

Blood Cancer Alliance

Minutes of the Industry Partners meeting held on Thursday 19th March 2020

Members present: Julie Child (JC), Race Against Blood Cancer; Daniel Cairns (DC), Myeloma UK; Amelia Chong (AC), Anthony Nolan; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Phil Reynolds (PR), Bloodwise; Stephen Scowcroft (SS), Lymphoma Action; Chris Walden (CW), Bloodwise; Sophie Wintrich (SW), MDS Support.

Partners present: Shelley Anderson (SA), Kyowa Kirin; Asha Kaur (AK), Sanofi; Michael Collins (MC), Janssen; Lolita McGee (LM), Celgene; Emily Pegg (EP), Takeda; Layla Robinson (LR), Kyowa Kirin; Barbara Taylor (BT), Novartis; Mike Thompson (MT), Incyte; Nicola Trevor (NT), Janssen; Dominic Wake (DW), Novartis; Lee Wilmott (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	Update on BCA priorities and workplan	<p>SS welcomed all attendees and explained the agreed process for the meeting, highlighting the shared agenda.</p> <p>SS explained BCA activity in the last year had focused on:</p> <ul style="list-style-type: none"> • Agreeing the following BCA policy priorities: <ul style="list-style-type: none"> ○ Securing access to the most effective treatments. ○ Raising awareness of blood cancer to improve early diagnosis. ○ Ensuring blood cancer patients have the emotional and psychological care and support that they need. • Deciding as a membership the following calls for actions: 	

		<ul style="list-style-type: none"> ○ Adopting improved mechanisms by which blood cancer patients needs can be factored into the treatment appraisal processes. ○ Improving and expediting appraisal processes to ensure patients can access new and life-saving treatments. ○ Creating an overarching access policy in each UK health administration. ○ Closing the diagnosis gap by delivering specific strategies for blood cancer. ○ Incentivising a focus on blood cancer outcomes. ○ Future provision of emotional, mental health and psychological support for people diagnosed with cancer. <ul style="list-style-type: none"> ● Discussing and agreeing a response to the NICE review. ● Updating the BCA website. ● Building a group of 10 industry partners. ● Supporting the creation of the Blood Cancer Dashboard. ● Securing meetings in Westminster and devolved Parliaments. ● Expanding the reach of the membership across the UK. <p>SS then disclosed that for the next year the BCA has agreed on these three main activity strands:</p> <ul style="list-style-type: none"> ● Producing a policy report on barriers to access to new medicines and treatments for blood cancer patients. ● Launching a policy campaign based on the access to treatment policy report evidence and calls to action. 	
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		<ul style="list-style-type: none"> • Creating a comprehensive evidence base of unmet needs within blood cancer care. <p>DW asked whether the slides will be shared? BP confirmed the slides will be distributed after the meeting.</p> <p>AK requested further clarification on the timeline for the unmet needs report. SS responded the plan was for the report to be concluded at the end of this year or the beginning of next year.</p> <p>SS then opened the floor for questions.</p> <p>SA queried the timings on the unmet needs policy report. SS reiterated the previously provided current proposed timings.</p> <p>DW suggested it was good to see this level of collaboration; highlighting the Blood Cancer Dashboard and asked what work the BCA was planning around the commercial framework and the NHS people plan. KB responded the BCA work programme will be dominated by the research emerging from the reports, but that if the research reveals relevant issues the BCA will feed this into the appropriate consultations and conversations.</p> <p>EP concurred it was positive to see an agreed focus on key policy areas and that she is keen to hear more about the proposed report on the evidence on unmet needs.</p>	<p>AP to share slides following the meeting - Complete</p>
3	Securing access to best treatments policy report	<p>SS then introduced the presentation on securing access to the most effective treatments.</p> <p>KB confirmed that following agreement from BCA members resulting from a prioritisation process, the BCA leadership had agreed this report will be treated as a priority and had now</p>	

