

**Blood Cancer Alliance**

**Minutes of the Industry Partners meeting held on Tuesday 30<sup>th</sup> November 2021**

**Members present:** Yasmin Sheikh (YS), Anthony Nolan; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Charlotte Martin (CM), Leukaemia Care; Ella Guthrie (EG), Leukaemia Care; Christopher Walden (CW), Blood Cancer UK; Dawn Farrar (DF), Leukaemia UK; Jane Nicholson (JN), WMUK; Rachel Allison (RA), DKMS; Sophie Wintrich (SW), MDS UK; Amanda Harris (AH), Lymphoma Action; Daniel Cairns (DC), Myeloma UK.

**Partners present:** Keti Tavdshvili (KT), Novartis; Deborah Roebuck (DR), AbbVie; Toby Kent (TK), AbbVie; Danielle Smith (DS), Takeda; Jerome Penn (JP), Takeda; Pia Ballschmieter (PB), Roche; Rachel Howell (RH), Janssen; Richard Gardner (RG), Janssen; Sasha Daly (SD), BMS; Patrick De Barr (PdB), Incyte; Rich Allen (RA), Roche.

**Atlas Partners Secretariat (AP):** Katie Begg (KB), Bethan Phillips (BP), Mike Hough (MH), Keisha Bullock-Singh (KBS).

No.	Agenda Item	Minutes	Actions
1	Welcome and Introductions	<p>ZPW started the meeting, announcing YS as the agreed replacement for CF as chair of BCA Policy Group due to CF going on maternity leave.</p> <p>ZPW welcomed attendees, stating his role as chair of the meeting with all attendees providing short introductions including name, organisation and role.</p>	
2	Access to Medicine Campaign	<p>KB introduced the Access to Medicine campaign, sharing an update on progress achieved on the campaign since the last Industry Partners Forum meeting, noting:</p> <ul style="list-style-type: none"> <li>• The messaging and the policy calls</li> <li>• Meetings with policy stakeholders</li> <li>• Ongoing priorities of the campaign agreed by BCA members at the last Access to Medicine Campaign</li> </ul>	<p>BCA to include a request in Friday emails for members to share information for Innovative Medicines Fund consultation response – <b>Ongoing</b></p> <p>Industry partners to share points for inclusion in the extension of the Access to Medicine campaign – <b>w/c 03/01</b></p>

