

Blood Cancer Alliance

Minutes of the meeting held via Zoom on Tuesday 16th February 2021

Members present: Joanne Badger (JB), Leukaemia and Lymphoma NI; Dawn Farrar (DF), Leukaemia UK; Caitlin Farrow (CF), Anthony Nolan; Will Franks (WF), WMUK; Nigel Gordon (NG), DKMS UK; Orin Lewis (OL), ACLT; Sarah Mallick (SM), Leukaemia Cancer Society; Charlotte Martin (CM), Leukaemia Care; Shelagh McKinlay (SM), Myeloma UK; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Stephen Scowcroft (SSc), Lymphoma Action; Christopher Walden (CW), Blood Cancer UK; Charlotte Wickens (CW), Anthony Nolan.

Apologies: Julie Child (JC), Race Against Blood Cancer; Dave Ryner (DR), CML Support Group; Steffi Sutters (SSu), CLL Support Group; Sophie Wintrich (SW), MDS UK Patient Support Group.

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

No.	Agenda Item	Minutes	Actions
1	Welcome	Introductions made and minutes agreed.	AP to upload November minutes to the BCA website - Complete
2	Secretariat update	<p>BP reported back on activities from the last month highlighting work had focused on the following developments:</p> <ul style="list-style-type: none"> • Progressing the Access to Medicine Campaign • Kicking off Unmet Needs project • Drafting Unmet Needs BAME tender • Participating in meetings with politicians in Westminster and across the devolved administrations • Continuing to draft tweets for the BCA Twitter account • Attending National Cancer Taskforce meetings • Welcoming new Industry Partners • Writing to political stakeholders re Covid-19 <p>BP then moved on to discuss the latest funding updates, revealing that the BCA had:</p>	

		<ul style="list-style-type: none"> • Confirmed funding total currently at £86,295, with contributions from Gilead, Amgen, Kyowa Kirin, Janssen and Incyte. • Funding in the pipeline from Takeda, Roche, Abbvie and BMS. • Sent letters to Fibrogen, Novartis, Pfizer, GSK, MSD, and Amgen. • Meeting confirmed with Sanofi. <p>BP then opened up the floor to questions.</p> <ul style="list-style-type: none"> • ZPW confirmed all of the BCA's existing projects are fully funded, so any surplus funds can be designated to new projects or extension of projects coming out of existing campaigns. ZPW recommended having a further discussion on how to allocate the funding and the determination of any new projects at the next meeting. • CW questioned whether any of the grants had any specific commitments attached to them. BP responded that in approaches to partners, the BCA is not specific about how the money is spent with recent letters implying that money will be allocated to further projects. BP added there are no existing constraints in terms of a specific timeframe for spending the money, but for a number of grants, the BCA needed to ensure they could give details of where the money will be allocated, even if the funding had not yet been spent. 	
3	Members Update	ZPW introduced the next agenda item, opening the meeting to members to update on existing workstreams.	

