

May IPF Meeting – Wednesday 19th July 2023

Members present: Dawn Farrar (DF), Yasmin Sheikh (YS), Orin Lewis (OL), Sarah Galley (SG), Ella Guthrie (EG), Scott Purdon (SP), Tara Steeds (TS), Andrew Todd (AT)

Atticus Partners Secretariat (AP): Katie Begg (KB), Keisha Bullock-Singh (KBS), Joe Watts-Morgan (JWM).

Section	Minutes	Actions
Welcome	DF began the session & welcomed members to the call. DF alerted members to Charlotte Crowley's non-attendance due to illness.	
New CIO Process & Strategy	<p>DF outlined the new CIO structure. DF says that BCA has a new set up and governance, with its own trustees. DF said BCA would be recruiting for policy and public affairs positions & would be advertised in the near future, with AP no longer being secretariat. As part of that, the CEOs have called on BCA leadership to formulate a strategy with a tender going out to a company to complete this strategy, with Firetail receiving a beginning contract.</p> <p>DF opened the floor to questions.</p> <p>No questions.</p> <p>DF said that they did this to better serve the members & to get a better understanding of the members' views.</p> <p>DF outlined the questions on the CIO slide & asks members present for their thoughts on "What does the group understand to be the impact of the BCA's current policy and public affairs work?"</p> <p>OL said that it feels that the stakeholders in the blood cancer community are more aware of what BCA stands for but questions whether the public affairs brand has reached its potential.</p>	<ul style="list-style-type: none"><li data-bbox="1675 671 1688 687">•

	<p>YS asked if there are other charity alliances that can serve as examples.</p> <p>OL said the National BAME Transplant Alliance has a public & political awareness of their brand, which the BCA could copy. OL outlined a speech he gave at the Great Ormond Street Hospital where BCA did not resonate when mentioned, indicating BCA needs to up its game in his opinion.</p> <p>TS echoed OL's point but says the work done on a policy level is "brilliant." TS says that presence is needed to improve with campaigning and awareness needing a boost. TS mentioned Cancer52 in reply to YS question.</p> <p>DF thanked TS for her point & outlined that striking a balance between the BCA members size and their activity is difficult. DF agreed with OL and TS points about doing more to grow the BCA brand and is what the new strategy is hoping to resolve.</p> <p>DF asked if there are any more comments.</p> <p>SG said that if BCA wants to be more visible, One Cancer Voice submitted a petition to Downing Street in March regarding the Long-term cancer plan, with BCA having the potential to copy the more visible aspect of this campaign.</p> <p>DF moved onto the second question, "Does the group understand how priorities are determined," & opened the floor to discussion.</p> <p>DF outlined the current process to get the debate started.</p> <p>EG said in principle it is good to have members deliver input & mentions the Quarterly meeting positively, saying she doesn't have many issues with the current process.</p> <p>DF mentioned that Cancer52 could hold lessons for BCA, saying they meet</p>	
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	<p>very often but feels BCA aren't big enough to do that yet.</p> <p>KB said one thing that used to work was when the BCA would meet in person & workshop priorities pre-COVID.</p> <p>YS picked up on this and said that they have an open-door policy, and any members can approach the secretariat or policy group with ideas. YS asked if it would help if they had a form so members could submit ideas, or if the status quo be maintained.</p> <p>OL said it is not a bad idea to have a more formal process for questions and ideas. OL asked what impact the secretariat has had in terms of shaping priorities.</p> <p>YS said it has been a collaborative process with it being member driven but it has been helpful to have secretariat providing advice.</p> <p>OL said the new secretariat could change the dynamics of how it works.</p> <p>DF said it is her understanding that the secretariat will answer to Charlotte, but this will be done collaboratively with the CEOs. The new secretariat will take a more administrative role, with one of the people employed being an admin assistant.</p> <p>DF said it is a case of finding a balance of how often the BCA meets and what they priorities are. DF thanked members for their comments.</p> <p>DF moved onto the third questions: "Do they feel informed on progress as members?"</p> <p>TS mentioned that she really values the weekly emails & is keen to continue these going forward.</p> <p>DF followed up, asking if the Quarterly Meeting is valuable.</p>	
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	<p>TS replied that the Quarterly Meetings are still valuable & a potential fortnightly call would be unnecessary.</p> <p>DF moved onto the fourth point: “Do they feel they can contribute to the priorities?”</p> <p>No answer.</p> <p>DF moved onto the fifth point: “Are there any areas for policy development or change that are missing from current priorities?”</p> <p>No answer.</p> <p>DF moved onto the sixth point “How could the BCA support your work as a member organisation who conduct policy, public affairs and campaigning activities?”</p> <p>OL said it could be worthwhile utilising social media in a collaborative way, with each organisation showing support for BCA members’ posts.</p> <p>DF thanked OL for this point and reiterated it.</p> <p>DF asked if there are any more questions.</p> <p>DF moved onto the next section.</p>	
<p>Update on BCA Workstream</p>	<p>KB opened the floor to KBS to handle this section.</p> <p>KBS outlined the work on the Major Conditions Strategy, with BCA submitted five commitments to the Call for Evidence. KBS then said that AP had sent letters to parliamentarians and sent social cards to members. KBS called on members to use the social cards on their social media accounts to expand its reach further.</p>	<ul style="list-style-type: none"> • YS to share Unmet Needs video from the University of Hertfordshire with BCA members • YS to brainstorm with OL about potential PR

