

Blood Cancer Alliance

Minutes of the meeting held via Zoom on Thursday 25th November 2021

Members present: Rachel Allison (RA), DKMS UK; Dallas Pounds (DP), DKMS; Amy Capper (AC), Myeloma UK; Dawn Farrar (DF), Leukaemia UK; Caitlin Farrow (CF), Anthony Nolan; Orin Lewis (OL), ACLT; Ella Guthrie (EG), Leukaemia Care; Amanda Harris (AH), Lymphoma Action; Thomas Mallon, Leukaemia and Lymphoma NI; Charlotte Martin (CM), Leukaemia Care; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Yasmin Sheikh (YS), Anthony Nolan; Christopher Walden (CW), Blood Cancer UK; Sophie Wintrich (SW), MDS UK Patient Support Group.

Apologies: Daniel Cairns (DC), Myeloma UK; Julie Child (JC), Race Against Blood Cancer; Norah Grant (NG), CLL Support; Shelagh McKinlay (SM), Myeloma UK; Dave Ryner (DR), CML Support Group;.

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

Guest Speakers: Sandra Hicks (SH), Clearview; Kenny Imafidon (KI), Clearview; Niamh McGarry (NM), Clearview; Sara Main (SM), University Hospital Southampton NHS Foundation Trust.

No.	Agenda Item	Minutes	Actions
1	Welcome	Introductions made and minutes agreed.	AP to upload minutes from the August quarterly meeting to the website – Complete
2	Secretariat update	<p>BP reported back on activities from the last quarter, highlighting work had focused on the following developments:</p> <ul style="list-style-type: none"> • Submitting response to Health and Social Care Select Committee Inquiry on Cancer Services • Drafting and sent a letter to Health and Social Care Secretary • Continuing to liaise with partners re: support for the BCA Policy Group 	

		<ul style="list-style-type: none"> • Sharing updated social media plans and continued to update the BCA website • Sharing final approved Year 4 Budget with the BCA leadership • Liaising with The Foundry to confirm logistics for upcoming event • Drafting agenda for upcoming Industry Partners Forum and sharing with partners • Updating the BCA Policy Group MoU and attending CEO group meetings • Sharing relevant parliamentary updates from the Budget and the Spending Review • Confirming and signing funding agreements with Takeda and Janssen <p>BP moved on to provide a funding update revealing the following developments:</p> <ul style="list-style-type: none"> • By the end of Year Three, the BCA had £93,784 in the bank account with £83,834 allocated to campaign activity and supplier costs. • Current BCA Policy Group expenditure for Year Four from August to November is £60,103. This expenditure had been spent on the following workstreams and projects: <ul style="list-style-type: none"> o £19,850 spent on secretariat fees, o £21,030 on suppliers costs o £19,223 on campaigns and public affairs. • The current remaining funds in the bank account are £48,691. 	
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	<p>BP then disclosed the BCA leadership had been participating in a number of conversations with industry partners, divulging:</p> <ul style="list-style-type: none"> • The BCA Policy Group had received funding commitments from Takeda, Janssen, AbbVie and Incyte. • There had been warm conversations with Gilead and Roche. • Meetings had been held with Pfizer, Amgen, Novartis, BMS. <p>BP opened the floor to questions, confirming the funding update will also be shared with the minutes.</p> <p>KB accelerated to discuss the Access to Medicines campaign, highlighting the desire to continue the campaign in a more targeted manner through focusing on one or two key recommendations from the report. KB progressed to concentrate on the actions emerging from the Access to Medicine workshop in September, including the decision to centre activity on how data can be improved to improve patient treatment. KB announced that to achieve this, the following actions will be the main priorities:</p> <ul style="list-style-type: none"> • Gaining real world evidence through talking to industry about how data can be included in submissions and how industry can work with other stakeholders to improve submissions. • Talking to HTA agencies to ascertain data needed to ensure submissions are accurate. 	<p>AP to share funding update alongside draft minutes – 17/12</p>
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		<ul style="list-style-type: none"> • Focusing on clinical uncertainties and talking to NICE and relevant stakeholders. • Working with NHS England to secure access to relevant data. <p>KB proceeded to raise ongoing conversations with the BCA leadership, stating that to coincide with funding timetables, this action will be paused until the funding agreements with partners had been signed. KB confirmed that upon receiving the funds, the work will begin with the immediate priorities including messaging and stakeholder map. BP added that as soon as the agreed money is received from Janssen we will be in a position to begin the work.</p> <p>KB then opened the floor to questions:</p> <ul style="list-style-type: none"> • SW highlighted a conversation on the Harmony project about real world evidence and using data generated in HTAs, which had generated interest from a representative at NICE. ZPW confirmed he is also part of these conversations. KB suggested this information will be useful for the messaging with SW confirming she will research the relevant representative from NICE. • CM raised the NICE methods review revealing conversations with partners and their ongoing lobbying. KB suggested that this could be explored further at the IPF next week. • SW asked about commercial value vs cost effectiveness of a drug highlighting latest cases in 	<p>AP to proceed next stages of the campaign - Ongoing</p> <p>KB and SW to arrange follow up call to discuss messaging – Ongoing</p> <p>SW to research relevant individual from NICE- Ongoing</p>
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		<p>across the world, suggesting there might be some work to be done in this area. KB responded that when the funding situation developed, a new priority session could be arranged at the next quarterly meeting, where we could investigate future workstreams.</p> <ul style="list-style-type: none"> • CF emphasised that CW has sent through the IMF consultation, recommending the BCA produce a unified response instead of preparing individual responses. CW concurred, arguing a joint response will have more power. CM added she will be drafting a Cancer52 response. <p>KB concluded saying it was her assumption that there would be a BCA group submission and that it would be helpful if members could send through initial thoughts in December, with the aim of completing the first draft by mid-January.</p>	<p>Members to share thoughts on IMF consultation – 7/1 AP to complete first draft of consultation – 14/1</p>
3	Unmet Needs Campaign	<p>MH provided an update following the launch of the Unmet Needs Campaign, confirming:</p> <ul style="list-style-type: none"> • Sharing of press release with over 50 different outlets securing piece in CharityToday. • Participating in call with NHSE to discuss press release. • Designing nine social media cards, securing support from Henry Smith MP and Alex Norris MP. • Sending over 300 emails to a range of different stakeholders, gaining interest in meetings from the ABPI, Jackie Baillie MSP, Paul O’Kane MSP, Russell George MS and Lady Finlay of Llandaff. • Updating website to create a new page for the #TheForgottenFifth. 	