		<ul style="list-style-type: none"> • CW initiated the discussion, revealing Blood Cancer UK (BCUK) is heavily focused on the vaccine and ensuring blood cancer patients are being offered the vaccine, adding there is not yet enough data to determine if the vaccine is effective for those with blood cancer. CW continued saying BCUK is actively trying to ensure family members living with blood cancer patients are prioritised in the vaccine distribution list and that there is ongoing communication with the JCVI. BCUK is also focusing on post-vaccine research and bringing together different groups and individuals, but that there might need to be further communication with Government. • SSc followed disclosing Lymphoma Action (LA) had been concentrating on developing information on the vaccine, with work beginning on delivering activities for the next year. SSc added LA had been engaging in virtual webinars with other members of the BCA but were also focusing on looking at non-COVID issues and returning to business as normal, citing the recent interest in NICE proposals. • JB continued that Leukaemia and Lymphoma NI (LLNI) had been working on keeping in touch with the consultant community and providing and sharing advice, revealing information and advice from members is a really important resource. JB also articulated uptake on the vaccine is quick in Northern Ireland and that LLNI is now finalising its strategic plan for the next five years. • OL confirmed ACLT is undertaking a handful of online registration drives with educational and corporate organisations adding ACLT is embarking on a series of conversations with prominent individuals in the 	
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		<p>community. OL also retorted work is ongoing on educating individuals in the BAME community who are hesitant about taking the vaccine due to existing misinformation and that on Thursday 25th February, ACLT will be hosting a webinar to discuss the vaccine and answer any questions or concerns.</p> <ul style="list-style-type: none"> • SM highlighted Myeloma UK (MUK) is now conducting its third and final covid survey, now handed over to the research team and likely to be carried out in May. SM also revealed ongoing discussions about alternative oral prescribing, with MUK actively seeking feedback on timelines and any impact on treatment. SM added she had been hearing from clinicians that lines of treatment might be changing and will share any relevant information with members. SM also shared that since the last meeting, a further drug had been approved but there had been confusion about eligibility, causing a level of fallout with pharmacies. Concluding, SM stated MUK has some money to research into delayed diagnosis. • NG stated that over the last year donors had fallen by 28%, and DKMS is conducting virtual registration drives as unable to run physical drives. NG added DKMS is striving to keep patients updated on COVID-19 related information with emphasis placed on providing clarity for potential donors and patients. NG concluded DKMS is also considering a BAME strategy and will be conducting further work in this area over the next year, alongside providing clear messaging on COVID and speaking to potential donors. • DF followed articulating that Leukaemia UK (LUK) doesn't have the manpower to run its own campaigns but is actively sharing as much information about 	<p>SM to share relevant information on lines of treatment with members – Ongoing</p>
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		<p>COVID as possible. DF moved forward, saying LUK is looking at its patient support strategy and is hoping to increase its manpower. DF ended by clarifying that individual patients still appeared to be concerned about the efficacy of the vaccine and questioned whether the BCA should be trying to find out if there is more that can be done to comfort blood cancer patients. CW responded that a number of blood cancer patients had been involved in the specific testing and will be asked for antibodies, but that the scheme is limited.</p> <ul style="list-style-type: none"> • CF confirmed Anthony Nolan (AN) is conducting research around vaccines and ensuring that everyone is in the right vaccine group, following earlier confusion. CF added that AN had been hearing questions about the vaccinations, with patients inquiring about which is the best vaccine, with AN encouraging patients to vaccinate and then shield following the vaccination. AN is also continuing to run the APPG Stem Cell Transplant inquiry and is hoping to report back in April. CF revealed there are no surprises in the evidence received to date, but that it is useful to hear first-hand about barriers from patients and researchers and will share the findings with the alliance when published. • CM confirmed Leukaemia Care is pushing for enhanced data on uptake of the vaccine among the clinical vulnerable and is asking questions of NHS England. CM said LUK's other concerns correlated on supporting patients and that a few patients had been asking about antibody tests and that LUK would appreciate any further information in this area. CM concluded by raising concerns about shielding letters coming to an end and that LUK is waiting to hear on the results of next priority 	<p>CF to share findings from APPG inquiry - Ongoing</p>
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		groups, adding that Access to Medicine is biggest driver of LUK's work at the moment.	
4	Access to Medicine Campaign	<p>MH updated on developments from the Access to Medicine campaign, highlighting the following achievements since the beginning of the campaign.</p> <ul style="list-style-type: none"> • Launch event being attended by 50 attendees including 30 non-BCA members. • Sharing of report with over 150 stakeholders. • Arranging and participating in nine online meetings with parliamentarians, the ABPI and health stakeholders. • Submission to the NICE Methods Review and NICE Topics Selection Consultation. • Tabling of 15 parliamentary questions in Westminster, Holyrood, Cardiff Bay and Stormont. <p>MH added that the document being displayed on achievements from the campaign will be shared with members.</p> <p>MH then expanded on progress since the last quarterly meeting disclosing the following actions:</p> <ul style="list-style-type: none"> • Arranging and participating in meetings with six politicians from across Westminster and the devolved administrations with a further meeting agreed. • Organising and running meetings with ABPI, Institute of Cancer Research and Cancer Research UK. • Updating website to include a new section on the Access to Medicine campaign. • Submitting consultation response to the NICE Methods Review and Nice Topics Selection Consultation 	<p>MH to share campaign achievement document with members – Complete</p>

