

**Blood Cancer Alliance**

**Minutes of the meeting held via Webex on Thursday 13<sup>th</sup> August 2020**

**Members present:** Joanne Badger (JB), Leukaemia and Lymphoma NI; Amelia Chong (AC), Anthony Nolan; Dawn Farrar (DF), Leukaemia UK; Caitlin Farrow (CF), Anthony Nolan; Orin Lewis (OL), ACLT; Alan Miller (AM), DKMS UK; 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.

**Apologies:** Lindsey Bennister (LB), WMUK; Julie Child (JC), Race Against Blood Cancer; 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.	AP to upload May minutes to the website – <b>28/8</b>
2	Secretariat update	BP reported back on activities from Year 2, explaining progress had focused on: <ul style="list-style-type: none"> <li>• Hosting the first Industry Partners Forum, attended by 10 industry partners and organising the second Industry Partners Forum scheduled to take place in October.</li> <li>• Co-ordinating Access to Medicine report and liaising with Leela Barham (LB).</li> <li>• Agreeing the Unmet Needs project brief.</li> <li>• Arranging a number of meetings with politicians across the devolved administrations.</li> <li>• Drafting letter to NHS England re: blood cancer and COVID.</li> </ul>	

		<ul style="list-style-type: none"> <li>Producing response to Health and Social Care Select Committee inquiry on Delivering Core NHS and Care Services during the Pandemic and Beyond.</li> </ul> <p>BP provided an update on funding, setting out that:</p> <ul style="list-style-type: none"> <li>In Year 2, BCA had secured £147,000 from 10 pharma partners, spending £137,175, achieving a small surplus of £9,285 which will be put towards activity for Year 3.</li> <li>The funding secured had been spent on secretariat fees, Access to Medicine report and campaign and set aside for the upcoming Unmet Needs report and potential campaign.</li> <li>Partners were now being approached re: Year 3 Funding with the Industry Partners Forum being used as an incentive.</li> </ul> <p>SM questioned the costings around the Access to Medicine report.</p> <ul style="list-style-type: none"> <li>KB confirmed Leela was to be paid £20,000 with an additional £25,000 going towards the campaign.</li> <li>ZPW suggested this level of split will be similar when considering the Unmet Needs Report.</li> </ul>	<p>AP to continue to approach partners re: Year 3 funding - <b>Ongoing</b></p>
3	Access to Drugs Treatment Report	<p>KB updated on developments on Access to Medicine Report, confirming a new draft has been circulated to members. KB opened the floor for comments from the members on the report:</p> <ul style="list-style-type: none"> <li>SSu argued the report was hard to read, citing the length of the Executive Summary, adding she was also worried about a number of inaccuracies, suggesting</li> </ul>	