	<p>KBS outlined that letters that have been sent to Parliamentarians, as well as the specific ones we've heard back from. KBS mentioned the responses who have responded, including Martyn Day and Henry Smith. Lord Mendelsohn also committed to submit a Parliamentary Question on the issue due to his lack of availability for a meeting.</p> <p>KBS moved onto the Major Condition Strategy Civil Service Letter, which was slightly adapted from the letter to Parliamentarians. KBS made clear that this would be sent to Tim Jones and Verity Algar at the Department of Health and Social Care.</p> <p>KBS asked members what they've done for the Major Conditions Strategy & what AP could do to support</p> <p>KB also added if members made individual submissions to the Major Conditions Strategy Call for Evidence.</p> <p>EG said that Leukaemia Care did their own submission, social media & did a blog on the Major Conditions Strategy.</p> <p>DF said Leukaemia UK did their own submission & will do a blog for social media soon.</p> <p>SP said the Major Conditions Strategy was a great example of BCA's impact as given capacity constraints they were able share respective responses so they could see what was captured by respective organisations. SP praised the social media strategy & said it was an example of why BCA come together and called for more of it in the future.</p> <p>KB thanked SP for his answer & opened the floor to more contributions.</p> <p>TS said Lymphoma Action did make a submission and echoed SP's point on social media.</p>	<p>to done with the video upon its release</p>
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	<p>KB said AP would share the Major Condition Strategy submission to members to ensure there is a consensus between members and industry partners.</p> <p>DF said going forward there would be a mini review in July between members.</p> <p>KB agreed & outlined the 500 words limit in the submission, in response to large submissions the year before. KB mentioned that the process involved ensuring that all members' views were represented.</p> <p>KB moved onto the Unmet Needs stream of work. KB said that after the poster at the British Society of Haematology in partnership with the University of Hertfordshire, the university has said they have the budget available to commission a video explaining the research in more detail which they will share with the BCA.</p> <p>YS said BCA has been promised the video by the end of the month by the University & would share with members.</p> <p>KB moved onto BCAM. KB said the plan is to use the video as the basis for the Social Media Action Day for the 18th of September, with the video being launched. KB opened the floor to thoughts.</p> <p>OL asked if there would be PR on the video around the day to get national and/or local media attention on the video upon launch.</p> <p>KB said she would like there to be some, but the biggest concern is budget to see if this is possible.</p> <p>YS said this was welcome idea & she would love to brainstorm with OL afterwards about this.</p>	
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	<p>OL indicated his approval & said this could be effective in getting the media's attention.</p> <p>YS said it would be useful if they could find someone with lived experience to connect with journalists for a story.</p> <p>KB said this should be possible given existing contacts during the Clearview research. YS said the policy group would pick this up with budgets & timelines.</p> <p>KB asked if there were any more comments.</p> <p>TS said she would be supportive & flagged it would be lymphoma support day on the 15th of September, around the time of Social Media Action Day. KB said TS could share anything regarding lymphoma support day for BCA to include in their calendar & AP would include this into the BCA's social plan for September.</p> <p>SG said she would be supportive of the Social Media Action Day as well.</p> <p>KB said it was important to receive the video and have discussion outside of the call about what would occur during the day, with a plan shared with members. KB asked if members had any BCAM plans they want to update.</p> <p>TS said they plan refresh their campaign on lymphoma this year & would launch a signs and symptoms animation in September, as well as key case studies with a focus on 20–40-year-olds.</p> <p>KB asked if there were any more questions.</p> <p>No more questions.</p> <p>KB outlined the work on Early Diagnosis, saying that the Policy leadership team had put together a data tender project. KB continued that the project</p>	
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	<p>would allow the BCA to find out what data sets are available across all four regions of the UK to better inform understanding of diagnosis in blood cancer, as well as to understand what is accessible on a public level. This would then lead to comparing differentials amongst data sets whether the data is working on a national level. KB said that the data tender is ready & they have been looking at a list of potential organisations who are effective are data analysis/research that could be interested and welcomed any suggestions from members. KB mentioned that AP have written to David Fitzgerald from NHSE on their plans for public awareness campaigns on blood cancer outlining BCA's concerns on the broader approach.</p> <p>KBS said there has been a response with David Fitzgerald & she is currently liaising with BCA leadership on a possible response.</p> <p>KB opened the floor to questions.</p> <p>No questions.</p>	
<p>BCA Funding Update</p>	<p>KB went through the Y5 Funding Summary. KB mentioned that BCA was near the end of the Y5 funding, and that the majority of the existing funders have funded again. KB said that the Y6 funding begins in August and that the process of fundraising has already begun, with Sanofi replying soon about potential funding for Y6.</p> <p>KB asked if members had any questions about funding.</p> <p>SP asked if the funding is unrestricted. KB confirmed it is. SP followed up by asking why a company would fund more than another. KB said one of the drivers of having a bank account with the CIO, is that there is a VAT issue with AP receiving the money. KB clarified that there isn't a tiered funding rating, with there instead being a range of funding with the maximum and minimum of £15,000-£30,000. KB said one of the things the CIO would review would be the possibility of other funding streams, such as the pharmaceutical industry.</p>	

