

Blood Cancer Alliance

Minutes of the meeting held via Zoom on Thursday 5th August 2021

Members present: Rachel Allison (RA), DKMS UK; Joanne Badger (JB), Leukaemia and Lymphoma NI; Daniel Cairns (DC), Myeloma UK; Dawn Farrar (DF), Leukaemia UK; Caitlin Farrow (CF), Anthony Nolan; Ella Guthrie (EG), Leukaemia Care; Amanda Harris (AH), Lymphoma Action; Charlotte Martin (CM), Leukaemia Care; Zack Pemberton-Whiteley (ZPW), Leukaemia Care; Yasmin Sheikh (YS), Anthony Nolan; Christopher Walden (CW), Blood Cancer UK.

Apologies: Julie Child (JC), Race Against Blood Cancer; Ropinder Gill (RG), Lymphoma Action; Norah Grant (NG), CLL Support; Orin Lewis (OL), ACLT; Shelagh McKinlay (SM), Myeloma UK; Jane Nicholson (JN), WMUK; Dave Ryner (DR), CML Support Group; Sophie Wintrich (SW), MDS UK Patient Support Group.

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

Guest Speakers: Greg Judge (GJ), Anthony Nolan; Dr Cathy Henshall (CH), Oxford Brookes.

| No. | Agenda Item | Minutes | Actions |
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| 1 | Welcome | Introductions made and minutes agreed | AP to upload minutes from the May quarterly meeting to the website – 13/08 |
| 2 | Secretariat update | <p>KBS reported back on activities from the last quarter, highlighting work had focused on the following developments:</p> <ul style="list-style-type: none"> • Progressing Access to Medicine campaign and agreeing the date for the workshop. • Continuing BCA Twitter account • Writing to political stakeholders including the Prime Minister and the Health Secretary re: Covid-19 • Organising media opportunities around Covid-19 securing an op-ed in CharityToday and an appearance on Channel 4’s podcast ‘Fourcast’ | |

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| | | <ul style="list-style-type: none"> ● Managing Unmet Needs project ● Continuing building relationships with Industry Partners and introducing partners to Caitlin. ● Participating in meetings with health stakeholders such as The Genetic Alliance and Dr Bygrave ● Drafting parliamentary consultation responses to the APPG on Radiotherapy's consultation on the cancer backlog and the joint APPG for Blood Cancer and APPG for Stem Cell Transplantation on the impact of coronavirus on blood cancer. <p>CF thanked KBS before highlighting that the access to medicine workshop on Thursday 2nd September is available to all members. BP confirmed diary invite had been sent but that she is happy to reshare if members had not received the invite.</p> <p>BP moved on to provide an update on funding revealing that following conversations with the leadership funding for Year Three had been allocated to the following projects:</p> <ul style="list-style-type: none"> ● £58,600 for the secretariat. ● £40,000 for BAME Unmet Needs Project. ● £31,100 for the Access to Campaign extension and upcoming workshop. ● £18,050 for COVID work. ● £5,360 for campaign assets. <p>BP also confirmed a number of meetings had already taken place with partners, with further meetings agreed, disclosing:</p> | <p>Members to confirm if they have received the invite to the Access to Medicine workshop – 02/09</p> |
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| | | <ul style="list-style-type: none"> • Confirmed meetings with Pfizer, Janssen, Takeda, AbbVie and Incyte. • Meetings being organised with Roche, Sanofi, Gilead, Kyowa Kirin and BMS. • Awaiting a reply from Amgen. <p>BP then opened the floor to questions before handing over to KB.</p> | |
| 3 | Members Update | <p>KB introduced Dr Cathy Henshall (CH), from Oxford Brookes University discussing her existing relationship with Blood Cancer UK and the research commissioned exploring the emotional and psychological support provided for people diagnosed with blood cancer.</p> <p>CH begun by indicating there is limited evidence in this field, underlining why Blood Cancer UK had commissioned this work before stating the key aims from the project were to assess:</p> <ul style="list-style-type: none"> • The current nature and level of emotional and psychological support offered and provided to people following a diagnosis of blood cancer across England. • Whether the mainstream blood cancer workforce receive adequate training or support to provide this support to patients. • To what extent the competence/knowledge/skills of the blood cancer workforce should be developed to better meet patient needs. | |