		<p>there needed to be a greater focus of CLL in the publication. She indicated CLLSA cannot accept the report in its current form, but that she will share her thoughts via email with KB.</p> <ul style="list-style-type: none"> <li>• ZPW confirmed that a foreword is to be added, hopefully allaying fears about complexity and that the Executive Summary will be further assessed. KB also agreed that other sections can be simplified. SSc intimated the final design process will help with clarity.</li> <li>• CW questioned who the publication will be aimed at, and whether it will include political and industry stakeholders and whether the recommendations will reach both groups. KB confirmed the report will be aiming to reach a wide range of people. ZPW expanded that the report will be as comprehensive as possible.</li> <li>• CF concluded that AN were hopeful the report will produce key recommendations and material, which can be used in the future.</li> </ul> <p>KB asked SSu for any broad themes which can be raised in conversations with Leela, accurately setting out CLLSA's concerns. SSu highlighted the variable uptake of the survey, suggesting the small survey size overrepresented certain blood cancer types, noting CLL's status as the most common blood cancer is not reflected. SSu added certain sections are liable to be misread and a number of questionable statements remain.</p> <p>KB acknowledged these concerns, explaining she is adapting the language to reflect these concerns, notably around immediate treatment and CAR-T. SSu explained she is keen to ensure the report reflects the current situation and is accurate to the concerns of the CLL community.</p>	<p>SSu to share comments on the report with KB – <b>21/8</b></p> <p>KB to share updated language with SSu – <b>21/8</b></p>
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		<p>KB confirmed LB values feedback of this nature and welcomed further comments. KB surmised that the patient survey response appeared high but is intrigued about the success of other surveys and concluded she is confident further changes will be satisfactory.</p> <p>KB moved to explain the planned campaign, highlighting the first stage is to write a campaign strategy, ready for the first week of September. KB suggested that given the nature of the document, there are a couple of ongoing questions about engagement, revealing these options for a campaign.</p> <ul style="list-style-type: none"> <li>• The first option is to focus on a few key recommendations in all engagement with various stakeholders, considering whether to pick up different recommendations in the coming years and using the report primarily as an evidence base.</li> <li>• The second option is to oversee concurrent engagement work with different groups, combining political and health stakeholders. The political engagement might focus on recommendations easier to digest such as the changing of the CDF into the IMF and ensuring blood cancer treatments receive the same level of funding. This campaign will be supplemented by a targeted stakeholder engagement campaign which raises more complex and substantial issues, specifically aimed at HTAs and NHS England with the desire of agreeing meetings to further discuss recommendations.</li> </ul> <p>KB then asked for thoughts and views from the members, suggesting the second option is her preference.</p>	<p>Members to share further feedback with KB - <b>Ongoing</b></p> <p>AP to draft campaign strategy document – <b>28/8</b></p>
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		<ul style="list-style-type: none"> <li>• SSu responded that she is broadly in agreement but is concerned that politicians remain overly focused on COVID and that they will not be open to communications. KB accepted this consideration, but stressed it is our job to hold the government to account and that the BCA need to raise these issues. CW reiterated this view, believing the BCA is duty bound to raise concerns of the blood cancer community. ZPW believed the report will achieve a decent uptake, pointing at the strength of the suggestions and issues raised. KB stated that it is important to ensure there is consistency in all our approaches to stakeholders, so no group feels blindsided or overlooked.</li> <li>• CF suggested she is supportive of the second approach. SM concurred, believing it was vital to prioritise and target recommendations, but also saying time needed to be allowed for members to present back to own organisations. SM concluded by asking who will be leading the engagement. KB confirmed that when final recommendations are agreed, there will be time to discuss the next stages and there will be opportunities for members to become involved in the engagement. ZPW expanded, stating all support from member organisations will be valuable.</li> <li>• AC questioned how long the campaign is going to last and whether there will be opportunities to assess progress. KB confirmed planning for the campaign will take place in August and September, with the campaign launching in October and running until February 2021. KB also stated progress assessments will be conducted every couple of months. AC added there needs to be clear success barometers, ensuring focus. KB affirmed,</li> </ul>	
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		<p>saying targets can be built in the strategy. AM also expressed his support for the campaign.</p> <p>KB confirmed Henry Smith MP is to chair the event and that the invitee list will go to a range of different groups. KB requested any further speaker suggestions to be shared with her.</p>	<p>Members to share speaker suggestions with KB - <b>Ongoing</b></p>
4	Unmet Needs Report	<p>CW introduced the next section on the Unmet Needs Report, explaining the purpose of the brief, highlighting the following points:</p> <ul style="list-style-type: none"> <li>• The work will focus on the hypothesis that those with blood cancer often face more severe challenges.</li> <li>• The purpose of the research will be to agree clear recommendations, whilst considering the COVID perspective. Following this process, there will then be a discussion on which recommendations to campaign on.</li> </ul> <p>CW then opened the floor to questions, and ZPW suggested that if there were any specific language issues, they can be shared separately.</p> <ul style="list-style-type: none"> <li>• ZPW initiated the conversation, indicating that he was broadly very supportive but might suggest a few language changes.</li> <li>• AC asked to what extent the report will we be able to understand the causes of these unmet needs, and whether the report will be fully referenced or based on a range of evidence-based reports. CW said the priority will initially be internal, with the BCA then deciding which actions to take forward.</li> </ul>	<p>Members to feedback to CW on Unmet Needs brief – <b>Ongoing</b></p>