	<p>KB asked if there are any more questions.</p> <p>No more questions.</p>	
<p>Access to Medicines Engagement incl. VPAS</p>	<p>YS outlined the BCA's work on VPAS. YS said this stemmed from the Access to Medicines report from a few years ago which highlighted blood cancer medicines being particularly affected by inflexibilities in the current system, with data indicated this is becoming worse in recent times. YS said that most recently BCA has been focusing on the voluntary scheme (VPAS) with the negotiations currently taking place. YS mentioned that the BCA is arguing that 1) the BCA wants to be involved in the process due to the charities' role as patients' representatives 2) that fewer innovative blood cancer medicines are being brought to NICE due to current access environment. YS brought up that the BCA has been invited to some of the VPAS meetings & have met Claire Foreman and Jack Turner from NHSE, indicating some progress. YS qualified this by saying BCA has not been invited to the crucial discussions on pricing and how NICE works, but they have submitted their summarised point of view to NHSE for consideration during negotiations, with an update coming soon. YS made clear that this would not be the end of the BCA's role with a view to obtain more of a meeting focus. YS opened the floor to discussion.</p> <p>SP said YS framed it really well & asked why the BCA is getting involved in VPAS and what the BCA's role would be.</p> <p>YS thanked SP for his contribution & said the BCA is neutral on the issue of the level of the rebate. YS said the BCA's main priority is seeing pricing flexibility in the NICE process & for new medicines to come through the NICE process.</p> <p>KB asked SP if the government statutory instrument is a negotiating tactic.</p>	

	<p>SP said all schemes have been in parallel & that the statutory scheme does not merely focus on generics.</p> <p>KB asked DF about the statutory scheme and if they were reviewing it in case there is no success in VPAS.</p> <p>DF said it the scheme was published yesterday.</p> <p>YS asked if there are any other examples of non-submission from members.</p> <p>No contribution.</p> <p>YS asked if there were any final comments on VPAS from members.</p> <p>No final comments.</p>	
AOB	<p>YS thanked members for attending & for their participation.</p> <p>YS invited members to follow up if they have something to share or want to know more from information raised in the call.</p> <p>YS brought the meeting to a close.</p>	