	<p>commissioned research into securing access to the most effective treatments.</p> <p>Following the completion of the research tender process, health economist Leela Barham (LB) was commissioned to conduct the research. KB underlined that the report will cover the following areas:</p> <ul style="list-style-type: none"> • The forthcoming challenges facing the NHS across the UK when considering whether to commission new and innovative treatments for blood cancer. • Whether the NICE appraisal is fit for process. • The context in the devolved health administrations and what barriers exist to the quick adoption of new treatments and medicines for blood cancer patients. • The role of pharmaceutical companies and specifically whether they are investing in research into treatments for small patient groups for example specific blood cancers or age groups. <p>KB then discussed what the report is hoping to achieve, which includes:</p> <ul style="list-style-type: none"> • Producing policy proposals and recommendations which the BCA can adopt when seeking to influence relevant stakeholders. • Feeding into the ongoing NICE review. • Providing the context for an ongoing campaign. <p>KB expanded on the timetable; revealing LB is currently focused on desk research, but in May will be conducting an online survey of patients to be distributed by BCA members.</p>	
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		<p>LM fed back on Celgene's recent activities and priorities, sharing the following:</p> <ul style="list-style-type: none"> • The completed acquisition of Bristol Myers Brigg. • A continued commitment to an existing policy programme building on last year's parliamentary roundtable. <p>MT disclosed Incyte is concentrating on:</p> <ul style="list-style-type: none"> • Influencing NICE procedures and building relationships with politicians. • Supporting patients through a range of measures. <p>LR stated Kyowa Kirin's work was focusing on:</p> <ul style="list-style-type: none"> • Working through trade associations and responding to relevant consultations. <p>MC stressed Janssen were working in these areas:</p> <ul style="list-style-type: none"> • Providing access to therapies. • Shaping response to NICE methods review and the need for innovation and reform in the framework. • Working with industry trade bodies. <p>SS confirmed we would later be discussing the NICE review.</p> <p>DW indicated Novartis was presently focusing on:</p> <ul style="list-style-type: none"> • Working with trade associations and with NICE and NHS England, particularly in regards to new therapies. 	
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4	NICE methods review	<p>Presenting on current BCA thinking; ZPW confirmed that the BCA response is going to be informed by what emerges from the evidence project, but that a number of consistent themes and messages are emerging.</p> <p>Expanding, ZPW said there are three topics in the NICE review which the BCA believe require specific attention:</p> <ul style="list-style-type: none"> • Modifiers and if there needs to be an introduction of a higher disease burden. 	

		<ul style="list-style-type: none"> • Uncertainty and the need to maintain a balance between making sure this is balanced with opportunities to innovate; particularly as many blood cancer medicines remain at the bottom of the threshold, and whether a new process and more flexible criteria should be introduced. • Patient involvement and the importance of ensuring patients are involved in the decision-making process; whilst acknowledging this can be hard to demonstrate. <p>ZPW opened the floor to questions and feedback.</p> <p>NT argued it was important to ensure consistency across industry and relevant stakeholders and that these were all areas Janssen will support. SS added that reaching a consensus at the earliest possible stage was a really important consideration from a BCA perspective.</p> <p>ZPW agreed being aligned is vital; adding he was seeing a desire for change from NICE. There was a necessity for patient groups to work towards the same aims in order to maintain consistency, although this is not always straightforward.</p> <p>KB added the interim report on securing access to best treatments policy reports will be published in the next few weeks and will help the BCA form their position. This document will be shared when completed.</p> <p>SS concluded by highlighting a question from SW about involving patient groups in the survey and asked whether there any other questions about the NICE methods review.</p> <p>The meeting broke for a short tea break.</p>	<p>AP to share interim report when published - Ongoing</p>
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5	Closing the diagnosis gap	<p>SS welcomed all attendees back; explaining the BCA was doing the following in regards to closing the diagnosis gap:</p> <ul style="list-style-type: none"> • Feeding into the NHS Long-Term Plan whilst avoiding any duplication of work. • Securing and analysing new and existing data. <p>SS then welcomed comments from partners:</p> <p>EP explained Takeda was prioritising:</p> <ul style="list-style-type: none"> • The impact of the genomic hub and ensuring patients receive the most appropriate treatments. • Helping professionals navigate the different challenges. <p>DW and BT confirmed Novartis' work was looking at:</p> <ul style="list-style-type: none"> • Understanding and explaining the diagnostic infrastructure and how this brings through new tests. • Being part of a coalition in Scotland to establish a pathway allowing pharmas to have tests validated. • Understanding what can be done to support the NHS Long Term Plan, although not yet in a position to share their work. <p>SA and LR said KK was focusing on:</p> <ul style="list-style-type: none"> • Understanding the landscape and whether there is a need to be more proactive with policy and public affairs as this is still a new focus for the company. 	
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		<p>MT revealed Incyte was looking specifically at the whole treatment journey.</p> <p>LM revealed the majority of Celgene’s medicines came later in the pathway and that early diagnosis wasn’t a policy priority.</p> <p>LW spoke to the shared slides; confirming Amgen was:</p> <ul style="list-style-type: none"> • Looking at the importance of genomic testing. • Pursuing a shared agenda and working collaboratively with other stakeholders. • Working with the Cancer Vanguard and care delivery that can be replicated nationally. <p>MC indicated Janssen was currently focused on these priorities:</p> <ul style="list-style-type: none"> • Building a raft of evidence through the blood cancer dashboard and providing quarterly updates. • Planning a strategy for Make Blood Cancer Visible 2020. <p>PR then presented on Bloodwise’s ongoing research; explaining their work was focusing on:</p> <ul style="list-style-type: none"> • Existing challenges with the roll out of genome testing in the NHS. • The ongoing APPG inquiry on genomics. • Creating opportunities for treatment optimisation and better prognosis and happy to share further information. 	
6	Providing care and support for patients	SS introduced the last BCA policy priority to produce a report into unmet needs, but confirmed this activity had not yet	

