

Blood Cancer Alliance

Minutes of the meeting held via Zoom on Tuesday 11th May 2021

Members present: Joanne Badger (JB), Leukaemia and Lymphoma NI; Dawn Farrar (DF), Leukaemia UK; Caitlin Farrow (CF), Anthony Nolan; Nigel Gordon (NG), DKMS UK; Amanda Harris (AH), Lymphoma Action; Orin Lewis (OL), ACLT; Charlotte Martin (CM), Leukaemia Care; Shelagh McKinlay (SM), Myeloma UK; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Christopher Walden (CW), Blood Cancer UK; Sophie Wintrich (SW), MDS UK Patient Support Group.

Apologies: Julie Child (JC), Race Against Blood Cancer; Orin Lewis (OL), ACLT; Jane Nicholson (JN), WMUK; Dave Ryner (DR), CML Support Group; Steffi Sutters (SSu), CLL Support Group.

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

No.	Agenda Item	Minutes	Actions
1	Welcome	Introductions made and minutes agreed	AP to upload minutes from the February quarterly meeting to the BCA website Complete
2	Secretariat update	BP reported back on activities from the last quarter, highlighting work had focused on the following developments: <ul style="list-style-type: none"> • Writing to the JCVI and Matt Hancock regarding the efficacy of the Pfizer vaccine • Sharing suggested written questions regarding the Pfizer vaccine with parliamentary supporters • Leading the Industry Partners Forum meeting • Liaising with DHSC about webinar on cancer services • Confirming appointment for BAME Unmet Needs project • Managing Unmet Needs project • Sharing letter to trade unions regarding shielding guidance 	

		<ul style="list-style-type: none"> • Continuing to draft tweets for the BCA Twitter account • Sharing draft minutes from February Quarterly Meeting <p>BP then highlighted recent communication with leading trade unions, asking if members had any content, they are willing to share. CF promised to share materials after the meeting.</p> <p>BP moved on to provide an update on funding revealing:</p> <ul style="list-style-type: none"> • Confirmed year three funding of £131,295 from Gilead (£20,000), Amgen (£10,000), Kyowa Kirin (£15,000), Janssen (£15,000), Incyte (£15,000), AbbVie (£15,000), Takeda (£15,000), Roche (£15,000) and Year 2 surplus (£11,295). • £30,000 of funding is also in the pipeline • Letters had been shared with Pfizer, Fibrogen, GSK, MSD, and Amgen • Current year three expenditure of £100,435 • The year three unspent funds of £30,860 added to the £30,000 in the pipeline left total available funds of £60,860. <p>BP thanked ZPW for sharing recent Pfizer contact details, pledging to follow up with the relevant individuals. BP then opened the floor to questions, promising to also share the updated excel document.</p> <p>SM thanked BP for providing information on the Industry Partners Forum revealing internal conversations at Myeloma UK on engaging with industry, suggesting the Industry Partners Forum is viewed as a good model.</p>	<p>CF to share relevant materials with the secretariat - Complete</p> <p>AP to contact Pfizer re: Year Three Funding - Ongoing</p> <p>AP to share funding update with members - 14/05</p>
--	--	---	--

		<p>CW queried if there are stipulations on how funding secured from pharma can be used. BP responded there is a need to demonstrate all funding has been allocated.</p>	
3	Members Update	<p>ZPW welcomed AH to the meeting, revealing this is her first meeting. AH introduced herself, providing detail on her role at Lymphoma Action.</p> <p>CW initiated the next section of the agenda, detailing Blood Cancer UK's (BCUK) ongoing work on post vaccine research and efficacy of vaccine for people with blood cancer alongside the booster jab and how this might be combined with the flu vaccine. CW expanded that BCUK is working with other charities, seeking to bring together a group of researchers to research further and that BCUK is lobbying the Government to ask for further funding, revealing a meeting with Matt Hancock and conversations with his special adviser.</p> <p>CW progressed to update on the work of the APPG for Blood Cancer, detailing a suggestion from Lord Mendelsohn that the APPG should conduct a short inquiry into post-COVID recovery and how the NHS is going to improve its care of blood cancer patients. CW stated the next stages of the inquiry is to hold meetings with parliamentarians and arrange oral evidence sessions with the aim of completing the inquiry by the end of the year. CW concluded by musing that the APPG is considering a survey, suggesting this might be carried out under the BCA banner with further details to be announced in the coming months.</p> <p>ZPW asked about timelines for feedback by on the consultation. CW indicated that he will share details of the consultation following the meeting and then provide updates.</p>	<p>CW to continue updating on progress of APPG on Blood Cancer Inquiry - Ongoing</p>

