

Blood Cancer Alliance

Minutes of the meeting held on Wednesday, 15th August 2018

Members present: Orin Lewis (OL), ACLT; Simon Butler (SBu), Anthony Nolan; Christopher Walden (CW), Bloodwise; Marc Auckland (MA), CLL Support; Dave Ryner (DR), CML Support Group; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Stephen Scowcroft (SS), Lymphoma Action; Shelagh McKinlay (SM), Myeloma UK; Roger Brown (RB), WMUK

Not present: David Innes (DI), CLL Support; Sophie Wintrich (SW), MDS UK

Atlas Partners Secretariat (AP): Vanessa Pine (VP), Katie Begg (KB), Nina Doehmel-Macdonald (NDM), Mike Hough (MH), Toni Heijbroek (TH)

NHS England: Sarah Benger (SBe), Holly Cheshire (HC)

No.	Agenda Item	Minutes	Actions
1	Introductions	Introductions made.	
2	Overview of Atlas Partners plans	AP presented a shortened pitch document and reporting frequency was agreed.	<ul style="list-style-type: none"> AP to arrange fortnightly call with SBu and share monthly report with all BCA members (ongoing)
3	BCA priorities and messaging	<p>KB lead a discussion on what BCA's priorities and messaging should be. The following territories were discussed:</p> <p>As Cancer Strategy emphasis is on early diagnosis, there is little focus on treatments within blood cancer strategy.</p> <p>It is difficult to assess treatment. There are issues around cost effectiveness and constraints within the system mean blood cancer survival rates are affected.</p>	

		<p>Targets for lives saved is a deceptive measurement for blood cancer, and there has been little change in how blood cancers are treated.</p> <p>NHS England has the worst cancer survival rates in Europe, and stats are particularly bad for blood cancers. Doctors are constrained by the system.</p> <p>Members agreed the blood cancer message is diluted compared to that of the 'big four' cancers. This could be due to the limited and fractured data available. The need to distil the blood cancer message in an easily accessible way was highlighted. Blood cancer has a systematic disadvantage against other cancers, as they are not a priority for policy makers.</p> <p>The BCA message needs to be about cost, quality of life and what early detection means for survival and long-term NHS savings.</p> <p>KB highlighted that raising and unifying the blood cancer profile might be the win that the BCA needs.</p> <p>The BCA's priority should be finding and influencing key policy makers. It was agreed that due to high drug costs and low charity contributions blood cancer is frequently forgotten, and that this pattern needs to be disrupted with new conversations and evidence. The BCA should learn from organ donation, where great advances have recently been made.</p> <p>Blood cancer's terminology affects public perception. Cultural and racial measures also contribute to recording of statistics and how it is perceived. It was agreed that how</p>	
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		<p>blood cancer is referred to within the policy landscape needs to shift.</p> <p>BCA needs to influence the right people to push for the necessary cultural shift on how blood cancer is perceived. Blood cancer needs to be considered on similar terms to long term chronic illnesses.</p> <p>Potential reputational issues were raised. The more the Alliance is noticed, the higher the chance it's criticised. The need to make a decision about relationships with pharmaceutical firms was highlighted.</p> <p>KB added that NHS England Cancer Strategy is driven by the media agenda which focuses primarily on the efficiency/inefficiency of the NHS including waiting times.</p>	
4	NHS England	<p>SBe and HC joined meeting. SBe discussed NHS's long-term cancer plan and highlighted the forthcoming call for evidence.</p> <p>Key achievements within the Cancer Strategy include:</p> <ul style="list-style-type: none"> • The National Cancer Programme • Cancer Alliances • £200m investment in Cancer Alliances to transform services • CADEAS, a PHE and NHS England partnership focused on alliances • 5 cancer alliances testing quality of life metric in colorectal and breast to see how it can be rolled out. <p>NHS England wants to engage meaningfully with stakeholders and would like them to facilitate discussions among their networks and feed back to NHS England.</p>	<ul style="list-style-type: none"> • AP to draft outline consultation response and share with SBU (31 August)