		<p>MH added that going forward, the policy group will be focusing on the following activities:</p> <ul style="list-style-type: none"> • Confirming and securing a meeting with NHSE. • Following up with stakeholders to secure meetings. • Continuing to update website with relevant information. <p>MH then progressed the conversation to discuss policy asks related to the campaign, opening the floor to conversation:</p> <ul style="list-style-type: none"> • SW highlighted the need to ensure MDS is not forgotten. KB concurred, saying we need to ensure that we have all of the information about summary codes available and that this conversation could continue offline. • YS questioned what the existing barriers are to implementing the policy recommendations, querying who is responsible for these areas and who we need to engage with. YS also raised the possibility of providing tangible examples of where we would like to see change. CF concurred, expanding that it will be highly beneficial to have good on the ground experiences of where blood cancer is forgotten. • CF then raised feedback from NHSE on blood cancer dashboard, contending it is NHS Digital who are now running the dashboard, posing what practical process NHSE will need to go through to implement the asks. • KB believed meetings with NHSE will help, suggesting we could ask supportive parliamentarians to put down 	<p>KB and SW to continue conversation about summary codes – Ongoing</p>
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		<p>PQs asking about the data dashboard to draw out answers. CF said her instinct was to be cautious and that it is important to liaise with NHS Digital before being too forward, recommending an alternative option of asking parliamentarians to draft a supportive letter.</p> <ul style="list-style-type: none"> • BP posed a question on the tactical asks that we might ask industry. CM talked about if the recommendations were linked. KB confirmed this is where we started and then as we developed the campaign the other asks centred on working towards achieving the first policy recommendation and that there is a desire to develop more policy asks as we go along. • KB expanded that this campaign lends itself towards a Westminster Hall debate and that she would like to give supportive MPs some activities to proceed the campaign. • KB then looked at how we could secure a meeting with NHSE and that the next stage might be to follow up with the cancer team starting with the assumption that a meeting had been agreed and be more forward. CF agreed that this would be a good approach. CW concurred highlighting his conversations with David Fitzgerald, suggesting he could follow up. KB concluded that the secretariat would draft an email to share with the leadership. • CF moved back to the ABPI and IPF. CF asked if members could also email their thoughts about these areas to the leadership and the secretariat. 	<p>AP to draft approach email to David Fitzgerald – Complete</p> <p>Members to share updates on policy recommendations for engaging with industry - Ongoing</p>
4	Devolved Nations Update	CF introduced TM to provide an update on the situation in Northern Ireland.	