		<p>started. SS then called on partners to share further details on their work in this area.</p> <p>LW said that for Amgen they had a couple of priorities:</p> <ul style="list-style-type: none"> • Being a supportive partner to the NHS and welcoming the publication of the NHS Long-Term Plan. • Resolving persistent barriers and actively engaging partners through care delivery. <p>MT revealed Incyte was focusing on supporting patient organisations and engaging with the NHS.</p> <p>LR indicated Kyowa Kirin had little to reveal at this stage but were working to support a number of patient groups.</p> <p>MC stated Janssen was doing the following:</p> <ul style="list-style-type: none"> • Scaling up outcome reports methods and working with charities. • Supporting initiatives being conducted by patients and patient groups. <p>BT explained Novartis was working on these activities:</p> <ul style="list-style-type: none"> • Developing and providing necessary treatments. • Exploring ways in which the burden can be eased on the healthcare system. • Working and building relationships with clinicians. • Discovering the best way to support charities and patient groups. 	
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		<ul style="list-style-type: none"> • Looking to drive greater insights to help the NHS to develop better and newer care models. <p>DW expanded on BT's information, explaining:</p> <ul style="list-style-type: none"> • Novartis had completed around 50 joint working projects with the majority focused on helping specialists. • Novartis is the leading commercial sponsor of clinical trials and they are pitching to bring the most exciting candidates to the UK. • Novartis is working with the Vanguard and have brought forward the first biosimilar. <p>EP concluded the partners feedback, saying Takeda was focusing on:</p> <ul style="list-style-type: none"> • The need for greater educational experiences and delivering a number of supportive programmes to ensure greater understanding. • Bringing the highest level of research to the UK. <p>KB moved to future BCA activities; stating the BCA is committed to producing an evidence base for unmet needs and was producing a briefing. KB explained this decision had been reached as a collective following a lack of confidence about the current level of data.</p> <p>KB added the decision had been impacted by the following:</p> <ul style="list-style-type: none"> • Issues around data and blood cancer. • Issues in provision of care and psychological support. 	
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		<ul style="list-style-type: none"> The need for an evidence base identifying actual gaps and flagging up some of the known unknowns. <p>SS concluded by saying there was an ongoing discussion about how the BCA will run the project.</p>	
7	Future logistics and AOB	<p>BP concluded the meeting by thanking all for joining and confirmed the date for the next Industry Partners will be shared alongside the presentation after the meeting.</p> <p>SS reiterated the plan was to host a meeting every six months and hoped all had found the meeting useful. He then opened the floor to concluding remarks from members:</p> <p>SW suggested a lesson could be about the importance of working together consistently and collaboratively.</p> <p>The meeting concluded.</p>	AP to share date (1 st October) for next meeting with partners - Complete

Next Meetings

Date	Agenda
Thursday 1 st October	TBC