		<p>CM followed, conversing that Leukaemia Care (LC) is continuing its webinar programme with patients looking recently at antibody tests. CM added that LC is also monitoring research being conducted by other charities and responding to NICE consultations, suggesting a possible meeting with AP to discuss developments on Access to Medicine.</p> <p>SM spoke of Myeloma UK's (MUK) recent activities, beginning by discussing the launch of a third and final survey relating to covid hoping to find out more information about diagnosis and stem cell transplants and is working closely with BCUK. SM expanded that MUK is continuing to host webinars which are enjoying massively increased engagement. SM concluded by highlighting that previous concerns about the impact of alternative COVID treatments had now been resolved.</p> <p>CF stated that Anthony Nolan (AN) has now closed its third patient survey on COVID and wellbeing, thanking members who had shared information and that AN is trying to improve representation of patients from an BAME background with more tailored questions. CF revealed the APPG on Stem Cell transplantation is to launch a new report looking at barriers to access and will send an invite to the online event taking place in May, ending by saying AN's workstream is looking at how to deliver post-transplant care in the new climate.</p> <p>DF reiterated Leukaemia UK (LUK) remains committed to signposting patients to relevant information and that going forward LUK is looking to expand its policy arm and remit.</p> <p>JB intimated that LLNI's funding position remained healthy, providing an opportunity to expand the research team. JB discussed a recent meeting with Jim Shannon, revealing he</p>	<p>CW to share details of the APPG on Blood Cancer consultation – 14/5</p> <p>CM/AP to arrange a meeting to discuss Access to Medicine – Ongoing</p> <p>CF to share event invite for new APPG on Stem cell transplantation update with members - Ongoing</p>
--	--	--	---

		<p>had sent a letter to Matt Hancock outlining some concerns, but that an official response had not yet been received. JB ended by saying there is concern about the political insecurity in Northern Ireland but that progress is being made with diagnosis levels and referrals now back to a similar pre COVID level.</p> <p>SW said MDSUK is concentrating on meetings and whether to hold meetings in person with online events being very successful. SW expanded that MDSUK is looking at issues of access and inequalities in access to certain drugs and that MDSUK had hired a range of new committee members and patient engagement officers. SW moved to speak about engagement with biobanking and the lack of transparency accompanied by ongoing conversations with CPES as MDS had not been included in the data despite previous requests, suggesting this approach had created a few inroads, notably with David Bowen. SW concluded by revealing a lot of international work is ongoing, questioning whether other charities had heard from post-transplant patients on possible removal from the vulnerable person list.</p> <p>CF announced she had heard of conversations via a consultant, that there might be some changes to the clinically vulnerable list and had followed up with NHS England who denied they were looking at changes. SW added she had shared details on social media to investigate if it is more widespread and has a meeting next week with NHS England which will provide an opportunity to discuss further.</p> <p>NG revealed DKMS is planning for a return to life as normal and that on May 28th there is DKMS Blood Cancer Day, coinciding with the 30th anniversary of DKMS in Germany. DKMS is also conducting BAME research, attempting to</p>	
--	--	---	--