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| | | <ul style="list-style-type: none"> • How well national mental health initiatives address the psychological and emotional needs of people with blood cancer. <p>CH outlined a number of methods utilised to aid the research, including:</p> <ul style="list-style-type: none"> • Online survey of 200 health care professionals from across England invited to take part via email from Blood Cancer UK and social media advertising. • Interviews with 25 blood cancer patients incorporating a variety of different blood cancers through semi-structured telephone interviews. • Interviews with 10 key stakeholders including nurse specialist and consultant haematologists. • Priority Setting Workshops. <p>CH expanded that the main findings from the online survey of health care professionals were as follows:</p> <ul style="list-style-type: none"> • Less than half (47.3%) agreed that patients were well supported in terms of emotional / psychological well-being. • About two-thirds (68.9%) felt that providing emotional and psychological support was part of their role. • Half (50%) felt the emotional/psychological needs of patients were not routinely assessed. • Three quarters (76.5%) indicated the nurse specialist was involved in providing support. • The main barriers were time (69%) lack of resource (59.5%), patient factors (35%). | |
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| | | <ul style="list-style-type: none"> • Around half (55%) had access to in-house specialised psychological support. • Referrals triggered by clinician opinion (52%), patient request (47.5%) or relative's request (37%). • 31% felt confident and 32% unconfident providing emotional & psychological support. • Many doctors (85.3%) and nurses (39.4%) had received no training for assessing and managing psychological needs. <p>CH then revealed the thoughts of the blood cancer patients interviewed, revealing:</p> <ul style="list-style-type: none"> • Blood cancer patients faced a wide range of emotional and psychological impacts. • Blood cancer is perceived to be different. • Blood cancer patients often reached a stage of acceptance and normalisation. • Blood cancer patients experienced fears of progression and uncertainty of changed prognosis. • Blood cancer patients believed a strong relationship with healthcare team with sensitive, empathetic communications and well-co-ordinated, consistent care was felt to be important to psychological well-being. • Blood cancer patients received a considerable variation in support received with nurse led support variable. • Blood cancer patients received a lack of consistency in referring to counselling. | |
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| | <p>CH concluded by divulging the main findings from the stakeholder interviews declaring:</p> <ul style="list-style-type: none"> • Physical treatment is prioritised over psychological treatment. • Existing challenge of supporting patients undergoing lifelong treatments. • The system suffers from time constraints and a lack of training. <p>Before opening the floor to questions, CH shared some recommendations from the report:</p> <ul style="list-style-type: none"> • Benefits seen in Gold standard services should be shared to help other services develop successful business cases for service development. • Strategies to provide timely access to specialised psychological support important for patients/ family members with complex needs. • Health care professionals need training/skills to get patients to open up, and to feel confident in assessments. • Role of nurse specialist is key with funding required to enable emotional and psychological needs to be addressed comprehensively. <p>DF asked whether there is a drive within the NHS to provide the Gold Standard Services as a routine service, before questioning if there are geographical differences in the findings. CH responded that while the findings are limited by the number of hospitals spoken to, some hospitals enjoyed</p> | |
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| | | <p>better infrastructure and demonstrated better signposting qualities. CW interjected this correlated with other research, intimating there is a big difference between the level of support in urban and rural areas.</p> <p>CF asked to what extent healthcare professionals saw this aspect of the work as part of their role, arguing it is important to ensure patients have the level of support at every stage of the journey. CH responded that for healthcare professionals it is about recognising the limits of your role and that while they may not always be qualified for every area, they should still be able to signpost to relevant services. CH expanded that presently healthcare professionals are unsure about the parameters and what is expected of them.</p> <p>CF then introduced GJ to the meeting, revealing that the plan for future meetings is for members to contact AP if they are keen to share an update in this section.</p> <p>GJ then discussed the recent workstreams of the Blood Cancer Alliance’s sub group on data, revealing its main aims are:</p> <ul style="list-style-type: none"> ● Promoting and communicating data through the dashboard. ● Ensuring decision makers have access to the data – pushing blood cancer up the agenda. ● Continuing strengthening the evidence base investigating if there any other datasets that can be continued and what improvements can be made to blood cancer data. | <p>Members to contact AP if they would like to share updates in future meetings – Ongoing</p> |