		<ul style="list-style-type: none"> <li>• CF suggested the report can help the Alliance understand the issue and that the next step might then be commissioning further research.</li> <li>• ZPW stated that the purpose of the report is to provide an evidence base, differentiating blood cancer from other cancers. ZPW added the report will open up the conversation and provide relevant evidence, which will later be used for further projects.</li> <li>• CF indicated an interest in exploring the differences that arise because blood cancer is biological different to other cancers and whether this impacts the level of attention blood cancer receives. SSu expanded, highlighting blood cancer patients are often looked after in haematological departments, not specifically designed for blood cancer patients.</li> <li>• SM questioned the remit of the expert roundtable presently included in the brief. CW explained the expert roundtable and specific recommendations should be included in an outcomes section. SSc expressed his thanks to CW for progressing the report.</li> </ul> <p>ZPW concluded the session by saying the next stage of the process is to share the tender and that if any members wished to be involved in the process, they should reach out to the secretariat.</p> <p>The meeting broke for a short tea break.</p>	<p>Members to contact AP if interested in becoming involved in the tender process and to share suggestions on possible research partners - <b>Ongoing</b></p>
5	Devolved nations update	<p>SM provided an updated on devolved nations, highlighting the work of her colleague Daniel Cairns who sits on Scotland Cancer Coalition and Wales Cancer Alliance. SM explained the latest developments in Scotland and Wales, raising:</p>	

