

**Blood Cancer Alliance**

**Minutes of the Industry Partners meeting held on Thursday 1<sup>st</sup> October 2020**

**Members present:** Julie Child (JC), Race Against Blood Cancer; Daniel Cairns (DC), Myeloma UK; Caitlin Farrow (CF), Anthony Nolan; Orin Lewis (OL), ACLT; Sarah Mallick (SM), Leukaemia Cancer Society; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Stephen Scowcroft (SS), Lymphoma Action; Steffi Sutters (SSu), CLL Support; Chris Walden (CW), Bloodwise; Sophie Wintrich (SW), MDS Support.

**Partners present:** Matt Bonnington (MB), Kyowa Kirin; Michael Collins (MC), Janssen; Sasha Daly (SD), Celgene; Vicky Hargreaves (VHa), Novartis; Victoria Hayes (VHs), Kyowa Kirin; Asha Kaur (AK), Sanofi; Frances Luff (FL), Gilead; Lolita McGee (LM), Celgene; Bemil Odunlami (BO), Novartis; Emily Pegg (EP), Takeda; Anita Ralli (AR), Gilead; Barbara Taylor (BT), Novartis; Nicola Trevor (NT), Janssen; Lee Wilmott O'Brien (LW), Amgen.

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

No.	Agenda Item	Minutes	Actions
1	Welcome and Introductions	Introductions made.	
2	Presentation from BCA: Update on BCA priorities and workplan in context of COVID19	<p>ZPW welcomed all attendees to the meeting and explained BCA progress in the last six months, since the last meeting had focused on:</p> <ul style="list-style-type: none"> <li>• Agreeing the Access to Medicine report.</li> <li>• Beginning work on launch campaign for Access to Medicine report.</li> <li>• Sharing tender document for the Unmet Needs project.</li> <li>• Confirming priorities for the upcoming year including agreeing a report on the impact of blood cancer on BAME patients.</li> <li>• Welcoming new member Leukaemia Cancer Society to the BCA.</li> </ul>	

		<ul style="list-style-type: none"> <li>• Participating in meetings with politicians in Westminster and across the devolved administrations.</li> <li>• Drafting responses to relevant DHSC consultations.</li> <li>• Creating a BCA Twitter account.</li> <li>• Securing participation on the National Cancer Taskforce.</li> </ul> <p>ZPW then opened the floor to contributions from the attendees.</p> <p>SD asked when industry partners will be able to see the draft Access to Medicine report. ZPW explained a specific section in the agenda had been set aside to discuss the report and that whilst the BCA leadership had agreed it was not appropriate to share the full document with industry ahead of its release, they were keen to discuss some of the specific recommendations in today's meeting.</p> <p>EP expressed she appreciated the clear focus on a few priorities and the emphasis placed on delivering on these aims.</p>	
3	<p>Access to Medicine Report: Discussion on recommendations to industry</p>	<p>ZPW then moved to the next agenda item, handing over to KB.</p> <p>KB updated on the progress achieved on the Access to Medicine report, reinforcing previous statements from ZPW. KB explained the reasons for commissioning this report, highlighting the issues facing blood cancer patients and the requirement of different techniques and treatments and that the report aims to build confidence in discussing issues around access and enhancing the evidence base.</p>	