		<p>KB expanded that BCA members also considered different areas of policy, reaching decisions on which priorities to focus on, concluding that the campaign would look at data. KB confirmed this will involve engaging with policy stakeholders to assess real world data and exploring what organisations would accept as real-world evidence.</p> <p>KB then conveyed the second stream focusing on data will involve looking at uncertainties in first appraisals and addressing how NICE and NHS England can work together to address these uncertainties.</p> <p>KB concluded by discussing details of the action plan created to forward the Access to Medicine campaign, sharing that the process of engagement will begin in late winter / early spring, also confirming the intention of the BCA to draft responses to the National Institute for Health and Care Excellence (NICE) appraisal consultations. KB opened the floor to questions</p> <p>RG asked if the BCA has begun work on the Innovative Medicines Fund (IMF) consultation response. KB responded the drafting of this consultation had yet to start, but that the secretariat will be asking BCA members for input in the upcoming Friday email. KB also revealed that a BCA representative will be attending an IMF event in December, which will help to provide context for the response.</p> <p>DS asked if the BCA will be engaging with patient groups to gather real world evidence as part of the consultation response. KB suggested that the BCA does intend to engage with clinical groups.</p>	<p>BCA to continue engaging with NICE re. Access to Medicine campaign – <b>Ongoing</b></p> <p>BCA to draft letter to Wes Streeting MP introducing BCA campaigns – <b>w/c 03/01</b></p>
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	<p>DR questioned if there are any recommendations specific to industry, upon which they can help. KB divulged the BCA is keen to have conversations with industry, seeing how the BCA can work with them to address the needs of blood cancer patients.</p> <p>RG argued a method of ensuring patients receive good treatment is through ensuring clinicians are aware of the best treatments, asking if this was raised in the Access to Medicine workshop. KB shared this issue was not raised, but that the BCA would be happy to consider the suggestion, reiterating the BCA is keen to review the original policy recommendations in the Access to Medicine campaign and assess if they are still relevant. KB asked if the industry partners would be willing to share points of concern that will be useful for the development of the campaign.</p> <p>ZPW asked if any attendees had any further questions on the Access to Medicine campaign.</p> <p>DS asked if there have been any early conversations with Health Technology Assessment (HTA) and NICE, expressing this is a very important area of work.</p> <p>MH shared the BCA met with NICE in the spring of last year, providing NICE with an update on the campaign and sharing details of the issues the BCA was looking to work on. MH highlighted this was an initial conversation and that the BCA is keen to continue engaging with NICE.</p>	
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	<p>DS queried if the BCA is finding it difficult to engage with HTAs regarding the Access to Medicine campaign, with as considerable developments ongoing in the health sphere currently. MH concurred that there is a lot happening in the health sphere but that the BCA is engaging in very valuable conversations and is keen to progress these conversations past just introductory meetings.</p> <p>DS followed by asking what industry partners can do to assist the BCA's engagement with HTAs.</p> <p>KB responded, asking DS how Takeda is finding engagement with HTAs. JP intimated it is not as productive as they would like. BP agreed, saying it is a challenging time of the year to engage with HTAs.</p> <p>DR asked if the BCA plans to engage with Jonathan Ashworth MP and Wes Streeting MP. KB highlighted the very positive relationship the BCA holds with Alex Norris MP, revealing the BCA approaches to Labour had focused on Alex Norris MP. MH reiterated the support Alex Norris has offered the BCA, through the tabling of questions and attending BCA events and will also reach out to Wes Streeting to introduce the BCA.</p> <p>DS asked if necessary whether there is a campaign the BCA will prioritise over the other, regarding Access to Medicine or Unmet Needs, if there was difficulty promoting both.</p> <p>BP shared that at present, the focus is on the Unmet Needs campaign due to the recent launch date, revealing that the BCA intends to pick up the Access to Medicine campaign in the new year..</p>	
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		<p>KB said that the most pressing criteria in terms of campaigns to prioritise is looking at what will deliver the best outcomes for patients.</p> <p>ZPW added these issues are all important and deserve campaigning, reiterating that it is a case of approaching the campaigns in a staggered way.</p> <p>SD asked, if there is a crossover with the work being performed by the APPG on Blood Cancer.</p> <p>CW responded that currently the APPG is focusing on its report considering Covid and blood cancer, sharing it will likely be published at the end of the year. CW said there will be further engagement between the BCA and the APPG going forward.</p> <p>ZPW asked if there were any further questions from attendees, to which all attendees declined.</p>	
3	Impact of COVID-19	<p>CW moved to the next agenda item, sharing details about groups that provided recommendations regarding Covid-19 and blood cancer, providing further information on the two reports being worked on by the National Cancer Recovery taskforce.</p> <p>CW expanded that during the pandemic, NHS England used private health care services to provide support to cancer services, before detailing other recommendations from the task groups including asking NHS England to provide psychological support to patients with blood cancer and highlighting the limited number of patients that have been referred to psychological support.</p>	<p>CW to liaise with the National Cancer Recovery taskforce re. recommendations – <b>w/c 03/01</b></p> <p>CW to enquire with the National Cancer Recovery taskforce re. publishing of reports – <b>w/c 03/01</b></p> <p>CW to share link to research published on BCUK website with industry partners – <b>w/c 03/01</b></p> <p>DR to share information on regulation approvals – <b>w/c 03/01</b></p>