		<ul style="list-style-type: none"> <li>• The Scottish Cancer Coalition is in regular contact with the Scottish Government and has arranged a number of meetings with important stakeholders.</li> <li>• A new group has been convened on data and cancer outcomes in relation to COVID.</li> <li>• The Scottish Government is asking for any groups with reports or data on cancer to be shared with them.</li> <li>• The Scottish Government is working on a 10 point recovery plan mirroring the One Cancer Voice plan.</li> <li>• The SMC is re-starting appraisals and is looking at dealing with its workload in different ways.</li> <li>• Scottish Government is working on a new cancer strategy which is paused.</li> <li>• The Wales Cancer Alliance participated in a meeting with Health Minister Vaughan Gething talking about cancer and Covid recovery and that there is an upcoming meeting with Tom Crosby.</li> </ul> <p>AC expanded, confirming Vaughan Gething will only meet with the Alliance and not individual members, but is very happy to continue to update. SSc confirmed SM's suggestions, sharing that the SMC is now working more on a case by case basis. SM ended by saying DC is compiling a short note which she will share when complete.</p> <p>ZPW added he is happy to share information about appraisals if this is useful for context and that fast tracking will allow earlier access but might limit patient engagement in the process.</p> <p>SM raised the latest developments in Northern Ireland, discussing the range of subgroups feeding into cancer strategy</p>	<p>SM to share note from DC on devolved nations - <b>Complete</b></p>
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	<p>in Northern Ireland. MH then shared an update from JB on Northern Ireland highlighting:</p> <ul style="list-style-type: none"> <li>• In terms of patient landscape things have returned to some level of normality following the pandemic. Appointments have been maintained quite well over the past 4 months, with telephone appointments more suitable for some patients. Trials are almost back up and running after 4 months of cancellation and recruitment is planned to start again in September.</li> <li>• JB is presenting at the Abbvie roundtable event on Blood Cancer in the NI Cancer Strategy on September 2<sup>nd</sup> and will be highlighting the BCA key policy asks and discussing the inequalities for NI patients.</li> <li>• LLNI is hoping to secure a meeting with health minister Robin Swann MLA ahead of the roundtable event to highlight the importance of sustainable research funding and will also mention the BCA here and our shared asks.</li> <li>• LLNI has a new patron who was previously a political correspondent.</li> <li>• Funding has been approved to restart the MOSAICC study in Belfast, recruitment of patients with MPN throughout 14 centres in the UK will start again in September.</li> </ul> <p>ZPW noted AC's involvement, thanking her for the work she had performed on behalf of the BCA as she goes on secondment.</p> <p>CW raised the Wales Cancer roundtable event coordinated by AbbVie and who will speak for the alliance at the roundtable. ZPW said all can be involved in this.</p>	<p>Members to confirm if they would like to attend the virtual Wales roundtable - <b>Ongoing</b></p>
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6	Workplan proposals for next year	<p>KB updated the group on the BCA workplan, revealing the last time the BCA had conducted a full workplan was in December 2019, adding that a workplan and list of projects could provide a clear sense of priorities and will be beneficial in conversation with partners.</p> <p>KB shared a possibly new priority idea, explaining the discussions which had taken place between the BCA leadership on a new Unmet Needs Project specifically looking at the unmet needs of the BAME population within blood cancer. KB expanded there had also been a debate about whether this could be incorporated into the current Unmet Needs Project, but that the conclusion is that this should be a standalone project, adding the affirmation from the BCA leadership that this is the next issue that we would like to focus on.</p> <p>KB reiterated this is an area that has been poorly researched and that major data gaps existed and that there are two main options for the nature of the project; either comparing the treatment of BAME blood cancer patients with other blood cancer patients or comparing BAME blood cancer patients with other cancer patients in the UK as a whole.</p> <p>KB asked for feedback from the members on the project:</p> <ul style="list-style-type: none"> <li>• OL queried how wide the remit will be in regard to looking at unmet needs. KB responded the plan is to look across as much of the pathway as possible and as far as the data will allow, suggesting it will be a disservice if we miss elements of their experience.</li> <li>• SSu raised a call she had recently joined, explaining many charities do not conduct an equality assessment</li> </ul>	
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		<p>before producing a report or engaging in any research and that any project needs to be scoped properly.</p> <ul style="list-style-type: none"> <li>• CW intimated as an alliance and as individual charities; we should actively encourage challenge from external parties about how we are operating. ZPW concurred, arguing this is an area all charities need to be working on. KB followed, clarifying that one of the roles of the BCA is to help charities put their houses in order and that this could represent a step forward.</li> <li>• OL spoke about his experiences representing ACLT, and the challenges he had encountered in regard to scoping because of resources. OL raised the importance of historical research, indicating many patients are willing to provide relevant information, but often felt excluded from the journey and that additionally, real time analysis is often missing. OL concluded by suggesting we are also now in a position to learn from the outcomes experienced related to COVID situation. KB responded that she believed this echoed CW's thinking in devising this idea, and that the research will identify new suggestions.</li> </ul> <p>KB affirmed the research will be conducted in coordination with the members and asked if there were any other comments on the proposal.</p> <ul style="list-style-type: none"> <li>• CF argued the qualitative piece of this research is also very important and there is a clear connection with the Unmet Need project. ZPW expanded, saying there is a desire to look at inequalities more generally and that all research will be driven by the evidence.</li> <li>• CF believed it might be beneficial to initially concentrate on the outcomes of BAME blood cancer patients</li> </ul>	
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		<p>against other blood cancer patients, rather than comparing against the cancer community as a whole. KB agreed, saying the first step is to look at blood cancer and that a comparison is the starkest way of addressing the problems.</p> <ul style="list-style-type: none"> <li>• OL asked if the report will be a combination of qualitative and quantitative research. KB confirmed, saying the report needed to be both qualitative and quantitative, suggesting a patient survey, in depth interviews and focus groups to understand the issues being raised.</li> <li>• SSu opined that big pharma is also lost on these issues, and the topic is extremely topical, but very complicated, citing there are many issues which are multi-layered. KB responded stating she will not pre-empt research but suggested these areas might come up as part of the research process and that she can envisage potential partners being enthusiastic about this campaign.</li> <li>• CW asked whether the report will operate to a similar timetable as the Unmet Needs report. KB confirmed this will depend on funding, but that having a set workplan will make it easier to raise funding. BP added that there are a number of warm leads in play, but the funding will not be confirmed until a contract is signed. KB concluded that if the membership agreed that this is a priority, then work can begin as soon as new funding is confirmed. ZPW contended there is time to work up the tender, whilst new funding is confirmed.</li> </ul> <p>KB confirmed this meeting will be taken as agreement the BCA will prioritise a BAME Unmet Needs project as our next project. KB asked for any further new ideas, raising the BCA's three main policy areas:</p>	
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		<ol style="list-style-type: none"> <li>1. Securing access to best treatment for blood cancer patients.</li> <li>2. Improving early diagnosis for blood cancer patients.</li> <li>3. Ensuring blood cancer patients have all the care and support they need.</li> </ol> <ul style="list-style-type: none"> <li>• CF speculated the BCA could commission research looking into the vulnerabilities of blood cancer patients during COVID-19, citing mental health and well-being as areas to be explored. CF added she is supportive of any high level work to improve blood cancer’s standing amongst policymakers. ZPW agreed this is a good point to consider for the future and that the Unmet Needs Report will provide further detail.</li> </ul> <p>Ssc surmised psychological support is an area that may come out of any Unmet Needs report and is one of the reasons we decided to concentrate on this topic. ZPW confirmed these thoughts will be useful to feeding into the Unmet Needs Report and that those with any further suggestions should not hesitate to get in contact.</p>	<p>Members to share any further suggestions on BCA workplan with ZPW/secretariat - <b>Ongoing</b></p>
7	BCAM 2020	<p>MH explained that after a discussion with the BCA leadership, that for BCAM 2020, the BCA will be doing the following:</p> <ul style="list-style-type: none"> <li>• Drafting and sending a standard letter via email to all of the parliamentary contacts on the completed and agreed political audit in the second week of September, explaining the letter will update parliamentarians on the BCA and its main workstreams in the context of BCAM as well as discussing ongoing issues impacting blood cancer patients.</li> </ul>	<p>AP to draft letter and share with contacts on political audit list – <b>11/9</b></p>