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| | | <p>GJ revealed that the group had, had its first meeting for this year in July where M & F had provided an update on improvements to the dashboard, outlining the following:</p> <ul style="list-style-type: none"> • A 17% drop in emergency admissions during covid. • The adding of devolved data to the dashboard which is not yet as granular as England. • NCRAS emergency presentation data due to be released in September will be added to the dashboard. <p>GJ then spoke of how the meeting considered what other elements of data are missing from the dashboard, mentioning deprivation, representation, ethnicity and access to care and services as layers which can be added. The meeting also included discourse over how the data can be visualised more effectively and that M & F will shortly be preparing a one page update on developments to the tracker which GJ is happy to share.</p> <p>GJ moved to discuss BCAM, questioning if members had anything planned, asking if there a way of collating this, possibly through sharing a spreadsheet with AP. GJ added he is beginning to produce an influencing plan which can be shared with members examining if it is enough to communicate that the dashboard exists or if there is a necessity to craft a story/narrative, adding the sub-group is looking to meet in the next month to discuss if there is any consensus about what stats to highlight in September.</p> | <p>GJ to share one page update from M & F – Ongoing</p> <p>GJ to share influencing plan with members - Ongoing</p> |
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| | <p>GJ also highlighted the project on health inequalities, asking if there is a way to connect the project with the dashboard data. KB confirmed the intention is to talk about the Unmet Needs research later in the meeting but there is definitely an opportunity to work together inviting GJ to stay for this part of the meeting. GJ then discussed the upcoming data release from PHE and that the Blood Cancer Alliance data sub-group is looking at methodology split and how this might be represented in the final release with concerns expressed about ensuring rarer diseases are still being protected.</p> <p>CF then opened the floor to questions.</p> <p>DC echoed the comments on lack of data on devolved nations, revealing that a representative from the SMC had been invited to sit on the cancer data dashboard and there might be an opportunity to engage with the Government on this. GJ concurred, suggesting they arrange a meeting to discuss further.</p> <p>CM asked about the NCRAS release and potential timeline. GJ said the data should be released in September but not sure about the time period the data will cover, but that information will be included in the M & F one pager.</p> <p>CW concluded the agenda item by speaking about the vaccinations taskforce and the ongoing work to deliver direct comms to blood cancer patients that the vaccine might not be as effective. CW expanded that the vaccinations taskforce had recently met with DHSC and NHSE who had indicated that they will not be communicating directly with blood cancer</p> | <p>DC and GJ to arrange meeting to discuss Scottish Government cancer data dashboard - Ongoing</p> <p>Members to share relevant case studies about impact of vaccine on blood cancer - Ongoing</p> |
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| | | <p>patients in England, suggesting this might worry them unnecessarily, but are open to continuing the conversation. CW confirmed the vaccinations taskforce will continue to raise this issue and also asked if members were willing to provide case studies, adding there might be an opportunity to do some joint comms including the information about immunosuppressed, when there is information about the booster jobs.</p> | |
| 4 | Policy Priorities | <p>KB recapped on the conversation from the last session about policy priorities, outlining that following conversations with the leadership the following priorities had been agreed for the remaining budget:</p> <ul style="list-style-type: none"> ● Extending existing BAME research to include analysis of existing datasets and include a clinical survey. This work had now been commissioned with the University of Hertfordshire leading on the research. ● Continuation of COVID-19 work including pro-active public affairs and responses to government consultations. ● Arranging and running Access to Medicine campaign workshop and actioning priorities from the workshop so we have the resource to concentrate on the issue. <p>KB suggested the next meeting might revisit policy prioritisation and new areas of research depending on the findings of the Unmet Need research. KB opened the floor for questions, with CF adding that members could also share questions after the meeting.</p> | <p>Members to share questions with AP on policy priorities - Ongoing</p> |