	<p>CW concluded he is still waiting to hear back from the National Cancer Taskforce on the recommendations shared.</p> <p>ZPW asked if any attendees had any questions on CW's presentation on the National Cancer Recovery taskforce.</p> <p>DS asked if there are any possible timings for when the National Cancer Recovery taskforce will provide details of the next stages. CW said he is not aware of a timeline but that the BCA can enquire.</p> <p>DR asked if there is any potential for the BCA to become further involved. taskforce, CW shared that the BCA has tried and will continue trying.</p> <p>DS asked if the two reports have been published and are available publicly. CW shared that he is unsure if they are available online, but that he will check to investigate if they could be shared more widely.</p> <p>ZPW stated the meeting would progress to discuss the impact of Covid-19 on blood cancer patients.</p> <p>CM started by saying that there has been a decrease in the number of questions from patients regarding shielding, while acknowledging there have been a consistent level of questions regarding Covid-19.</p> <p>CM discussed the ongoing Leukaemia Care campaign about "forgotten shielders", focusing on how many patients are continuing to shield. CM expressed support for the government decision to extend the booster vaccine roll out, saying this is a</p>	<p>DS to share report from roundtable chaired by Lord Mendelsohn – <b>once available</b></p>
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	<p>good step in supporting blood cancer patients, reiterating that there are a large amount of blood cancer patients still shielding.</p> <p>CW articulated the Blood Cancer UK support line has been dominated by patients inquiring about the availability of their booster jab after being provided with conflicting advice by healthcare professionals. CW added there is a level of confusion regarding the definition of booster doses, arguing some patients are unsure of the information about boosters and whether it relates to them.</p> <p>CW shared it is a difficult time for the NHS in managing the booster roll out, highlighting it is also challenging for blood cancer patients with many having shielded for over a year.</p> <p>SW confirmed that most of the MDS patients are shielding, with many having no plan to stop shielding, sharing there are concerns the government is not doing enough to support MDS patients, particularly through the work of healthcare staff, given the complexities of MDS. SW explained the challenges being faced by MDS patients, including late diagnosis and difficulties accessing staff, concluding MDS UK wants there to be a greater focus on MDS.</p> <p>CM shared that there are a number of patients who have had one form of the booster but may be included in the official data of 100,000 who have not had their booster due to inconsistencies with data.</p> <p>DC said that there are specific challenges facing patients in the devolved nations, as support offered on the NHS website is only available to patients in England, before discussing the mask-mandate recently introduced in England.</p>	
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		<p>JP asked if there have been any developments regarding flexible working and employment.</p> <p>CM replied, saying that there has not been much conversation about it recently. CW reiterated this, saying flexible working was more of an issue towards the end of furlough. CW shared details of the impact of Covid on older blood cancer patients, highlighting patients who are in their 50s preferring to stop working rather than returning to the physical workplace.</p> <p>CW reiterated there is an issue with the 100,000 figure is made up of and said that there is an issue with NHS England not transparently sharing data.</p> <p>DS reiterated this issue, saying that data is being delivered by NHS England that does not paint a clear picture of what is actually happening.</p> <p>DS asked if others had been hearing through their organisations about late diagnosis as a result of COVID.</p> <p>YS provided a perspective from a stem cell transplant perspective, saying that the number of patients receiving stem cell transplants has fallen, further highlighting that it is difficult to understand why as there is limited data to provide insight.</p> <p>RH shared the issue with stem cell transplants is also down to capacity, adding there are issues with number of staff who are trained to deliver stem cell transplants.</p> <p>SW explained patients might not be receiving their transfusions as regularly due to a lack of time, arguing this is particularly</p>	