		<ul style="list-style-type: none"> <li>• It was also agreed we would attach a PDF copy of the already designed BCA leaflet to the email.</li> </ul> <p>AC asked if there was any intention of sending the letter to a wider group of health stakeholders. MH confirmed this letter will only go to parliamentarians, but a wider group of stakeholders will be invited to the Access to Medicine launch.</p> <p>ZPW then opened up the floor for members to update on their plans.</p> <ul style="list-style-type: none"> <li>• AC revealed Anthony Nolan’s plans for BCAM 2020 highlighting that Anthony Nolan is taking their annual Communities vs Blood Cancer campaign digital by hosting a day of action on Wednesday 9 September.</li> <li>• ZPW shared Leukaemia Care’s (LC) plans, raising the Spot Leukaemia Campaign. Additionally, LC will be focusing on primary care awareness, other ongoing treatment and new training. LC will also be hosting a series of webinars and will be working with the international leukaemia community to launch a new world Leukaemia Day.</li> <li>• SS contended Lymphoma Action will be focusing on the fundraising and will be engaged in activities around collaboration, including a couple of webinars and highlighting its involvement in the Blood Cancer Alliance. SS requested whether we could re-use and amend some of the tweets from last year. BP confirmed.</li> </ul> <p>ZPW then introduced the prospect of a possible BCA social media presence, indicating that there are messages that the</p>	<p>AP to re-work social media posts and share with members – <b>28/8</b></p>
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		<p>BCA might be keen to raise. ZPW concluded by asking if this sort of presence will be useful for members.</p> <ul style="list-style-type: none"> <li>• CF thought a social media presence will be helpful and can be useful in pushing out messages and will add an identity to the BCA. AC concurred, suggesting it will be beneficial to have an account for members to link to. OL added a BCA social media presence can be used to help advance individual members messaging and is a really good idea. AM said a Twitter account will cement that collaborative group that we are all members of. KB argued that whilst social media can be useful, there will also be a cost element and that the account will need to be updated regularly to avoid reputational damage.</li> </ul> <p>CW then fed back on Blood Cancer UK's plans for BCAM 2020, sharing it is the charity's 60<sup>th</sup> birthday and that they will be looking back at some of their historical research. The charity is hoping to publish an impact report, but that, that work is ongoing. SW shared that MDS UK will participate in an international awareness campaign on MDS, led by the MDS Alliance, engaging in a number of UK webinars and will also be supporting world leukaemia day activities.</p>	
8	Industry Partners Forum	<p>MH updated on the latest plans for the Second Industry Partners Forum in October, revealing that the meeting is again likely to be virtual, and that the agenda will focus on:</p> <ul style="list-style-type: none"> <li>• Conversation on early diagnosis</li> <li>• An update on the BCA workstream</li> <li>• Discussion about NICE methods review</li> <li>• Calls to industry from the Access to Medicine Report</li> </ul>	<p>AP to draft agenda for Industry Partners Forum meeting – <b>28/8</b></p>