		<ul style="list-style-type: none"> • TM subsequently highlighted that LLNI had held an online engagement event and were planning for a board away day where the strategy of the charity is to be discussed. TM added that LLNI had submitted a response to the Northern Ireland Cancer Strategy and are investigating how to influence further and are likely to make decisions in the next couple of days. • YS then proceeded to analyse the situation in Wales, noting that there was an ongoing meeting with the Wales Cancer Alliance (WCA) and that she will share an update after this meeting. YS expanded that there had been a significant transition since the last meeting, with limited developments since the Quality Statement, but that there is due to be an implementation plan. YS highlighted the WCA is meeting with the new minister in January and requested members sharing any questions with her in advance of the meeting, adding there is a webinar arranged with Dr Keith Wilson who will be delivering a seminar on advanced therapies and infrastructure for delivering CAR-T. • YS concluded, revealing that the Welsh Assembly Health and Social Care Committee had issued a new consultation, asking if any members had any Wales specific data they could share. CW responded that Blood Cancer UK could secure access to patient and healthcare professionals but didn't have easy access to data. YS followed by questioning if there is any data on blood cancer and role of the third sector in tackling backlog, recommending we discuss further as an 	<p>YS to provide update from Wales Cancer Alliance – Complete</p> <p>Members to share questions with YS ahead of WCA meeting with Health Minister – Ongoing</p> <p>YS to share link for seminar with Dr Keith Wilson – Complete</p> <p>Members to share relevant data with the BCA leadership and secretariat re: consultation – 17/12</p>
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		<p>alliance and decide if the BCA can produce a response.</p> <ul style="list-style-type: none"> AC delivered an overview of developments in Scotland, sharing that the Scottish Cancer Coalition had met with Cabinet Secretary for a Question and Answer session, where the Cabinet Secretary highlighted that there will be a challenging winter ahead and that further updates will be provided in December. AC added that Myeloma UK are continuing to attend the coronavirus response group, and will provide an update in the next meeting, offering to share any questions members had with DC. 	<p>Members to share questions on Scotland with DC - Ongoing</p>
5	CEO Group Update	<p>CF then introduced ZPW to provide an update on the BCA CEO Group.</p> <ul style="list-style-type: none"> ZPW announced that the BCA CEOs group has now approved the new Terms of Reference considering the ways it will be working and how to correlate groups effectively. ZPW added that going forward the CEO Group is looking at formalising a leadership structure and formal strategy for ways of working, adding that any further questions could be shared offline. 	<p>Members to share questions on BCA CEO group with ZPW - Ongoing</p>
6	Impact of blood cancer on BAME population	<p>KB moved onto the next agenda item, welcoming SH, KO and NM to provide an update on their recent research.</p> <p>SH introduced ClearView setting out the recent work of the organisation and their ongoing work, before progressing to discuss the research proposal, highlighting that the research had the following aims and objectives:</p>	

