

Blood Cancer Alliance

Minutes of the meeting held via Zoom on Tuesday 3rd November 2020

Members present: Dawn Farrar (DF), Leukaemia UK; Caitlin Farrow (CF), Anthony Nolan; Orin Lewis (OL), ACLT; Sarah Mallick (SM), Leukaemia Cancer Society; Shelagh McKinlay (SM), Myeloma UK; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Stephen Scowcroft (SSc), Lymphoma Action; Christopher Walden (CW), Blood Cancer UK; Sophie Wintrich (SW), MDS UK Patient Support Group.

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; Steffi Sutters (SSu), CLL Support Group.

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

Guest Speaker: Gemma Peters (GB); Blood Cancer UK.

No.	Agenda Item	Minutes	Actions
1	Welcome	<p>Introductions made and minutes agreed.</p> <p>ZPW highlighted the ongoing invitation to join the BCA leadership team, requesting volunteers to join the team, before moving to discuss current conversations occurring in the blood cancer leadership teams, citing possible concerns about a disconnect between what is happening within the BCA and what is happening at a senior level, posing whether there was an opportunity for greater collaboration going forward.</p> <p>ZPW then handed over to BP.</p>	<p>AP to upload August minutes to the BCA website – Complete</p> <p>BCA members to contact ZPW or secretariat re: joining the BCA leadership team - Ongoing</p>
2	Secretariat update	<p>BP reported back on activities from the last quarter highlighting the following developments:</p>	

		<ul style="list-style-type: none"> • The publication of the Access to Medicine Report and ongoing campaign. • Sharing of the tender document for Unmet Needs brief. • Welcoming Leukaemia Cancer Society to the Blood Cancer Alliance. • Participating in meetings with politicians in Westminster and across the devolved administrations. • Creating a BCA Twitter account. • Securing participation on the National Cancer Taskforce. <p>BP then moved on to discuss the last funding updates, revealing the BCA had:</p> <ul style="list-style-type: none"> • Received funding from Gilead (£20,000), Amgen (£10,000) and Kyowa Kirin (£15,000). • Confirmed funding from Janssen (£15,000), BMS Celgene (£15,000) and Takeda (TBC). • Sent letters to Abbvie, Incyte, Novartis, Sanofi and Pfizer. • Meeting confirmed with Abbvie. • Letters being drafted to Fibrogen, GSK, MSD and Roche. <p>BP then opened the floor to questions.</p> <ul style="list-style-type: none"> • SS queried the current level of Year 3 expenditure. BP explained the current graphs included only the received funding, not the confirmed pipeline funding and that the BCA is expecting to receive more support. • SM asked whether members could view an updated note, showcasing the current financial outlook and 	
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		<p>when commitments had been made from different partners. BP set out the range of different timelines from various partners, explaining the differences in process and confirmed a funding update will be shared with members.</p> <ul style="list-style-type: none"> • SM asked about transparency about funding from partners. BP established that these details are published on the website. <p>KB intimated the BCA is cautious not to commit to spending any money that had not been received, even if it had been confirmed, suggesting this might explain any discrepancies. BP also confirmed that any initial funding goes towards the base costs with additional funding being prioritised towards projects.</p>	<p>AP to share funding update with members Complete</p>
3	<p>Access to Medicine Campaign</p>	<p>KB updated on developments from the Access to Medicine campaign focusing on the virtual launch of the report, asking whether any of the members had any feedback from the event or the report:</p> <ul style="list-style-type: none"> • ZPW raised the different reactions of industry partners at the Industry Partners Forum and the launch event, articulating that the partners were more vocal at the forum than the event. KB considered a better approach for upcoming publications might be to change the timings of a launch so that an Industry Partners Forum could take place after the launch of a publication, concluding that the discussion between the two meetings were quite different. • SS suggested the feedback he had received had been largely positive but acknowledged concerns existed over the large number of recommendations. KB accepted the report included a lot of recommendations but that a decision had been taken to run a multi- 	