		<ul style="list-style-type: none"> Engaging with the offices of supportive parliamentarians. <p>MH progressed by revealing the BCA is reaching out to stakeholders at NICE, SMC and NHS England, highlighting progress in recent days in securing interest from NICE for a meeting. MH concluded by asking members for further suggestions of individuals to contact. SM confirmed she would research potential figures at the SMC and respond accordingly.</p>	SM to share details of relevant individuals to contact at the SMC - Ongoing
5	Unmet Needs Report	<p>KB initiated the conversation on the Unmet Needs Project, confirming that since the last meeting the BCA had commissioned Quality Health (QH) to oversee the project due to its existing expertise in the area and that work had begun on the project four weeks ago.</p> <p>KB continued that the research in the report will be considering the experiences of different blood cancer patients and looking at whether there are regional differences between blood cancer patients which will hopefully inform any further research. KB disclosed that the BCA is expecting to receive a final report from QH in early May, with QH now conducting a literature review, investigating the different updates provided by members. KB invited members to continue sharing patient surveys from the last five years.</p> <p>Concluding, KB revealed the secretariat will be holding fortnightly calls and updates with QH, who will also be speaking to specific BCA members who have expertise in relevant areas and that the secretariat will continue to keep members updated.</p>	Members to share relevant patient needs Unmet Surveys with KB - Ongoing
6	BAME Unmet Needs Report	KB moved on to deliberate the agreed project on BAME Unmet Needs, highlighting a tender document had been produced and is ready to share with research partners. KB then opened the floor to questions:	

		<ul style="list-style-type: none"> • CF suggested there might be a problem with a stat in the context section and recommended using the more general text included later in the document. KB confirmed she will update the tender document accordingly. • CW questioned if there is an updated tender document. KB said an updated document had been shared with members on Friday reflecting previous comments. • CF posed the question of whether the BCA will like the research to look at the variations between different ethnic minority groups, as it is unlikely all groups are having different experiences. KB revealed these considerations will form part of our conversations with potential partners and the BCA is seeking to determine what is achievable within the budget. <p>KB then raised recurring conversations with the leadership about the next stages of the process.</p> <ul style="list-style-type: none"> • OL articulated the importance for the research of moving beyond normal research parameters and using more effective methods. KB responded that the secretariat and BCA leadership will first go to existing research organisations and see what they can provide, but if not content, will approach other research partners. OL added on this specific topic historical research has left a lot to be desired, failing to tackle the nuances and differences in the groups they are trying to reach and the findings have not been as comprehensive as they should have been. <p>KB asked whether any members had any more thoughts.</p>	<p>KB to update tender document – Ongoing</p>
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		<ul style="list-style-type: none"> CF revealed AN had recently shared a research proposal on a similar project, suggesting she can recommend other consultancies AN have been talking to. KB thanked CF and recommended OL overseeing the proposals shared by the research partners to ensure they met the required standards. OL confirmed he is happy to do so. <p>KB asked if the leadership was happy with this approach and for any further recommendations. ZPW indicated his approval, whilst acknowledging the process might take longer.</p> <p>CW suggested there is a possibility we could split up the work, allowing different organisations to concentrate on other areas of work. KB believed this could definitely be a possibility.</p>	<p>CF to share details of research partners AN have been talking to - Ongoing</p>
7	Blood Cancer Dashboard Update	<p>ZPW handed over to CW to provide an update on the Blood Cancer Dashboard.</p> <p>CH begun by discussing that she had been working with Henny in the Blood Cancer CEO Data Group and they had been looking at recent proposals from Janssen on the blood cancer dashboard. CH explained that the dashboard now includes information on the devolved nations and that further additions are likely, with Janssen indicating they will instruct M & F health to provide quarterly reports on different trends in the report. CH added that the Blood Cancer CEO Group will meet ahead of these findings becoming public to discuss the major proposals, raising the upcoming roundtable event likely to take place in the Spring. CH concluded by revealing Janssen had raised whether going forward the BCA might own the dashboard, supported by Janssen funding before opening the floor to questions.</p>	<p>CH to share proposals from Janssen re: Blood Cancer Dashboard – Ongoing</p>

		<ul style="list-style-type: none"> • CF asked whether there are any more details about a possible transition and what this might envisage. CH said under these proposals, the dashboard will be BCA branded and hosted, but that there are ongoing compliance issues. • SSc added that this conversation had also taken place when the dashboard was created. CH said she is happy to share updates and proposals when received. • SSc asked for any additional information about the roundtable. CH believed there might be an opportunity to try and link the roundtable to BCA requests on data. CM confirmed there are ongoing discussions in this regard and invited members to contact her if they would like any further information. • ZPW questioned how advanced the conversations are on the blood cancer dashboard and how long Janssen is committed to funding the dashboard. CH responded at this stage they were only proposals, but that conversations are ongoing and Janssen is committed to funding to 2022. ZPW added that long-term funding would need to be considered. 	<p>Members to contact CM re: further information on roundtable and Blood Cancer CEO Group on Data - Ongoing</p>
8	Blood Cancer CEOs group	<p>ZPW initiated conversation on the blood cancer CEOs meeting, highlighting they will be meeting on Monday and will be looking at further ways for the charities to collaborate, recommending members speaking to CEOs on topics they would like discussed.</p> <p>ZPW then raised whether any members are interested in the leadership. ZPW added he is happy to have a further call to discuss the role, which is open to all members.</p>	