	<p>KB clarified the report is a 60 page document and that research had been compiled using the following methods:</p> <ul style="list-style-type: none"> <li>• A rapid evidence review</li> <li>• An environmental scan</li> <li>• Expert interviews</li> <li>• Online survey of patients</li> </ul> <p>KB expanded that the research had been conducted and led by Leela Barham; an independent health expert and that the report had now been agreed with members and will be launched at a virtual event on Monday 19<sup>th</sup> October. KB added there is also a plan to launch an engagement campaign with various stakeholders, revealing the key findings from the report were as follows:</p> <ul style="list-style-type: none"> <li>• New blood cancer treatments are coming through and HTA agencies and companies need to prepare for their appraisal.</li> <li>• There is a necessity to involve patients from R&amp;D and beyond and for their involvement to have an impact.</li> <li>• A revisiting of modifiers that are not easily incorporated into the approach to the clinical and economic evidence and used in HTA.</li> <li>• Whilst, the CDF has enabled access for blood cancer patients, the change to an Innovative Medicines Fund is causing concern for future access.</li> <li>• There is a need for real-world evidence to investigate uncertainties which are a common feature in the evidence base for blood cancer treatments at the time of appraisal.</li> </ul>	
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		<p>findings and recommendations, including the specific evidence base that has been uncovered.</p> <ul style="list-style-type: none"> <li>• VHa queried which stakeholders we will be approaching within NHS England. KB answered the BCA is presently finalising the list, but that any advice and guidance will be much appreciated.</li> </ul> <p>KB moved the conversation on to the report's recommendations explaining that there is a total of 19 policy recommendations. KB expanded by suggesting the report has tried to find a balance of recommendations but that there were a number of key recommendations aimed at industry, highlighting the following:</p> <ul style="list-style-type: none"> <li>• Industry should develop an evidence base with NICE on the benefits of early engagement, including when patients and their representative organisations are part of the dialogue.</li> <li>• Industry should work with patients and their representative organisations to develop an evidence base on the benefits of early engagement with patients and their representative organisations in industry R&amp;DV.</li> <li>• Industry should work to address the issue of multi-indication pricing.</li> <li>• ABPI to update on progress on combination pricing and publish a road map to adopt a solution.</li> <li>• ABPI and the DHSC to provide a public statement on progress with the commitments on horizon-scanning made in the Voluntary Scheme.</li> </ul> <p>KB opened the floor to questions from attendees.</p>	
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		<p>KB concluded by reiterating all partners are invited to the launch event on Monday 19<sup>th</sup> October.</p> <p>The meeting broke for a short tea break.</p>	
4	NICE methods review	<p>ZPW introduced the next section on the NICE Methods Review, clarifying the purpose of this section is to have a general discussion about the NICE methods review, explaining that most of this is happening at a member level, with various members involved in the different stakeholder groups.</p> <p>ZPW revealed there is an ongoing concern about NICE's appetite for general change and whether all participants are being provided with the opportunity to feed in, citing the lack of communication between the groups is challenging. ZPW confirmed that the review has now been delayed, and that from a Leukaemia Care perspective the three biggest priorities were as follows:</p> <ul style="list-style-type: none"> <li>• Ensuring there are opportunities for patient involvement leading to a tangible impact on outcomes.</li> <li>• Dealing with existing uncertainties and guaranteeing that new therapies and innovations are not viewed with uncertainties.</li> <li>• Addressing the specific technical issues which are within scope of the review but that NICE appears reluctant to address or change such as zero pricing.</li> </ul> <p>ZPW then opened the discussion to further attendees:</p> <p>SM explained she had been sitting on the modifiers group and was glad to be involved but concurred with ZPW's</p>	