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	<p>affecting patients who are newly diagnosed, as they are less confident asserting their needs to healthcare providers and as such is impacting patients' quality of life.</p> <p>DR asked if the reported lack of response to vaccines for blood cancer patients is affecting uptake of the vaccine amongst blood cancer patients.</p> <p>ZPW said this is an issue he recognised, asking CW for his opinion.</p> <p>CW said that patients have shared these concerns stating there is no point in having further doses due to lack of response. CM agreed with this, articulating the third dose was marketed as providing blood cancer patients with the same protection as others and anticipates that there will be further concern from the blood cancer community about receiving further doses of the vaccine.</p> <p>SD asked if the vaccine taskforce shared any information about findings, from a research/academic perspective, regarding vaccinations and blood cancer patients. CW said that most findings have been published on the Blood Cancer UK website.</p> <p>YS said the general consensus is the vaccine response varies depending on the type of blood cancer had by patients. YS also highlighted the varying response the vaccine has on different variants of Covid-19. CW said he will share the link to the research that has been published thus far, with industry partners.</p> <p>DS said there is an element of scaremongering amongst the British media, highlighting the importance of pushing out the</p>	
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	<p>data to patients, in order to encourage them to receive further doses.</p> <p>ZPW asked if the work being done by BCA member organisations is cutting through the negative reputation surrounding the vaccines. CW argued it is cutting through to people who are looking for information but that there are a lot of people who are unaware.</p> <p>CM shared details of a Leukaemia Care webinar delivered, exploring the difference between the third vaccine and the booster, stating although it was fruitful, many people still left the webinar confused.</p> <p>DS asked if there is anything that can be done in primary care.</p> <p>ZPW asked CW what work is being done to communicate directly with the GP community. CW responded saying it is challenging to engage with the GP community as it is very often only those who want to be engaged that will reach out. CW stated that sharing updated messaging with GPs is perhaps something the BCA should consider.</p> <p>SW said MDS patients have been looking to purchase antibody tests themselves as they could not be included in the cancer antibody survey, due to not being on typical cancer treatment, adding there is limited reliability of these tests.</p> <p>SW also highlighted there is an issue around employment, with blood cancer patients living with others who do work and as such have difficulties living in the same house.</p>	
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	<p>DF said the biggest problems for blood cancer patients is there is no personalised test, arguing this provides no reassurance, stating that she does not anticipate this changing.</p> <p>ZPW opened the conversation on industry partners updates.</p> <p>DS shared details of the combination treatment challenge that is prevalent within access, highlighting the work Takeda has done on the challenge since 2016, revealing:</p> <ul style="list-style-type: none"> <li>• After holding a Westminster roundtable in 2016, Takeda formed an advisory group with members from the patient community, researchers, plus input from NHS England.</li> <li>• The recent publication of two white papers, with the second white paper looking at creating a standard arbitrary process.</li> </ul> <p>DS further provided details about the Takeda roundtable held in the summer, with a key output from the roundtable considering how to drive patient involvement when looking at solutions to combination treatment. DS added Takeda has held a roundtable with the legal community and with health economists, adding that the solutions delivered by Takeda are available on the Takeda website, saying they are continuing to engage with stakeholders on the issue.</p> <p>DR then shared details of the work AbbVie is conducting around regulation approvals, including by bringing together stakeholders within the community to advance the issue further. DR said she is happy to circulate further information after her meeting on Thursday.</p>	
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		<p>DR provided further insights of ongoing work, including roundtables and launching pilots to trials tools that already exist, with other work including AbbVie's cancer strategy work, which they are looking to develop in the devolved nations.</p> <p>DS shared her organisation is looking at different types of therapy for blood cancer patients, mentioning concerns around innovative treatments, before providing details of the roundtable held, and chaired by Lord Mendelsohn, and which examined the impact of Covid. DS said the write up of the report from that roundtable will hopefully be shared by the end of the year, before concluding by highlighting Takeda's event next Thursday and invited all attendees.</p> <p>KT asked if there is any potential for work around health inequalities.</p> <p>RG said there are concerns from industry around modifiers and discount rates and they are awaiting formal publications. RG also highlighted the issues around the scope of IMF, saying Janssen is looking to host a panel event in the new year looking at early diagnosis.</p> <p>RH expanded that a piece of work looking at routes to diagnosis, will hopefully be published at the end of this year and will inform work going forward, adding that a lot of Janssen's work aims to share information with other organisations and NHS England, in order to create a singular narrative about the role of industry.</p>	
4	Unmet Needs Campaign	MH shared an update on the Unmet Needs campaign, providing details of the campaign, including how blood cancer	