		<p>ZPW moved to ask if anyone involved in the research group or patient information group is keen to update on developments.</p> <ul style="list-style-type: none"> • JB said her group is looking at how to create links to ensure patients are receiving the most appropriate information, with a meeting scheduled for next Thursday. 	
9	Devolved nations update	<p>ZPW introduced the next agenda item, handing over to CF for an update on Wales</p> <ul style="list-style-type: none"> • CF began by talking about the Cancer Statement and concerns from the community about the lack of a strategy, revealing the Wales Cancer Alliance has now fed back with detailed comments including concerns on the impact for blood cancer patients. CF revealed a number of the comments centred on the need to strengthen the care and support aspect of the pathway and the need for new metrics, with possible suggestions including considering the proportion of patients who visit GPs more than three times before diagnosis or who needed emergency presentations to be diagnosed. CF added there is concern the statement did not mention COVID or lessons that could be learned from the crisis. CF concluded no further decisions will be taken on the quality statement ahead of the upcoming elections in Wales, but that she will also share documents about the cancer backlog in Wales which indicated haematological cancers seem to be doing better compared to other cancers. CF added there is a meeting with Vaughan Gething scheduled next Wednesday and that BCA members could feedback to her if they had any issues they would like raised. 	<p>BCA members to share questions with CF ahead of meeting with Vaughan Gething MS – Complete</p>

		<ul style="list-style-type: none"> • JB revealed a planned meeting next week to discuss a provisional new NI Cancer Strategy but is not hopeful that there will be a significant mention of haematology given past history. JB added that blood cancers also appeared to be doing better in the current backlog compared to other cancers. • SM highlighted the upcoming elects in May and that the cancer strategy is being pushed into next parliament, but that there are new developments on early diagnostic centres. SM added there is a meeting next week amongst cancer organisations to discuss producing a document to update manifestos and that if anyone was keen to feed into the process then they could share updates with her. SM raised concerns that the Cancer Recovery Plan has a lack of awareness about blood cancer, but that as with other devolved nations blood cancer seems to be faring better than other cancers, meaning it was often less of a priority for policymakers. 	<p>BCA members to share updates with SM Ongoing</p>
10	AOB	<p>ZPW raised the upcoming Industry Partners Forum event in March, confirming the event will take place over two hours, before asking about further AOB.</p> <p>SW intervened, revealing she had just arrived from an MHRA meeting where a lot of unanswered questions remained about PPI work. SW added she will follow up at the next public meeting and will share more information after the meeting and that there is ongoing monitoring of blood cancer patients and those less likely to be taking the vaccines.</p> <p>SSc then highlighted he is moving on from Lymphoma Action to work at the Macular Society. ZPW thanked SSc for his work</p>	<p>SW to share relevant materials from MHRA meeting after BCA meeting – Complete</p>

	<p>and commitment to the BCA, notably in regard to the Blood Cancer dashboard.</p> <p>CF asked if there is a mechanism that can be adopted to discuss a joint sector response when major updates come through, articulating that this might be an item to discuss further at the next meeting. ZPW concurred with this suggestion, highlighting any problems in communication might feature in overlap between policy and comms teams.</p> <p>SW asked whether we had discussed the international response to covid vaccines and blood cancer patients. CW responded that a taskforce had been set up with clinicians and that he had shared actions, with work ongoing in collating all of the information and working out where there are any gaps in research, adding he is happy to check the international response. SW added she is also happy to investigate further and had asked a question through Harmony at their board meeting, with the next move being to ask the EHA if there are any subgroups looking at malignant cancers. SW concluded she is asking all MDS groups if there are any monitoring studies they are studying and will share anything useful and that she will pick up conversations with CW outside of the meeting.</p> <p>ZPW concluded the meeting, thanking all of the attendees</p>	<p>CW to research international response to covid vaccines and blood cancer patients – Ongoing</p> <p>SW to share relevant updates from conversations with MDS groups with members – Ongoing</p> <p>SW to pick up with CW separately – Ongoing</p>
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Next Meetings

Date	Agenda
TBC	TBC