	<p>thinking that it is difficult to get an accurate picture of how it is fitting together, suggesting this is disappointing. SM expanded by saying we might have to wait and see what emerges from the report and some issues can be linked to the need for cultural change at NICE, before highlighting the relevant issues from a Myeloma UK angle are:</p> <ul style="list-style-type: none"> <li>• Cost pricing and whether this is in the scope of the review.</li> <li>• Issues of sequencing and uncertainties that follow, accompanied by a desire for a more realistic approach.</li> <li>• Addressing concerns about CDF drugs comparators and appealing to NICE to consider from a real world perspective.</li> </ul> <p>NT fed back on her experiences of the different groups, suggesting the academics within the groups are struggling with the appetite for change, but NICE appeared more open, but needed the green light from DHSC and NHS England and the issue might be coming from these groups. ZPW confirmed he agreed with much of this analysis and this appeared to be a review without a purpose with no stated aims and no clarity about the problems they are trying to address, adding that within NICE there is a tendency to believe the default is correct. ZPW specifically discussed the example of the cost effectiveness of treatment and drugs and the perception this is being adequately handled, concluding he is worried the review is being rushed and is not presently addressing some of the major issues.</p> <p>SSu interjected, stating she is troubled by what she is hearing about the review, believing the review had lost its</p>	
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		<p>way and the BCA needed to find a way to call out these problems, saying the opportunity could be lost if we did not act.</p> <p>SM responded by confirming she agreed with ZPW's reasoning and that we need to consider why this review is taking place in the first place, believing the result should lead to increased access. SM added she believed discussions should have originated on addressing and exploring the current problems. SM acknowledged whilst end results had to be about value for money, but also addressing unmet needs and keeping pace internationally.</p> <p>SSu asked how this might be achieved. SM said the next stages might not be clear until the final report is released but did say she had witnessed a pragmatic view coming from NHS England on a number of other issues and that they could be an ally in encouraging NICE to act.</p> <p>NT agreed and highlighted that at a ground level a number of people from NHS England such as Peter Clark can be pragmatic and influence the decision making process at NICE and that it is often more at a senior level where the problems exist and that if we wait until the end of the consultation then it might be too late. NT also acknowledged that it is unlikely there is ever going to be wholesale change at NICE, but there are aspects open to improvement, concluding by saying the best hope for the report might be the tidying up of a few issues and incremental change and that as we move into the Brexit era it is about keeping up with Europe.</p>	
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		<p>FL believed there is a need to be more vocal about the issues immediately, arguing there is a lot riding on this review if the UK is to continue being a leader post Brexit. FL suggested the launch of the report is an opportunity to put the views of the blood cancer community about what needs to change on the record.</p> <p>AR revealed, industry is often asked about the views of charities and it is important to engage immediately and that by waiting it might be too late and that there is a slight window now to intervene and engage earlier. FL concurred, adding there needed to be a meaningful review and the implications will be severe if there is no significant change, affirming industry needed to hear a strong voice from stakeholders.</p> <p>ZPW highlighted there are another 14 recommendations in the report many of which are targeted at NICE and that the report is going to put out a strong view from the blood cancer community. ZPW acknowledged that presently there isn't an aligned patient community position and with communication difficult, it is hard to decipher who is actively engaging.</p> <p>FL questioned if there is anything more that can be done. ZPW added he had written to NICE highlighting these concerns and setting out his worries with the methods group, reiterating that the whole process had been difficult to engage with and the issue is about securing alignment among different groups.</p> <p>SM asked what industry colleagues are planning to do and whether there are any overarching messages about what they desire from the NICE methods review? AR revealed</p>	
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	<p>they had been working with other groups and sat on a number of the Task and Force Finish groups but didn't have sight of the recommendations from other groups. AR added there is a consensus on the issues that need to change and is happy to look at how industry can facilitate the different patient groups, believing this is vital to achieving change.</p> <p>SM explained the priorities must be to feed into the methods review. AR responded by suggesting she could liaise with the ABPI in working with the different coalitions to put out a statement reflecting the whole industry. ZPW said the BCA couldn't speak on behalf of the other groups but thought this a good idea and that it is important the ABPI speak up. ZPW added it might be hard to explain that we disagree with a review happening behind closed doors and that it is difficult to find the right balance until the full report is seen.</p> <p>FL added she believed the release of the Access to Medicine Report could be used to call for greater patient involvement and engagement to ensure any assessment reflects the patients perspective and that this might also improve traction for the report.</p> <p>SM deliberated about whether a possible way forward is to talk about the process and not just specific issues. ZPW reiterated the blood cancer community was aligned on these issues, but that these conversations needed to be happening at a broader level and that a lot of these issues didn't just impact blood cancer patients.</p> <p>KB said the targets for the campaign included a strong list of decision makers and that the BCA is well aware of the good opportunity the report and launch event provides to</p>	
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		<p>communicate with these figures and that we will be following up with attendees.</p> <p>AR said that whilst there is speculation from NICE this isn't a one-stop review, this has not been a consistent experience of NICE, with reviews happening periodically and then closing. ZPW echoed those thoughts and hoped similar conversations were happening within other groups and there is a need to hear the voice we are hearing privately in public otherwise nothing changes.</p> <p>SM added she is pleased the BCA has published this report and responded the partners attending had not been seeing the more refined individual messages and that calling for a stronger patient voice and having a strong evidence base are not mutually inconclusive. SM believed it is really important to have this evidence base which will enable further conversation with peers, ensuring the alliance is taken seriously and talking to influential stakeholders.</p> <p>CF suggested this could be framed as part of a life sciences strategy, believing that grounding in this kind of language would make sure it is relevant to Government.</p> <p>SW highlighted concerns about access to patients and that charities were often not able to fully engage with the process. AR confirmed she could come back with more information if useful. SW expanded saying she had tried to engage with NICE but was often limited and found it hard to make progress on the appraisal system. VHa agreed the patient voice is really important and most of those conversations are driven with NHS England, but there had been some success in gaining updates but that there is room for further</p>	
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		<p>improvements and industry could push for engagement at patient meetings.</p> <p>BO asked to what extent the BCA is engaging with different stakeholders, including different academics and that as this is a methods review there is going to be a heavy focus on technicalities. BO added there is a tendency for NICE to listen to the academic bodies more than other stakeholders, wondering if there is a strong voice from the academics in the report. ZPW highlighted the literature scan which had happened at the beginning of the process, analysing the current evidence and all of the academic experience had been reviewed. KB also highlighted interviews had taken place with a full range of stakeholders.</p>	
5	Improving early diagnosis for blood cancer patients	<p>ZPW handed over to CW for next discussion item on improving early diagnosis for blood cancer patients.</p> <p>CW reiterated the importance of early diagnosis and argued this had only grown in importance in recent months. CW then highlighted the following activities had been ongoing in the medical and blood cancer sphere in this area:</p> <ul style="list-style-type: none"> <li>• Publication of an article from Henry Smith MP.</li> <li>• Receival of an invitation to the BCA to participate in the Cancer Recovery Taskforce and the revelation of a new campaign to be launched on non-specific symptoms.</li> <li>• Agreement of rapid diagnostic centre budgets.</li> <li>• Alignment from charities in responding to NHS England focus on surgery and radiotherapy and impact on referral processes.</li> </ul>	