		<p>faceted campaign, saying that following the publication of the report there should hopefully be more clarity about the recommendations. KB concluded by agreeing that continuing to update Industry Partners is vital and that the report is being repurposed for the upcoming NICE Methods Review Consultation.</p> <ul style="list-style-type: none"> • SM built on previous interventions, focusing on how the Industry Partners Forum had only discussed industry specific recommendations and not all recommendations, asking whether in the future the BCA could release embargoed copies for new reports. • SM expanded it was interesting to see where the pushback had originated from and that there was always likely to be some friction with industry because of the report's recommendations, but that this is being handled well and she fully supported the idea of a wide ranging approach. KB concurred with these thoughts, suggesting aligning too closely with partners adds to the risk the BCA is not able to discuss the major issues. KB also disclosed discussions were ongoing with the BCA leadership about ways of communicating with industry partners about the NICE methods review, but that the BCA needed to maintain its independence. • ZPW argued this is a rare situation with industry partners being a stakeholder actively involved in the publication of the report but also a stakeholder the BCA is trying to influence, arguing it is wrong to concentrate solely on NICE or industry. <p>KB asked if any members had any further feedback.</p> <ul style="list-style-type: none"> • CF suggested it was important the BCA is able to show its independence and challenge the pharmaceutical 	<p>AP to draft consultation response to NICE Methods Review – 19/12</p>
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		<p>industry. CF also raised the NICE Methods consultation, specifically citing the topic selection and whether the BCA is planning to respond on the topic selection or wait for the major consultation. ZPW confirmed Leukaemia Care is preparing to respond to the topic selection consultation, but that the BCA could also respond, specifically looking at the recommendations around HTC and the need to champion the importance of patient involvement.</p> <ul style="list-style-type: none"> • KB promised to assess the consultation and requested for any draft submissions to be shared with her. ZPW said he is happy to share the response from Leukaemia Care. ZPW concluded by revealing Leukaemia Care will be calling for patient involvement earlier in the process and is happy for some of that information to be used in the BCA submission. <p>BP initiated the next part of the conversation, suggesting the secretariat is keen to take this opportunity to update on the Access to Medicine campaign and that going forward a monthly update will be shared with members. BP highlighted that 158 letters had been drafted and shared with a variety of stakeholders, citing:</p> <ul style="list-style-type: none"> • The securing of meetings with Alex Norris MP (Shadow Public Health and Patient Safety Minister), Brian Whittle MSP (Scottish Conservatives Shadow Public Health, Mental Health, Sport and Wellbeing Minister) and Andrew RT Davies MS (Welsh Conservative Health Spokesperson) • Responses from Professor Gillian Leng (Chief Executive of NICE), Professor Peter Johnson (National Clinical Director for Cancer at NHS England), Mr Allan 	<p>AP to draft consultation response to NICE Methods Review Topic Selection – Complete</p> <p>ZPW to share submission from Leukaemia Care – Complete</p> <p>Members to confirm if they would like to attend future meetings – Ongoing</p>
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		<p>Nixon (Special Adviser to the Health and Social Care Secretary) and Mr Jason Yiannikou (Interim Director, NHS Legislation Programme Team).</p> <p>BP also suggested as more meetings are confirmed, it would be beneficial for as many members as possible to be involved in the meetings, adding that any interested members should get in contact with the secretariat, before requesting further questions from members:</p> <ul style="list-style-type: none"> • DF asked about the timeline for the campaign. BP stated the campaign had begun in October and will end in February. • SM asked whether Professor Peter Clark had been approached. MH confirmed we will be contacting Professor Peter Clark. SM suggested focusing on non-submissions in the approach and that it represented a good opportunity to understand his thinking on the topic. BP said we will flag the non-submissions in our ongoing conversations. 	<p>AP to approach Professor Peter Clark and update members on developments - Ongoing</p>
4	Unmet Needs Report	<p>CW introduced the conversation on the Unmet Needs Tender confirming that to date we had received responses from:</p> <ul style="list-style-type: none"> • Open Health • WA Comms • Picker • Quality Health <p>CW then raised the ongoing timeline process, saying the BCA leadership is very happy for members to put themselves forward for interviews, adding the project will inform the BCA's</p>	

		<p>ongoing activity and should not necessarily be viewed as simply a public outreach interview.</p> <p>ZPW asked whether any members would be keen to join the interview process and that any interested members should contact the secretariat. CF indicated she would like to be part of the process.</p>	<p>Members to contact AP if they would like to join the interviews process - Complete</p>
5	<p>Unmet Needs Project BAME proposal</p>	<p>KB moved to provide an update on the suggested proposal, confirming the project brief is to be put together by the end of December, with January and February viewed as an appropriate time to begin the tender process.</p> <ul style="list-style-type: none"> • SS raised current discussions around health inequalities and whether this project could be used to try to bring together some of the aspects being discussed at the CEO level. KB suggested it would be helpful to understand more about these discussions. • SS revealed from his understanding the conversations included discussions on wider inequalities and questioned whether this project could be expanded to unpick wider health inequalities. OL expanded on the conversation, disclosing there has been general discussion about BAME and social equality factors at a CEO level, alongside discourse on the wider scale of health inequalities and the unmet needs. <p>KB intimated it is her recommendation for this piece of work that the aim should be the creation of a solid evidence base and that unmet needs within the BAME community is a good starting point, adding it is harder to unpick some of the wider socio-economic points, but that this could be looked at in the future.</p>	<p>AP to draft brief for the Unmet Needs Project – 19/12</p>