		<ul style="list-style-type: none"> ● Understand the lived experiences of people from Black, Asian and ethnic minority communities who have had a blood cancer diagnosis. ● Identify the challenges these communities have faced and specific unmet needs throughout their journey to diagnosis, treatment and access to support. <p>SH then outlined the methodology adopted to carry out the research, noting the following steps:</p> <ul style="list-style-type: none"> ● Conducting literature review ● Establishing a co-creation group of 6 paid advisors with lived experience of blood cancer ● Co-creation of an online survey ● Facilitating a workshop session to zoom in on areas of main interest ● Hosting two exploration labs and holding three 1-2-1 interviews. <p>SH progressed to share the main findings from the research, revealing the following information:</p> <ul style="list-style-type: none"> ● Patients from Black, Asian and ethnic communities are four times more likely to have delays to referral for their blood cancer diagnosis. ● Majority of participants did not feel as though they were taken seriously when they explained their symptoms to GPs. ● Many experienced racial discrimination during their diagnosis journey. 	
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		<ul style="list-style-type: none"> ● Patients felt they could have been told about their diagnosis in a more sensitive way. ● Participants felt there was no time to deal with their diagnosis and they were rushed into treatment, with under half not understanding their diagnosis. ● Patients were afraid to ask clinicians questions and seek information elsewhere. ● Patients did not feel involved in making informed decisions about their treatment. ● Patients felt like they had no control over clinical trial treatment decisions. <p>Drawing the presentation to a close, SH noted the following lessons and considerations:</p> <ul style="list-style-type: none"> ● Important to recognise and understand how diverse a patient's needs can be. ● Family members are not always informed about their loved one's diagnosis. ● Having access to the right information when you need it is key. ● Charities can be a key source of information and support when accessible. <p>SH then concluded, highlighting these considerations for charities:</p> <ul style="list-style-type: none"> ● Showcase stories and case studies ● Raise awareness ● Provide a clear guide ● Educate healthcare professionals 	
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		<p>SH and NM then opened the floor to questions.</p> <ul style="list-style-type: none"> • AC asked about the sample size and whether the data is statistically significant. KB said the sample is small, arguing that the data is indicative, reiterating that these patients are hard to reach, highlighting the value of the exploration groups. CF concurred, noting we needed to be careful with the language used when presenting these findings. • AC followed to query what strategies existed to further reach these groups. NM responded articulating that the survey allowed for a breadth of different experiences and the research should be viewed as a more qualitative than a quantitative piece, adding that to increase the number of respondents to the survey a very different approach might be needed. NM revealed that surveys originating from trusted medical contacts often had a far bigger reach, disclosing other work ClearView had performed with other charities, where four to six months had been set aside to build a relationships and trust and create a larger sample size. • OL stated the findings resonated with his past experience, outlining that nothing has really changed, explaining this is a possible reason for hesitancy amongst these communities. OL argued there is a lot more that needs to be done on all aspects of the journey and that the numbers are indicative of the experiences of BAME people and there are many lessons to be learned. 	
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		<ul style="list-style-type: none"> • KI expanded on OL's reasoning, talking about the lessons that can be learned and the time and investment that will be needed to secure a bigger sample, recommending that the BCA make this a bi-annual survey. • DF asked what the next steps might be, questioning whether there is a necessity to analyse BAME data being completed by CPES and whether this can add weight to the existing research. NM asked whether CPES will share data by ethnicity. CW and CF suggested this should be possible. • SM revealed her past experiences, stating that training didn't consider how blood cancer symptoms differed for individuals from a Black, Asian and ethnic minority communities and that there is a lack of education amongst healthcare professionals. KB thanked SM, saying this research could be a good evidence base to begin these conversations and could be viewed as indicative of the problems and should be assessed as a starting point for more work down the line. • NM argued there is value in Black, Asian and ethnic minority communities patients seeing this research has been completed, which will create a feedback loop, leading to more volunteers being willing to participate in the future. • KI asked for confirmation on the next steps and that it is important patients know their experiences are validated, suggesting responding publicly on website about what the BCA is going to do next. KB confirmed we will feedback on next stages, passing on relevant information to ClearView. 	<p>KB to liaise with ClearView re: next steps of research - Ongoing</p>
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7	Current situation on the frontline	<p>CF then proceeded to introduce SM from the University Hospital Southampton NHS Foundation Trust.</p> <p>SM shared an update from Wessex, revealing a catchment area of 3.75 million people, many of whom were located in distant areas. SM added that the service was very busy with the team being very small, pointing to an increase in activity of 97% from 2011 to 2018.</p> <p>SM discussed the impact of the lockdown and the desire of healthcare professionals to protect patients, revealing not all patients received a letter explaining their status. SM expanded that this challenge was happening among increased media attention about how care was to be delivered and ongoing fears about lack of equipment and lack of oxygen, confirming most hospitals totally rearranged their organisation and were very concerned about lack of capacity in intensive care.</p> <p>SM added lots of treatments were postponed with patients reporting difficulty in accessing care and were fearful of going to hospitals and A & E, disclosing a patient survey revealed that revealed 74% of transplant patients had worse mental health as a response of the pandemic.</p> <p>SM invited members to participate in a virtual exercise linking to a question debating which three words sum up working during the pandemic, deciphering that the most popular words chosen by members were uncertainty, communication, stress and anxiety. SM then revealed she had conducted a similar exercise with her team whose biggest words were anxiety, safety, change, flow, auto backlog and swabbing.</p>	
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		<p>SM articulated that the change and uncertainty were very difficult to deal with and many senior doctors and nurses had to shield and work from home which impacted staff and patients. SM confirmed the presence of a hot phone where patients could communicate with the healthcare professionals. These calls revealed concerns from patients about seeing family and staying connected and expressing concerns about how treatment had changed. SM reiterated these patients already existed in a group where needs are not met and that the pandemic has shone a further light on this.</p> <p>SM indicated recovery planning has begun a long time ago and that healthcare professionals found new ways of working, all designed to protect staff and patients, ensuring vulnerable staff were not working in vulnerable areas. SM confirmed swift adjustments were made to cancer care and that all healthcare professionals had to work together to ensure the needs of cancer patients were maintained and that there were ongoing negotiations about how to look after cancer patients without neglecting covid responsibilities.</p> <p>SM concluded by saying there remain existing limitations in terms of staff and experience and there is a need to articulate clearly what was needed to decision makers, highlighting a 6 week pause in transplants had caused delays to 68 patients and that catching up on transplants is not as easy as other treatments. SM ended by saying it is vital patients receive the right treatment, but that the pandemic offered silver linings about how treatment and care could be flexible and how</p>	
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		<p>service can be offered in a more diverse way to meet patient needs.</p> <p>CF concluded by thanking SM for all that her and the team have done, suggesting if there are any follow up questions, they can follow up with the Anthony Nolan team</p>	<p>Members to follow up with CF and YS -</p> <p>Ongoing</p>
8	AOB	<p>ZPW ended the meeting by thanking CF for all of her work and wishing her all the best as she went on maternity leave.</p>	

Next Meetings

Date	Agenda
TBC	TBC