas;	

		<ul style="list-style-type: none"> <li>• Data sharing</li> <li>• Research</li> <li>• Patient information</li> <li>• Shared statistics</li> </ul> <p>ZPW handed over to AC:</p> <ul style="list-style-type: none"> <li>• AC highlighted that the meeting had originated as a casual conversation, but that the group is evolving to concentrate on specific workstreams and the importance of not having two separate workstreams. KB reiterated the importance of having one workstream and ensuring relevant stakeholders are not confused. AC suggested members should have oversight of what is being discussed but it was important to keep monitoring. AC suggested having this as a standing item on the agenda. ZPW agreed.</li> <li>• ZPW raised a new document from Janssen outlining the areas they are concentrating on such as new data types and would share the document following the meeting.</li> </ul> <p>SW argued it is important for us all to work more closely with the BCA CEO group. SSu endorsed this message.</p>	<p>AP to include section on BCA CEO group in future agendas – <b>Ongoing</b></p> <p>ZPW to share report from Janssen – <b>Complete</b></p>
8	Industry Partners Forum	<p>MH introduced the next agenda item and asked whether members had any feedback from the Industry Partners Forum meeting in March:</p> <ul style="list-style-type: none"> <li>• SSc said the feedback that he had received was that the meeting had been of value and that the sharing of the submission to the Health and Social Care Select Committee had been useful in maintaining dialogue.</li> </ul>	

		<ul style="list-style-type: none"> <li>• ZPW confirmed the date of the next forum will be Thursday 1<sup>st</sup> October and suggested using the next quarterly meeting to finalise the agenda.</li> <li>• SSc said he is pleased with where the BCA was and believed that the Unmet Needs report will also be beneficial in maintaining contact.</li> </ul>	
9	BCAM 2020	<p>ZPW moved to discuss BCAM 2020, raising conversations with Janssen about Make Blood Cancer Visible. ZPW added that based on previous feedback he was aware the BCA was not looking to engage in a campaign with Janssen. ZPW then asked about whether members had any existing plans:</p> <ul style="list-style-type: none"> <li>• AC argued the month can be used as an opportunity to increase awareness. AC also highlighted AN had in previous years sent a briefing to every MP and MSP on the stem cell transplant list in their constituency, but this year will be sending out a press pack and were looking at hosting a virtual APPG session. The Day of Action being considered is the 7<sup>th</sup> September.</li> <li>• SSc asked whether the BCA can say something about blood cancer and Covid-19. KB agreed saying that it was important to stay current to the conversation and debate. SW expanded on this point raising issues about blood cancer patients returning to work and the mixed messaging they were receiving from employers about shielding. OL concurred and said at this stage patients will be expecting the BCA to share up to date learnings.</li> <li>• SSu asked whether there will be an opportunity to explore a new message about shielding and that for many blood cancer patients this was not a new situation.</li> </ul>	AP to share ideas around BCAM with BCA leadership – <b>29/05</b>

10	Parliamentary engagement	<p>MH highlighted that since the last meeting, the political engagement had focused on:</p> <ul style="list-style-type: none"> <li>• Producing the updated political audit</li> <li>• Liaising with Northern Ireland health officials</li> <li>• Discussing an ongoing engagement plan in light of the COVID-19 situation.</li> </ul> <p>MH asked whether there were any questions on the audit or the political engagement programme. AC responded that AN was working out how best to run and organise the APPG in the current situation.</p>	
11	Devolved nations update	<p>ZPW introduced the standing agenda item slot on devolved nations.</p> <p>SM fed back from what was happening in Scotland highlighting the following:</p> <ul style="list-style-type: none"> <li>• Comms between cancer charities and the Scottish Government are improving after a slow start.</li> <li>• A lot of the key work happening in England was consistent with what was happening in Scotland.</li> <li>• Scottish Cancer Coalition is pressing on with research.</li> <li>• Scottish Government is conducting further research on shielding.</li> </ul> <p>SM concluded by saying she was happy to share any useful information. AC said that this information would be useful.</p> <p>AC then updated on the Wales Cancer Alliance, informing about the following:</p>	SM to share further research - <b>Ongoing</b>

		<ul style="list-style-type: none"> <li>• The Wales Cancer Alliance is meeting every three weeks and there was a call directly after this meeting.</li> <li>• Priorities for Wales are often more long term.</li> </ul> <p>AC added that the timelines were often very quick and that it would be easier to go straight to her with any further questions. AC then expanded on the situation in Stormont, explaining that it was proving hard to ensure that everything is linked up as it did not make sense to have different recovery plans. SSc said it was often very difficult to work out the different variances in the devolved nations and thanked AC for the updates.</p>	
12	AOB	<p>ZPW then concluded the session by confirming SSc had agreed to continue as a Vice-Chair following his tenure as Chair coming to an end.</p> <p>ZPW also extended the invitation to join the BCA leadership to the wider group and invited interested members to get in contact.</p> <p>ZPW raised the upcoming BCA webinar this afternoon and that it made the most sense to do this under the BCA logo. ZPW added that all are invited to attend and can email him if they needed further details. To date over 300 people had registered. The webinar is being broadcast via Zoom and Facebook Live.</p> <p>SW asked about the registration process. ZPW confirmed that the details for the registration process were included in last Friday's email and that the data would not be shared.</p> <p>ZPW brought this meeting to a close and thanked everybody for attending.</p>	<p>Members interested in joining the BCA leadership to contact secretariat - <b>Ongoing</b></p>

**Next Meetings**

Date	Agenda
Thursday 13 <sup>th</sup> August	TBC
Tuesday 3 <sup>rd</sup> November	TBC