		<ul style="list-style-type: none"> <li>• Ongoing concern that NHS England will default to concentrating on the big four cancers, reiterating the importance of having a representative on the taskforce.</li> </ul> <p>CW then opened the floor to further feedback from members on improving early diagnosis and BCAM 2020.</p> <ul style="list-style-type: none"> <li>• ZPW spoke about Leukaemia Care’s activities during BCAM 2020, citing the focus had been on patient presentation and delay and that a new e-learning programme had been launched accompanied by a number of webinars.</li> <li>• SSu raised concerns that presently the big focus in the sector remained on COVID and not possible blood cancer symptoms and that there were some very worrying figures.</li> <li>• SM clarified that it is really good to see Gemma Peters involved in the Cancer Taskforce. SM added there is concern from Myeloma UK about the impact of the move to remote consultations and the potential issues this raises. CW concurred, stating people with vague symptoms often do not go to their GPs and need even more persuasion in the current environment and there is a need to be wary of online consultations.</li> <li>• MJ revealed that for Janssen, the ongoing priority remained updating and developing the blood cancer dashboard and that Janssen is looking at securing greater data from devolved nations and is meeting with blood cancer CEOs tomorrow. MJ concluded by discussing emergency presentations and the impact of COVID-19. CW expanded, saying he feared we will</li> </ul>	
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		<p>see a depressing rise in early diagnosis, but that it is good to see a change in language encouraging patients to go to their GPs.</p> <ul style="list-style-type: none"> <li>• CF raised the ongoing APPG on Stem Cell Transplantation inquiry into accessing treatment and care, confirming this had been planned before COVID, but was now even more relevant. CF added the inquiry is trying to explore the different impact on patient groups and how to get to stem cell transplantation point, fearing that many from BAME backgrounds do not reach this point.</li> <li>• OL echoed these views, focusing on the impact blood cancer had had on different ethnic groups and that existing mistrust and fear had been exacerbated by recent developments, making it even harder to secure early diagnosis.</li> </ul> <p>MH then set out that the BCA had concentrated on the following activities during BCAM 2020, raising:</p> <ul style="list-style-type: none"> <li>• The drafting of a letter to relevant political contacts securing meetings with Alex Norris MP, Henry Smith MP, Paul Bristow MP and Pam Cameron MLA.</li> <li>• Sharing of a PDF document highlighting key facts around blood cancer.</li> <li>• Drafting of social media posts for the official BCA twitter account.</li> </ul>	
6	Future logistics and AOB	BP concluded the meeting by setting out the plans for the future, confirming that the next meeting will be in March, adding that further details will be shared nearer the time. BP also expanded by thanking all participants for their support	AP to share March 2021 event details

	<p>and confirming that a picture would be taken for the BCA twitter account.</p> <p>ZPW asked if there was any other AOB.</p> <p>BO interjected the debate around how patients can be involved at earlier stages, looking at the NICE Scientific Advice processes and engaging when it is still early enough to impact the outcome and capture the patient's voice. ZPW agreed this is a useful point and that this had been considered in the processes and there were specific recommendations in the report on this area.</p> <p>ZPW then drew the meeting to a close.</p>	
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**Next Meetings**

Date	Agenda
Thursday 18 <sup>th</sup> March 2021	TBC