		<ul style="list-style-type: none"> • OL agreed and said he is keen for clear evidence about existing health inequalities rather than relying on anecdotal evidence. ZPW added that the project might examine whether support is reaching those communities and whether charities are doing a good enough job at reaching specific communities with unmet needs. <p>KB reiterated she will share a first draft of the members in December and is confident that it can be put out to tender at the beginning stages of next year.</p>	
6	Industry Partners Forum	<p>MH shared update from latest developments from our industry partners, focusing mainly on the Industry Partners Forum, revealing:</p> <ul style="list-style-type: none"> • Representatives from Kyowa Kirin, Janssen, Celgene, Novartis, Sanofi, Gilead, Takeda and Amgen had attended. • There are ongoing conversations about further support. • A number of partners also attended the launch of the Access to Medicine report. • The next meeting is scheduled for Thursday 18th March and is due to take place at The Foundry depending upon existing restrictions. • Minutes from the meeting will be shared shortly. <p>MH opened the floor for questions.</p> <ul style="list-style-type: none"> • ZPW reiterated the meeting will only take place in person if appropriate and restrictions allow. • CF said she was happy with the meeting, suggesting that some parts of the meeting were challenging but this 	<p>AP to share minutes from the Industry Partners Forum – 4/12</p>

		<p>should be viewed as a positive, but that a shorter meeting might be more appropriate. MH confirmed the BCA leadership will discuss these thoughts.</p> <ul style="list-style-type: none"> • DF asked about the BCA's current agreement with partners. MH confirmed the BCA had a set internal governance policy towards its relationship with partners. • ZPW added the key part of the governance is that the BCA maintains editorial control but that partners are offered the right to attend the industry partners forum, intimating this is a defined benefit of being a BCA partner. • SM asked about the primary focus of the meeting, querying whether it is for the BCA to update partners or if it is for partners to update the BCA. KB disclosed that for the first meeting the BCA asked members to prepare presentations on their priorities but were met with reluctance and that she envisaged the meeting as an information sharing meeting. KB said partners had been happier to discuss company specific priorities in individual conversations with BCA, suggesting that for the March meeting we look carefully at which items we would like to include. • SS said this meeting is about a two-way conversation between the BCA and partners, highlighting the March meeting where partners expressed a clear interest in the Unmet Needs project. • SW asked whether the BCA should be having one to one conversations with partners. SM returned to KB's previous recommendation, agreeing that the idea about policy topics is a good one and strikes the correct balance, indicating a possibly area of discussion could focus on the ongoing activities of the ABPI. 	
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		<ul style="list-style-type: none"> • ZPW reiterated that in previous meetings we had tried to cover the priorities the BCA is focusing on; with the intention the BCA is driving the conversation. ZPW expanded confirming partners less willing to share information collectively but could be tried with a less sensitive topic. • SW argued there is always going to be a level of sensitivity and recommended arranging further meetings outside the Industry Partners Forum. ZPW said if the BCA did want to engage individually as charities or as an alliance then this option would have to be offered to all partners. • SW responded that the BCA could offer this as an option when the need arises. KB suggested we could adopt this practice depending on the situation and that if there is a particular issue facing blood cancer patients the BCA is always happy to meet individually with the specific partner involved. <p>MH concluded by suggesting we use the next quarterly meeting to discuss the agenda for the Industry Partners Forum.</p> <p>The meeting broke for a short coffee break.</p>	
7	Parliamentary engagement	<p>MH highlighted that since the last meeting, BCA had been engaging in the following parliamentary work:</p> <ul style="list-style-type: none"> • Meeting with Alex Norris MP; Shadow Public Health and Patient Safety Minister. • Meeting with Paul Bristow MP; Member of the Health and Social Care Select Committee. • Meeting with Pam Cameron MLA; Deputy Chairperson of the Committee for Health. 	