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| 5 | Ongoing Campaigns | <p>MH reported back on activities from the last quarter regarding the Access to Medicine campaign, highlighting work had focused on the following developments:</p> <ul style="list-style-type: none"> ● Running meetings with Dr Bygrave and the Genetic Alliance. ● Updating stakeholder mapping exercise. ● Drafting written questions on conversation around the IMF. ● Confirming workshop that is due to take place in September. ● Confirming meeting with the SMC. ● Drafting and sharing written questions on disparity of drug access for MDS patients. ● Updating website with relevant documents. <p>KB added, we are also awaiting further details on the consultation linked to the recent announcement on the IMF and had engaged in a call with Janssen, discussing their initial thoughts.</p> <p>DC then highlighted that this year is the 5th year of Montgomery Review and that this represented a good opportunity to perform some comms. CF and MH concurred.</p> <p>KB moved to discuss the Unmet Needs project, currently being delivered by Quality Health (QH), revealing:</p> <ul style="list-style-type: none"> ● QH are making the final amendments to the report, with the final report to be shared shortly. | <p>AP to draft IMF consultation response – 01/09</p> |
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| | | <ul style="list-style-type: none"> • The next stage for the project is to launch a campaign to coincide with BCAM, based on existing evidence base. <p>KB intimated a possible campaign bringing attention to concerns that blood cancer patients needs are not being met as well as other cancer patients in the journey pathway and finalising where the stark differences exist. KB added that the secretariat will be finalising the strategy and messaging over the next months and will also start copying GJ into the updates: KB also highlighted research carried out by KBS on how blood cancer patients are often not discussed in official documents.</p> <p>CF suggested this will work well with some of the BCA's ongoing workstreams including Access to Medicine and the National Cancer Dashboard only including the 'Big Four' cancers before asking for any questions. CF asked when an update will be shared. KB confirmed an update will be distributed to members in the next couple of weeks. GJ highlighted he was also happy to discuss further, suggesting he might have some stats which could be of use.</p> <p>KB then spoke of the BAME Unmet Needs Report Project, which ClearView is undertaking, updating on the following developments:</p> <ul style="list-style-type: none"> • Patient survey stage has now been launched and is ongoing. • After the survey stage, there will be a series of focus groups. | <p>AP to draft campaign strategy, copying GJ into updates – 01/09</p> <p>AP to arrange conversation with GJ after sharing update – 01/09</p> |
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| | | <ul style="list-style-type: none"> • The view is that we will have a final report by October. <p>KB added to compliment this research, the BCA has also commissioned the University of Hertfordshire to undertake a survey of clinical staff and a review of all existing datasets. The University of Hertfordshire is now completing the ethics procedure with a view to the research starting in September and reporting at the end of the year. KB concluded that the aim is to consider both projects in their entirety, before agreeing on a campaign to launch in February next year.</p> <p>CF questioned whether ClearView needed any more help with recruitment. KB responded that she is catching up with them today, but anything members can do to promote the survey is highly beneficial, while acknowledging these patients are often hard to reach during the survey and that we are expecting some more data to come out from other origins, notably the focus groups.</p> <p>KBS then updated on the work of the BCA and the secretariat, responding to COVID-19 developments, divulging:</p> <ul style="list-style-type: none"> • Drafting of consultation response to the APPG on Radiotherapy consultation on the cancer induced backlog. • Producing a letter to the Health Secretary and the Prime Minister on the impact of the removal of COVID restrictions on blood cancer patients. • Drafting of consultation response to joint APPG on Blood Cancer and APPG on Stem Cell inquiry on the impact of COVID-19 on blood cancer services. | <p>Members to continue sharing relevant materials from ClearView – Ongoing</p> |
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| | | <p>BP then outlined the completion of the following media activities:</p> <ul style="list-style-type: none"> • Drafting of a BCA op-ed on so-called ‘Freedom Day’ securing placement in CharityToday. • Appearance of BCA member from Leukaemia Care on Channel 4 News ‘Fourcast’ podcast. <p>MH then proceeded the conversation to discuss the Health and Social Care Select Committee inquiry into cancer services, revealing the inquiry will consider</p> <ul style="list-style-type: none"> • Why outcomes continue to lag behind comparable countries. • What impact disruption to cancer services during the covid-19 pandemic will have on efforts to catch-up and whether ambitions in the NHS Long Term Plan will help close the gap. <p>MH concluded that the secretariat plan to draft a response to the consultation which concludes on 3rd September 2021, requesting members share their views with the secretariat.</p> <p>CF asked if members are planning on feeding into BCA response or drafting individual charity responses. CW and CF confirmed they will be feeding into a joint one. DC confirmed that SM will update accordingly.</p> | <p>AP to draft response to the consultation – 03/09</p> <p>Members to share thoughts on consultation – 13/08</p> <p>SM to update on Myeloma UK plans – 20/08</p> |
| 6 | Devolved nations update | DC provided an update on developments in Scotland, highlighting: | |