	<p>is the 'forgotten fifth' and is not treated equally to the other Big 4 cancers.</p> <p>MH also highlighted some of the recommendations from the research, including asking NHS England to add data on blood cancer to the cancer dashboard.</p> <p>MH then shared an update on the progress of the campaign, including ongoing engagement with NHS England, and the sharing of social media posts by politicians. MH shared further details of the meetings agreed with parliamentarians discussing the campaign, raising the new page created on the BCA website promoting the campaign.</p> <p>MH moved to discuss the next stages of the campaign, including confirming the meeting with NHS England, following up with stakeholders to progress the campaign within Parliament and updating the website and the BCA Twitter account.</p> <p>MH then opened the conversation for wider discussion amongst attendees.</p> <p>DR asked if there will be a report to accompany the Unmet Needs campaign. KB said there is an evidence review which was delivered by Quality Health, looking at health across the board. KB then shared that the BCA chose not to publish a formal report due to desiring the evidence review to be a living document which is continuously updated, concluding that the BCA chose the key stats from the evidence review for the launch of the campaign.</p>	
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	<p>ZPW added that there have been discussions about uploading the document to the public domain, reiterating his support for the decision to keep it as a living document, further stating that there are ongoing conversations about providing additional collateral to promote the campaign.</p> <p>KB added that the BCA is keen to keep all of the evidence in one place and that this was a justification for not formally publishing the report but that there is potential to publish further reports and information about the campaign in the future.</p> <p>RH asked if there are specific asks that will be put to NHS England upon securing the meeting. KB said there are key asks, including around the cancer data dashboard and the potential to include blood cancer data within the dashboard. KB highlighted that they may move the conversation to engage with NHS Digital, due to the ownership of the dashboard changing, but added that the BCA is keen to see blood cancer data included in the dashboard in order to inform cancer policy.</p> <p>ZPW reiterated the need to include blood cancer as part of the cancer dashboard, including as a tool to help develop policy around other rare cancers. KB affirmed this by saying that generally, when there are pilot schemes it is for patients with Big 4 cancers and that it is important to look at potential developments in relation to blood cancer.</p> <p>RG asked the degree to which there is alignment with NHS England and their conversations on health inequalities. KB responded that the BCA is looking forward to working on these issues in the near future.</p>	
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		<p>DR questioned if there is any potential to engage with Macmillan around these issues. KB shared that the BCA is keen to engage with Macmillan on these issues.</p> <p>MH highlighted the existing relationship the BCA holds with Macmillan and that a meeting is being arranged</p> <p>RG asked if there is an opportunity around integrated care systems.</p> <p>KB responded that the meetings between the BCA and NHS England are important as they provide opportunities to impact policy on integrated care systems.</p> <p>DS said that is important that some of the responsibility is given back to the NHS, sharing the information from patients' groups, saying that they have been forced to push patients to charities due to the NHS not having the resources.</p> <p>SW highlighted how treatment is dependent on local authorities and how, in particular, for patients in Devon and Cornwall, this affects their ability to get treatment. SW emphasised that these regional inequalities need to be addressed.</p>	
5	Impact of Unmet Needs of blood cancer on BAME community	<p>KB shared the background around the BAME Unmet Needs project, explaining how the BCA prioritised work examining the unmet needs that exist within the BAME community.</p> <p>KB informed about the research commissioned to look at these issues, with the first project being delivered by ClearView, saying ClearView has concluded its research and the report is being finalised. KB added that this piece of research is largely focused on the patient, disclosing different elements of this research including; a literature review to examine the existing</p>	