		<p>KB suggested sharing an embargoed copy of the Executive Summary with partners before the meeting in order to progress the conversation. ZPW concurred, reiterating that he is happy sharing the recommendations for industry with the partners and that this is a good format to have an open conversation.</p>	
9	Parliamentary engagement	<p>CW shared an update on the APPG for Blood Cancer’s plans disseminating that the inquiry on genomics will now take place in the Autumn and that there remains an open invitation for submissions.</p> <p>CF discussed the workstream of the APPG on Stem Cell Transplantation discussing the inquiry on health inequalities for transplant patients, indicating the inquiry will explore the experience of patients and the barriers patients face because of their background. CF concluded by adding that written evidence is open until October with evidence sessions planned later in the month, ready for the report to be finalised before Christmas. ZPW suggested the BCA can submit a response to the inquiry.</p>	<p>AP and members to work together on producing a submission for APPG inquiry - <b>Ongoing</b></p>
10	Blood Cancer CEOs group	<p>ZPW confirmed this is being rebranded to the Blood Cancer CEOs group, suggesting this will help ensure there is no confusion.</p> <p>ZPW share his involvement in the data sub-group, contending the group is looking at the blood cancer dashboard and how to use the data. AC added it is important to discuss how we communicate the findings that arise from the data and that the group is working on progressing a plan around blood cancer dashboard and ensuring the data is used.</p>	



		<p>ZPW asked for feedback from the patient information workstream. SSu responded saying the main focus is on the issues previously highlighted in the meeting. OL agreed.</p> <p>ZPW queried if any members are involved in the research workstream. CW confirmed BCUK's engagement, highlighting conversations are ongoing with a number of charities and the plan to bring the alliance together to discuss the research sometime in September.</p>	
12	AOB	<p>ZPW concluded by raising the issue of BCA leadership, issuing an open invitation for any member to become part of the leadership. ZPW added the BCA is asking to be part of the Cancer Delivery taskforce and that AN is volunteering if we are successful and asked if there is any other AOB.</p> <p>CW expressed that she is in contact with Macmillan about the taskforce, confirming he will update when he hears more. CF shared her latest information, which indicated the taskforce is planning to report on September. AC then confirmed her 12 month secondment. ZPW thanked AC for her service to the BCA, bringing the meeting to a close.</p>	<p>Members to contact AP if interested in becoming part of the BCA leadership – <b>Ongoing</b></p> <p>AP to chase Professor Johnson re: Cancer Delivery Taskforce – <b>17/8</b></p>

**Next Meetings**

Date	Agenda
Tuesday 3 <sup>rd</sup> November	TBC