		<ul style="list-style-type: none"> • Updated Henry Smith MP on ongoing BCA activities. • Organising further meetings with Andrew RT Davies MS and Brian Whittle MSP. <p>MH asked CW about the ongoing work of the APPG for Blood Cancer. CW suggested the work of the APPG is likely to start in the New Year but that there is an ongoing conversation occurring about shielding and is happy to raise items with Henry as and when they arise.</p> <ul style="list-style-type: none"> • CF questioned whether the BCA might be able to engage in further activities linked to the clinically extremely vulnerable, citing the lack of clarity blood cancer patients are facing. CW responded that at this stage there is no certainty about the support available to blood cancer patients, especially around furlough and work, but that DHSC should update soon. • CW suggested he could update the secretariat on developments and the BCA could then support on social. CF added that Anthony Nolan had been in contact with the chair of APPG on Stem Cell Transplantation about the tabling of written questions, raising whether the BCA could write to a number of targeted individuals. • CW expanded that Blood Cancer UK had been receiving a large number of calls, asking whether other members were facing the same situation. ZPW said Leukaemia Care had also been receiving a lot of calls and that the updated guidance will be very important. • CF added that at this stage Anthony Nolan is not receiving the same volume of calls but is worried that the most vulnerable will not be in contact and could be left behind, reiterating the most important resource for 	<p>AP to draft letters to share with health stakeholders – Complete</p>
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		<p>any vulnerable patients is having a shielding letter that could be shared with an employer.</p> <ul style="list-style-type: none"> • SS said there must be a balance between those who are happy to be shielding and those who were keen to refrain from shielding. <p>ZPW suggested when the updated guidance is released, the guidance could be circulated amongst members with the BCA drafting a new letter asking for clarity on shielding and support, then sending across to leading health stakeholders.</p> <ul style="list-style-type: none"> • SS said it is unlikely the BCA is alone in these concerns, with CW highlighting that many on NHS England often seemed unaware of these concerns. ZPW agreed, suggesting he had seen a noticeable difference in engagement between NHS England and DHSC. • SM questioned whether we could write to Fiona Walsh, outlining what the key concerns are, revealing Fiona had seemed very open to an ongoing conversation. • SM proceeded to debate the conversation around geographical disparity and the very clear strategic framework which existed in Scotland, asking about the shielding advice. ZPW confirmed that under the previous furlough scheme, being clinically vulnerable was a legitimate reason for being furloughed. <p>KB concluded by asking for confirmation from members about who they are engaging with to ensure the BCA is not replicating any existing work.</p>	<p>CW to liaise with the MHCLG departmental team - Ongoing</p>
8	Devolved nations update	<p>CF begun by discussing the work of the Wales Cancer Alliance and that the current thinking of the Welsh Government is to not have an active cancer strategy, revealing the Welsh Government is looking to produce a quality statement rather</p>	

		<p>than a strategy. CF added there is a nervousness about the lack of a strategy and that these concerns are being fed back.</p> <p>CF also raised the latest communication from Welsh Government about ensuring the NHS is open and that services are running as normal and that she will share the latest documents with the secretariat, concluding that the next meeting is on the 26th November and that members are very open to get in contact should there be any further questions.</p> <ul style="list-style-type: none"> • CW asked about the lack of a strategy and whether this is a final decision. CF confirmed she hadn't heard anymore from the Welsh Government but didn't think the conversation is over and that they are slightly overwhelmed by the ongoing pandemic work. <p>SM highlighted that the Scottish Government is working on a draft cancer plan, but is not sure when this will be released, but cited several points had been raised about including blood cancer in the document as in previous drafts there had been no mentions. SM also confirmed Gregory McNee is staying in the Scottish Government team and is likely to be the main contact going forward.</p>	<p>CF to share relevant documents with the secretariat - Complete</p>
9	Cancer Recovery Taskforce	<p>ZPW welcomed GP to the meeting, thanking her for feeding back on the Cancer Recovery Taskforce, before handing over to GP.</p> <p>GP initiated the conversation by thanking members for previous briefings and for ongoing questions, before feeding back on the first few meetings of the Taskforce:</p>	