	<p>research, an online survey and a subsequent patient focus group.</p> <p>KB then shared details of the second piece of work being delivered by the University of Hertfordshire, looking at the clinical perspective of unmet needs within the BAME community. KB updated that this piece of research is ongoing and will most likely be concluded in the late winter / early spring. KB informed that once both pieces of research have been concluded, the BCA will then examine how to engage with stakeholders on these issues.</p> <p>DS asked if the research is across the entire patient journey. KB confirmed that it will cover the entire journey. KB further informed that the research was developed by a patient co-creation group and so examines all aspects of the patient journey.</p> <p>DR asked what the initial issues are emerging from the research regarding patient needs. KB responded that there are two themes emerging from the research; some issues that exist within the BAME community alone and some issues that are exacerbated.</p> <p>DS said this research aligns with work done by Blood Cancer UK on nurse clinical service trials. CW said that the research from that project fed into the BAME Unmet Needs project.</p> <p>RH said it would be interesting to see the results of the BAME Unmet Needs project before Janssen develops its own work on the issue. BP shared that it was interesting when speaking with ClearView and learning about how much time and energy</p>	
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	<p>needs to be invested to reach a wide patient group within the BAME community.</p> <p>BP said it would be useful to hear what tactics and methods the industry partners are using to reach these patients. RH reiterated this, saying there is a desire to reach as many patients as possible, but also to ensure the data is accurate.</p> <p>KB shared insights provided by ClearView on the issue, saying a paper approach via healthcare channels works better and added that this approach tends to have a greater impact, compared to other methods.</p> <p>KB discussed details of a survey being issued by the University of Hertfordshire, asking attendees for their support in sharing the survey once it is ready.</p> <p>KT said her organisation is looking into a community-based approach, as a method of engaging harder to reach groups. KT also highlighted church groups as an opportunity to reach these groups.</p> <p>KB shared details of work done at Anthony Nolan to develop information on stem cell donors, highlighting the use of churches in that project.</p> <p>DR offered to share research.</p> <p>ZPW added that a decision was made as the leadership to start the BAME Unmet Needs project alongside the Unmet Needs project.</p>	
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		<p>DS asked if the data will go into the depth of different disease experience. KB responded that she is unsure but that the BCA will discuss it with the University of Hertfordshire.</p> <p>KB further shared that the data will most likely be looked at across the board in this instance.</p>	
6	Future logistics and AOB	<p>SW asked if there are further views on the non-submission to NICE on treatments.</p> <p>DS said there are a multitude of factors that affect non-submission, including treatment and disease area.</p> <p>ZPW said this is something that the BCA witnessed in the Access to Medicine report, sharing that there is often no information in the public domain about reasons for non-submission.</p> <p>DS highlighted data recently published on non-submission by the ABPI and reiterated the issue of lack of transparency.</p> <p>ZPW said it is important to look at opportunities to include this information in the public domain.</p> <p>DR asked if the BCA has a plan for workstreams across 2022.</p> <p>KB responded by saying the Access to Medicine campaign is due to commence in the new year, with the Unmet Needs campaign concluding in the spring and the BAME Unmet Needs campaign will develop and commence upon receiving the completed reports. KB added that interspersed within this will include responding to the IMF consultation, responsive work including regarding Covid, and other pieces of ongoing work.</p>	<p>BCA to share date options for next IPF meeting with industry partners – <b>w/c 3/01</b></p> <p>BCA to share minutes with industry partners – <b>w/c 3/01</b></p> <p>BCA to share slides from IPF meeting with industry partners – <b>complete</b></p>

		<p>MH shared an update on logistics and the aim to do Industry Partners Forum meetings bi-yearly, with an in-person option. BCA will share date options for the next meeting shortly alongside the draft minutes, with the request to feedback on the minutes.</p> <p>MH also stated the BCA will share the slides from the meeting with attendees.</p>	
7	Close	ZPW then thanked attendees and closed the meeting.	

**Next Meetings**

Date	Agenda
	TBC