		<p>An outline of shared priorities for blood cancers will be helpful to feed into the cancer workstream. Common priorities and issues will be helpful. NHS England specifically would like assessment of newer initiatives or thoughts on progress of taskforce recommendations, including thoughts on which recommendations are progressing, which have not, and which need review and enhancing.</p> <p>BCA members asked SBe various questions around NHS England Cancer Strategy. Key outtakes include:</p> <ul style="list-style-type: none"> • Funding and budget for the forthcoming plan will be negotiated with HM Treasury • Stakeholders' involvement is vital to the plan's development and detailed examples should be included in the consultation response • The new plan is a chance to review which parts of the Cancer Strategy are and aren't working • The NHS England cancer team works together with specialised commissioning. • The plan presents an opportunity to have detailed conversations about how services can really be transformed • The BCA should respond to the Cancer Patient Experience Survey consultation • NHS England recognises that the focus should be across all cancers • 'Recovery packages' for blood cancer patients should be reviewed • NHS system infrastructure is evolving within cancer. Looking at the role of the Cancer Alliances is an opportunity to further develop and entrench their responsibilities 	
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5	Reputation management	<p>VP lead a discussion on key BCA reputational risks.</p> <p><u>Risk 1: BCA is funded by a single source</u> To mitigate this risk BCA should:</p> <ul style="list-style-type: none"> • Finalise Memorandum of Understanding (MoU). • Publish minutes of meetings. • Seek additional and alternative funding. • Produce a policy on criteria for working with pharmaceutical firms. <p>SBU highlighted that BCA should be confident in the source of the funding and its impact. KPIs, key messages and consultation response for BCA should reflect this.</p> <p><u>Risk 2: BCA is ineffective</u> To mitigate this risk, BCA should:</p> <ul style="list-style-type: none"> • Demonstrate quality output. • Be consistent and clear. • Not rush decisions. • Create a clear approvals process outside of meetings. • Safeguard patient advocates. 	<ul style="list-style-type: none"> • BCA to finalise MoU (31 August) • AP to develop a Q&A on reputation management (September) • AP to draft a statement about single source of funding (September) • AP to publish meeting minutes on BCA website once live (TBC) • SB to draft policy for funding partners (September) • BCA to discuss sources of alternative funding (November) • BCA to share pharmaceutical contact details (ongoing) • BCA to update AP on any further reputational risks (ongoing)

		<p><u>Risk 3: BCA having conflicts of interest</u> To mitigate this risk, BCA should:</p> <ul style="list-style-type: none"> • Agree on all campaign decisions 	
6	Blood Cancer Awareness Month planning (BCAM)	<p>It was agreed that BCA should drive forward 2019 BCAM agenda and strategy.</p> <p>Janssen is running its own lobbying campaign this year, using #makecancervisibile. Bloodwise is undertaking a Twitter takeover this year using the same hashtag.</p> <p>It was suggested that Janssen meet with BCA in November to present the outcomes of BCAM 2018.</p> <p>Members' awareness weeks were discussed:</p> <ul style="list-style-type: none"> • Lymphoma Week takes place during BCAM. • Myeloma Week is in June. <p>SBU raised the need for common, consistent messages during awareness dates.</p>	<ul style="list-style-type: none"> • BCA to discuss 2019's Blood Cancer Awareness Month at next meeting (November). • BCA to invite Janssen to next quarterly meeting for BCAM 2018 review. <i>(Since meeting AP have discussed point with SBU. Invitation to Janssen will follow once date has been finalised).</i>
7	Next Steps		
	Quarterly meeting dates	Dates and locations for forthcoming quarterly meetings were discussed.	<ul style="list-style-type: none"> • SBU and CW to check room availability at Anthony Nolan and Bloodwise (asap) • AP to share suggested dates for forthcoming meetings (asap)
	Additional projects	<p><u>MP polling</u> AP presented costs for MP polling. It was agreed that AP should discuss suitable questions with polling providers.</p>	<ul style="list-style-type: none"> • AP to follow up with polling providers regarding questions and share expected costs and proposed questions with SBU (31 August)

		<p><u>BCA branding</u> AP presented logo design costs. It was agreed that AP should proceed with the suggested provider. DR asked whether BCA business cards could be created.</p> <p><u>BCA website</u> AP presented website hosting costs. It was agreed that AP should draft content for website and manage the setting up process. The purpose of the website was discussed.</p> <p><u>Additional funding</u> SM explained Myeloma UK has additional budget available for BCA to use. It was agreed that this should be made available for additional projects, for example into research around survival outcomes.</p>	<ul style="list-style-type: none"> • AP to draft logo brief and share with SBu (24 August) • BCA to discuss how else logo is used once it's been created (November) • AP to draft proposal for website creation and share with SBu (31 August) • AP to liaise with SM to arrange transfer of funds to AP (asap) • BCA to discuss additional projects at next meeting (November)
8	AOB and close	<p><u>Industry reports</u> It was agreed that BCA needs to build relationships with pharmaceutical firms to receive advance notice of any upcoming reports.</p> <p><u>Weekly political updates</u> AP confirmed that weekly political updates will be shared with the BCA from September, once recess is over. Any urgent and high-profile updates will be shared straightaway.</p> <p><u>New members</u> SBu explained that any new BCA members should complete a form before joining Alliance.</p> <p><u>Macmillan/CRUK relationship</u> Macmillan and Cancer Research UK were called out as key BCA stakeholders.</p>	<ul style="list-style-type: none"> • AP to add pharmaceutical contacts to stakeholder matrix (ongoing) • AP to share political notes (from w/c 3 September) • AP to discuss content of form with SBu (September) • BCA to discuss how best to form relationship with these partners (November)

Next Meetings

Date	Agenda
November 2018 (date TBC)	TBC
w/c 4 February 2019	TBC
w/c 6 May 2019	TBC