		<ul style="list-style-type: none"> • The taskforce has a large number of members, not all of them representing charities so there are limited opportunities to contribute. <p>GP then expanded on her approach to the Taskforce, revealing:</p> <ul style="list-style-type: none"> • A focus on making two or three important points and keeping powder dry on other discussions to ensure voice is maximised. • Engaging in conversations outside of meeting where much of the work is taking place. <p>GP confirmed that to date her asks had centred on these items:</p> <ul style="list-style-type: none"> • Making sure the data on blood cancer is being shared by type. • Ensuring that the level of diagnosis, care and treatment for blood cancer recovered not just to the same level as pre-pandemic but improved beyond this level, especially with the considered focus on the second wave. <p>GP then opened the floor to questions:</p> <ul style="list-style-type: none"> • SS questioned the balance between blood cancer and cancer organisations as a whole on the taskforce, pondering what impact this had on the discussion. GP confirmed a decision had been reached to collaborate between different cancer charities and by boosting what other charities are talking about, this can allow the BCA to talk about the issues particularly important to blood cancer charities. GP added that where all charities felt 	
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		<p>strongly on a certain topic, all pushed back on concerns, indicating it is more difficult to ignore concerns if they are coming from a range of voices.</p> <ul style="list-style-type: none"> • ZPW asked about plans post April and whether the taskforce is looking at possible third waves or sufficient vaccine capacity. GP confirmed this is being considered, but she is unclear about the group's long-term role, but that the taskforce is united in believing the focus of the group should be about hitting performance measures rather than being timebound, but that this had not yet been followed through on. GP expanded there is a follow up conversation ongoing around vaccines and the taskforce is talking to the Oxford team and that Professor Johnson is amenable to these views. • OL deliberated on the attention being focused on the mental stress of patients waiting for a transplant. GP said that in the context of the taskforce there is a robust response from the cancer teams that transplants are back to the same level as last year, but that this is not necessarily reflective of what is happening on the ground. GP reflected there is concern amongst leading stakeholders of the role of charities, and a perception that charities need to be doing more to encourage patients back into the system but confirmed there is active pushback from charities who are arguing they need to be more confident about the system. • OL spoke of concerns that blood cancer is facing an uphill task to receive recognition. GP confirmed blood cancer is being raised in the group but accepted the ongoing frustrations and that certain issues are being excluded from the purview of taskforce. GP said Simon Stevens had attended the last meeting and reported his concerns that some charities were putting out 	
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		<p>messages that were then being used by people who were anti-lockdown and that messaging needed to be considered carefully, adding that giving fodder to these people is dangerous and will have a negative impact on the NHS. GP concluded by highlighting the presence of the one cancer patient at the meeting and his ability to cut through what is happening on the ground.</p> <ul style="list-style-type: none"> • SM thanked GP and CW for their ongoing work and that it was beneficial to have this conversation. SM specifically raised data and stem cell transplants and whether the system is picking up all patients, including those previously deferred. GP confirmed that officially all patients were being picked up but wasn't clear whether this is accurate. • CF highlighted the discussion around progress measures and that the current tracking of patients is missing stem cell transplants. GP concurred with these concerns and is worried that some people from the backlog group are not having treatment and asked what can be done about this. • CF retorted that NHS England is collecting backlog data which should give some indication of the current conversation. GP added she is happy to ask on behalf of the BCA at the next meeting. CF and SM suggesting catching up outside the meeting to discuss in more detail. • CW asked about the testing regime and prioritising staff within NHS England. GP reiterated staff who work with compromised patients being prioritised for testing, but that not all staff are receiving testing at the moment. GP added she had asked for confirmation at the meeting but had not received an answer and that the cancer team is in a different place to the rest of the DHSC team, 	<p>CF and SM to organise meeting to discuss backlog data - Ongoing</p>
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		<p>revealing that some within this team believed the number of false positives would be too much to handle if done on an individual and daily basis.</p> <ul style="list-style-type: none"> • GP posed what is the ratio of people working with immuno-compromised patients and suggested all needed to know about the numbers, clarifying that Henry Smith has been asking questions in parliament. • CF asked if there is a way of tracking how someone has been impacted and affected. GP argued that it is correct for the BCA to be pushing for more testing for those our patients come into contact with, adding that any feedback from members is always greatly appreciated. • SS asked about whether the same conversation is happening with the CEOs. GP confirmed she is doing a quick download after the meeting which she shares with the CEOs, with CW sharing minutes to the wider group. <p>ZPW thanked GP and CW for all of the work that is going into the taskforce and thanked GP for her time, asking if there were any additional questions or thoughts:</p> <ul style="list-style-type: none"> • GP added she is having a conversation with British Society of Haematologists and sharing relevant papers. ZPW agreed that this makes sense. • SM asked about the Oxford Risk Projection model and how it will be used in terms of clinical practice. GP said this had not been discussed at the taskforce, but that her understanding is that this is out for approval and that the plan is that it will be public facing. GP highlighted there is concern about ensuring that the way blood cancers is being scored tallies with knowledge about available data and that there needs to be a conversation about having a strategized approach to 	
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		<p>shielding but that it is not ready and being discussed. CW confirmed the committee is looking at the tool to strategize vaccinations and that there is a need to monitor these developments.</p> <p>GP left the meeting</p>	
11	AOB	<p>ZPW raised the MoU and asked whether BCA members are happy for the BCA leadership to sign on behalf of members.</p> <p>BP then asked about a possible picture for Twitter.</p> <p>The meeting concluded.</p>	MH to share picture from meeting - Complete

Next Meetings

Date	Agenda
Tuesday 16 th February	TBC