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| | | <ul style="list-style-type: none"> • The appointment of a new chair and new vice-chair to the Scottish Cancer Coalition. • The Scottish Government is completing an ongoing review of their cancer governance structures and are requesting patient and member involvement. • The Scottish Government is looking to draft the cancer strategy going forward. <p>DC then suggested the programme boards might be of interest to other members, representing opportunities to engage with the Scottish Government and the NHS, recommending members contact him if interested in becoming involved. CF asked if DC could share a quick update on the boards of interest. DC confirmed that he will send across an update.</p> <p>YS discussed ongoing activities in Wales outlining:</p> <ul style="list-style-type: none"> • The Wales Cancer Alliance had met with new Welsh Health Minister this morning and is trying to establish a good working relationship. • The priorities of the Welsh Government remain COVID recovery and cancer pathway, although there is an acknowledgment it is not good enough to return to business as normal. • The Welsh Government is in the process of reviewing the cancer quality statement and would like more clinical involvement. • There is frustration in the Welsh Government over planning and the need for a long term settlement. | <p>Members to contact DC if interested in becoming involved on programme boards – Ongoing</p> <p>DC to share update on boards of interest to members – Ongoing</p> |
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| | | <ul style="list-style-type: none"> Restarting of external Wales Cancer Alliance webinars open to all. <p>YS requested that if members had any ideas for guest speakers if they could share with her. DC added there is hope the new Minister will be more open to meeting with the Blood Cancer Alliance.</p> <p>JB revealed the situation in Northern Ireland remained a lot more stable than initially envisaged, but that the two main concerns centred on 'Freedom Day' and Brexit medicine shortages. JB added that freedom day is likely to be announced quite soon, adding that it is unclear how serious the issue is with Brexit medicine shortages. JB concluded by revealing ongoing criticism of the inquiry into the haematology stability plan and the cancer recovery programme in March, due to the limited progress to date.</p> <p>DC asked whether industry had discussed the medicine shortages. JB responded there had been nothing from industry, with concerns originating from patient groups. DC asked about the National Recovery Plan and if there had been any developments. JB suggested the expectation had been that it would be out to consultation earlier this year but is expected imminently.</p> | <p>Members to share recommendations for guest speakers with YS - Ongoing</p> |
| 7 | AOB | <p>CF asked if members had any further comments.</p> <p>JB confirmed this will be her last meeting before maternity leave and will confirm next stages with AP. CF also revealed she will be going on maternity leave in December.</p> | <p>JB to share details of maternity leave cover with AP – Ongoing</p> |

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| | | <p>CM disclosed that Leukaemia Care had been made aware of an NHS England audit into non-Hodgkin lymphoma, but a lack of detail on what will be audited. CM added that the NHS have confirmed they will consult with blood cancer charities but have not yet revealed who they will be meeting with, requesting if members had any further information to share with her.</p> <p>The meeting drew to a close.</p> | <p>Members to share details of NHS audit with CM - Ongoing</p> |
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Next Meetings

| Date | Agenda |
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| TBC | TBC |