		<p>decipher why messages are not cutting through to these groups and is happy to share information when received. NG ended by declaring DKMS is expanding its external affairs department and bringing on new members of staff.</p> <p>AH stated Lymphoma Action (LA) has just completed its first virtual action day, taking place instead of the annual conference and that LA is starting to think of service delivery, focusing on the wellbeing aspect. AH added LA is completing work within its comms teams about patients moving at their own pace as restrictions ease, linking this with Mental Health Awareness Week. AH concluded by saying LA is conducting a survey and is presently working its way through the results, keeping a close eye on the vaccination programme.</p>	
4	Ongoing Campaigns	<p>MH introduced the next agenda item, outlining the following actions which had been completed in regard to Access to Medicine since the last meeting:</p> <ul style="list-style-type: none"> • Arranging and running meeting with NICE and following up after the meeting. • Drafting and submitting response to NICE consultation on process review and updating website. • Updating stakeholder mapping process, reaching out to members for further suggestions about organisations to contact. • Reaching out to contacts at SMC, NHS England, Velindre Cancer Centre, and Wales Cancer Network to secure a meeting. • Drafting briefing note and attending IMF Patient Groups Listening Meeting on Government plans to extend the cancer drugs fund into a new innovative medicines fund. 	

		<p>MH added the BCA is still looking for contacts from certain groups, requesting relevant information from members. MH surmised by suggesting written questions on the IMF might be an option to consider, before opening the floor to questions.</p> <p>SW raised the issue of a postcode lottery around possible drug access for MDS patients, pondering what the BCA might be able to do to examine the situation. MH recommended tabling a written question in Parliament via one of our parliamentary supporters.</p> <p>ZPW then highlighted he was joining an upcoming meeting with the Institute for Cancer Research and DHSC and will feedback any relevant information.</p> <p>KB moved to provide an update on Unmet Needs Project, the piece of research commissioned looking at identifying an evidence base for the unmet needs of blood cancer patients, confirming we are entering the final stages of the project. KB revealed Quality Health (QH) have shared a draft review structure, draft chapter, and table of contents which the BCA leadership is considering.</p> <p>KB intimated that QH is conducting analysis on CPES data which will be fed back into report and that comments from the BCA leadership will be shared with QH next week, before concluding we are expecting to see first draft of final report by the end of the month with a published report by the middle of June and that as soon as we have received the first draft a call will be scheduled and all members will be invited.</p>	<p>AP to work with SW to draft suitable written question – 21/5</p> <p>ZPW to feedback on meeting with Institute for Cancer Research and DHSC – 28/5</p>
--	--	--	--

		<p>ZPW asked whether at this stage KB needed expressions of interest in joining the call. KB suggested waiting until the first draft of the report had been received.</p> <p>KB then highlighted the next project; the impact of blood cancer on BAME population confirming that since the last meeting, the secretariat has completed the following:</p> <ul style="list-style-type: none"> • Running a tender process and commissioning ClearView to undertake research, basing the decision on ClearView’s record of engaging different groups. • Agreeing and running a kick off meeting with ClearView. <p>KB then outlined ClearView’s plans for starting the project:</p> <ul style="list-style-type: none"> • Undertake a rapid evidence review of any existing data and literature to be completed in next two weeks. • Use the evidence review as a basis for creating a co-creation workshop which will include members of the BCA and a select group of patients. • Creation of a survey and focus group materials to direct the research. • Run an online survey and number of focus reports. • Share the final report by October. <p>KB asked for declaration of interests in the workshops and for any relevant literature to be shared with the secretariat.</p> <p>KB then raised an issue highlighted by ClearView on offering incentives for participation in the focus groups and completing online surveys, indicating a prize draw survey, small payment</p>	<p>All to share relevant literature with the secretariat – Ongoing</p>
--	--	---	---

		<p>or a donation to charity, questioning whether BCA members had used this model before and for feedback on the proposal.</p> <p>ZPW opined he had no problem with offering incentives for the workshop but is uncomfortable in paying for survey participation. CW added he instinctively agreed with ZPW and a gesture of thanks for a workshop is different to a survey. KB responded her initial reaction had been similar, but given the struggle to reach these communities, if ClearView believe this is a better form of interaction, then it should be considered.</p> <p>SM asked who is to be involved in the co-creation group. KB said it is a likely to be a mixture of BCA members, patients, and families and that if we received too many offers certain criteria would be used to narrow down the group. SM confirmed instinctively she preferred a prize draw to the fee model and that any incentives have to be open to everyone, acknowledging historical poor responses from BAME communities. SM then asked if ClearView has a two pronged approach which includes using better channels and using incentives. KB confirmed it was the latter option, agreeing a prize draw is a better incentive and less restrictive. SM believed any incentives should not limit participation and is happy for payments for a workshop.</p> <p>DF retorted she had assumed the incentives were within the budget guidance and questioned whether ClearView is asking for more budget? KB replied that the focus group work had been within budget, but indicated that the incentives for the online survey is not included.</p> <p>CF revealed AN had engaged in a similar conversation, agreeing it might be a useful tactic if it increases participants,</p>	
--	--	---	--

		<p>but was rejected at AN because they were working with an academic whose ethics department rejected the proposal. CF acknowledged we needed to reach out and be willing to do things differently and argued a Prize Draw might be the best option, and that we should not set a precedent for charities.</p> <p>CW asked if ClearView had provided any case studies of comparing examples of surveys with incentives and surveys without incentives. KB said she could look into this with BP adding that she had not seen any comparisons.</p> <p>ZPW brought the session to a close, concluding the majority appeared in favour of a Prize Draw for the online surveys rather than a direct incentive, but that the BCA required evidence that it is worth doing and asked whether the membership is happy for the leadership to make an informed decision when they received the information. The membership concurred.</p>	<p>AP to discuss comparison studies with ClearView re: incentives - Ongoing</p>
5	Policy Priorities	<p>KB introduced the conversation on the next agenda item, revealing there is extra budget available to allocate to priorities, but that we needed to decide as an Alliance how to prioritise the budget. KB suggested using this this session to discuss what we will need to do next, recommending investigating new areas of research or building on existing research models, pointing to aspects ClearView is not covering which could be supplementary such as interrogating existing NHS data by ethnicity or conducting a survey of clinicians and clinical leaders on Unmet Needs.</p> <p>CM intimated we could consider expanding the Access to Medicine report, with a focus on the SMC and devolved administrations, disclosing specific issues with patient involvement at the SMC.</p>	

	<p>CF agreed that we should consider continuing the Access to Medicine work arguing that we have had some momentum, but that there is more we can do, noting that the IMF will throw up issues. CF added there is also going to be changes to NHS payment structures and this is a consideration the BCA should be focusing on, alongside looking at what the medium to long term future for blood cancer patients is in the era of COVID.</p> <p>CW expanded that the upcoming APPG inquiry will give the BCA something to work on from late summer time and questioned whether we can be doing more as an alliance from an Access to Medicine perspective in terms of responding to consultations and that it might be necessary to have a further conversation on this.</p> <p>KB intervened, adding that any suggestions did not have to be standalone projects and could just focus on looking at what the Alliance is not doing and what it could be doing.</p> <p>SM agreed the BCA is making an impact on Access to Medicine and that this is even more important for blood cancers and should be a strong focus. SM highlighted her fears that joint submissions might not be effective but is happy to have the conversation and also argued the BCA needed to consider what happens post-Brexit from an HRA angle. SM concluded by suggesting a lot of emphasis is being placed on the IMF, but that she would also like to see the BCA prioritise diagnosis and learn lessons from CAR-T.</p> <p>ZPW interjected that many of the recommendations from Access to Medicine are projects in themselves and we could use the report to drive further proposals and even if the policy</p>	
--	--	--

		<p>priorities had not changed, the work outputs might have changed.</p> <p>KB argued that the purpose of BCA projects is creating a central evidence base which members can tap into, but that the BCA could also put some resource into talking to politicians about the IMF, adding that NHS Commissioning is an area of access that we have not begun talking about. KB pondered whether the BCA could help develop resources for members going through the commissioning process and that this is an area where the BCA has only scratched the surface.</p> <p>SW advocated considering emotional support for patients post-COVID, indicating we do not know when the situation will improve. SW added delayed submissions to NICE is also an issue and this is not the first time the blood cancer community has encountered this problem and it is often the pharma company deciding on the timetable.</p> <p>KB concluded that the next step is to look into what needs to happen next and how to make this happen, and that the BCA needed to carry on the momentum and not let any stakeholders off the hook.</p> <p>SM spoke about using Access to Medicine report as a repository of good ideas and picking some of the themes from the report to look at in more detail and unpicking some of the restrictions on what is deemed a line of treatment and what treatment criteria is.</p> <p>AH moved to highlight how the landscape of commissioning is changing and thinking beyond COVID, interesting to consider</p>	
--	--	---	--

		<p>what the impact of those changes will be and how the BCA can further our understanding of how to respond to those changes.</p> <p>KB queried whether we could invite NHS managers to come and talk to us and that the BCA can be useful in bringing groups together and that NHS England (NHSE) is normally good at this engagement and as pressure on NHSE reduces, would be great to reinvigorate the relationship. AH said conversations were developing in bringing primary and social care together and that it might be a good opportunity to bring some of these people together.</p> <p>KB thanked members for all of their thoughts, adding the next stage is for the secretariat to type up these notes and put together a more complete proposal.</p> <p>SW also highlighted the issue of satellite sites for clinical trial, questioning why these options not offered more frequently.</p> <p>ZPW ended the session by saying the next stage in the process will be to come back to the next quarterly meeting with some ideas. KB added for simple decisions, we will go through the leadership but for any bigger projects, proposals will be brought to the meetings.</p>	<p>AP to write up suggested proposals and priorities - Ongoing</p>
6	Blood Cancer CEOs group	<p>ZPW provided an update on the Blood Cancer CEOs group, revealing it is trying to establish terms of reference and what this will mean from a collective perspective and that this work is ongoing with CEOs keen to set up a model that works in a similar way and that conversations are going on in the background, but that all involved are conscious it does not impact on the day to day working of the BCA.</p>	

		<p>CW raised the question about a prospective new chair, highlighting CF's interest and what the timeline will look like. ZPW contended the next stages will depend on whether or not there is an intent for the CEOs to deliver a collective strategy and what the reporting structure is and that once this has been agreed, the next stages can be resolved, but that no decision has not been made yet. ZPW added that CF and DF have joined the leadership and that the next Blood Cancer CEOs group meeting is in June where they hope to progress these conversations.</p> <p>CW raised a question about a possible new application to join the BCA, indicating that it might cause several issues. ZPW confirmed this had been noted and the leadership will look at this.</p>	
7	Devolved nations update	<p>JB provided a brief update on Northern Ireland, revealing consultants are very positive and are keen on the changes that have been implemented and that currently the situation is positive.</p> <p>SM added she will ask DC to provide an update to circulate, adding there is ongoing consultation on Scotland on new cancer governance structure and that the new COVID recovery group will morph into the new group taking over the role of previous taskforce. SM concluded she will share details with AP who will distribute to the members and that Kirsty Flack from CRUK is moving on so there might be some movement in the Scottish Cancer Coalition.</p> <p>CF summarised the current situation in Wales, confirming that following the devolved elections, we are waiting to hear who the new Health Minister is and that Wales Cancer Alliance will conduct some research on the new cabinet. CF expanded that</p>	<p>SM to share update from DC on devolved nations – Ongoing</p> <p>SM to share consultation with AP – Ongoing</p>

		the rapid diagnosis centre conference coming up in June and that she will share details with the secretariat, before concluding that conversation on the quality statement and the implementation timetable is still ongoing.	CF to share relevant details on the rapid diagnosis centre conference - Ongoing
8	AOB	<p>ZPW initiated the last section of the agenda, highlighting an application to join the BCA from the AME Blood Cancer Trust, flagging the existing terms of reference, acknowledging that the AME Blood Cancer Trust currently does not meet the required threshold in terms of funding to be registered as a charity. ZPW asked if we wanted to amend the terms and references of the BCA to allow them to join the Alliance.</p> <p>KB argued that the terms of reference provide a very solid base and that when they reach the threshold to be registered as a charity they should be invited to join, but until this stage the application should be rejected. ZPW agreed with this approach.</p> <p>JB then briefly announced that she will be going on maternity leave shortly and that LLNI will be bringing in maternity cover and that she will introduce the maternity cover in due course.</p> <p>ZPW brought the meeting to a close.</p>	<p>AP to contact AME Blood Cancer Trust confirming next stages – Ongoing</p> <p>JB to introduce maternity cover - Ongoing</p>

Next Meetings

Date	Agenda
TBC	TBC