May IPF Meeting – Wednesday 3rd May 2023

Members present: Charlotte Martin (CM), Fiona Hazel (FH), Leanne Hampton (LH), Lewis Miller (LM), Annelie Thatcher (AT), Mary-Beth Peddell (MBP), Richard Garner (RG), Sasha Daly (SD), Gail Grant (GG)

Dialling In: Yasmin Sheikh (YS), Dawn Farrar (DF), Patrick Swain (PS), Sarah Galley (SG), Rachel Howell (RH), Hillary Lindsay (HL), Caroline Donaghue (CD1), Christopher Walden (CW), Kelly Gomes (KG), Joanne Badger (JB), Orin Lews (OL).

Atticus Partners Secretariat (AP): Katie Begg (KB), Bethan Phillips (BP), Callum Delhoy (CD2), Joe Watts-Morgan (JWM).

Section	**Minutes**	**Actions**
Welcome	CM introduced herself and welcomed attendees to the meeting. CM invited attendees to introduce themselves. Members introduced themselves.	
CIO Update	CM introduced FH from *Leukaemia UK* FH introduced herself. FH explained that she represented the chief executive group of the BCA. FH explained the new policy and governance structure for BCA and how it would work, with BCA now being a registered, membership charity. FH explained that they want BCA to be a legal entity because it would provide legal progress & to provide a joint strategy between the charities. FH added that she wanted BCA to have a clear strategy before the end of the year and they were tendering to outside parties to provide a clear strategy with the goal of having an agency in place by the end of May – with an agency or consultancy to help with this. Five agencies have been put out to tender with £20,000 being put aside for the work. FH ended her remarks and opened the floor to questions.	

	SD asked what would happen to the structure of the Industry Partners Forum. FH said that there would be few changes and industry partners would remain critical in strategy development & working collaboratively was still relevant. No more questions.	
BSH 2023 Conference Poster	CM laid out the history of the BAME Unmet needs project. CM outlined the poster at the British Society of Haematology 2023 conference. CM said that the researcher from the University of Hertfordshire has not got back in terms of how many people saw the poster but added that it received a lot of engagement at the conference. CM added that where the work goes next is to take this to parliamentarians again, as the inequalities white paper has been dropped. CM added that there has been an offer to turn the BSH work into an animation or video to make it more engaging with a possibility of a social media angle - she added that they were in the awareness phase with this line of work. CM asked YS, DF and CW for further remarks. YS raised that university staff they worked with were willing to use a grant to take this theme of work further and that she would keep the members updated on this. DF & CW did not comment. CM opened the floor to questions. MBP asked if she could receive a copy. CM confirmed she could send it.	• AP to send MBP the poster from the BSH conference • BCA to keep members updated on potential grant from the University of Hertfordshire • BCA to consider reaching out to prostate cancer patients • AP to send MBP a copy of the poster

	RG asked if there had been outreach to NHSE on this topic. CM said she was sure they had been on their stakeholder list & that they invited their Head of Inequalities, Dr Bola Owalabi, to the roundtable but there was still work to be done. KB said there had been engagement but that it was preliminary and was initial. RG said that they had found engagement challenging as well. AT said they were engaging with Dr Bola Owalabi last year & that they had a team dealing with health inequalities. AT offered to speak with them to provide possible contact information. KB said the headlines dominated healthcare inequalities was dominated by maternity care and said it was likely that NHSE's work was dominated by those healthcare inquiries. KB added they were finding it more challenging as well CM said they needed to reflect on how maternity care could be applied to the Unmet Needs project. CM asked RG explain his work at *Janssen*. RG asked CD2 to share the link outlining "Differentials in Clinical Severity and other Patient Activity Indicators amongst Black and South Asian Cancer Patients in England." RG explained Janssen's work into health equity in cancer and their research. RG said that they focused on the link between ethnicity and inequities in cancer patients with a particular focus on prostate cancer and blood cancer in the paper. RG said this research was driven by the idea that Covid-19's drove and revealed health inequalities in the NHS. RG added that it was peer reviewed paper.	

	RG said that the paper revealed that black and South Asian people with these cancers in England faced up to 20% severity of disease than the average person in England. RG said that their main vehicle was a complication of co-morbidity scoreboard as an indicative measure of clinical severity per patient. RG outlined the higher cost of this for the NHS & black and South Asian patients. RG also mentioned that there were more inpatient admissions for these groups as well & admissions during the pandemic fell for these groups. RG also added that they did not have all the answers and it was too soon to make definitive statements about long-term impact of Covid on healthcare inequalities. RH said there was an opportunity to do more for these groups and improve outcomes, but it would require a national policy focus combined with overt local actions which is tailored to the needs of specific minority populations. RG opened the floor to questions. RH added that the report is a lot of data, and that BCA needed to bring the figures to life to have more of an impact. CM agreed with the point but added that the quotes they had received were impactful in relation to this work and told a story and could be useful going forward. KB said that the poster was well received and that the stories told were impactful & said combining the data & the stories was key. BP said that *Clearview*, who they have worked with previously, gave feedback on BAME impacts and that they told us low engagement was to be expected. BP queried if anyone had found tactics that had worked in terms of engaging BAME groups. GG said that one of the examples cited to her BAME group outreach through churches & said it was about more than reaching people through the health service with trusted relationships being important.	

	AT gave a recent example of patient groups being effective, with it proving insightful and bonding but outlined the difficulties with different languages. FH asked if there were plans to disseminate the report further and to further the research to prostate cancer. RG said there wasn’t and that the report had reached a logical conclusion, with a national report and a call to action being the hope. RG added that they could extend the analysis with more recent analysis again to see the impact post-pandemic. RG wondered if there was an opportunity to focus on the issues raised by the report in a more regional way, through specific localities. FH wondered if as the BCA, they could react out to prostate patients in order to gain more attention. RG said they had good links with blood cancer patients and were willing to facilitate this. KB said a link AP had could also facilitate this. CM asked if there were any further questions. CM offered one reflection on data access mentioned in the report, saying it was very important. RG said that the research was quantitative but that the focus on data could be useful topic to explore at another time as a next step. AT asked if the paper explored how clinicians could potentially further these inequalities. RG said the paper did not explore this, but it did make inferences as to the challenges raised, such as language barriers. MBP asked if there was something to explore for early diagnosis centres, with there being a clear link in the report.	

	RG agreed and replied that was an option, with it being worth exploring how they optimise blood cancer pathways & early diagnosis being a good hook for this scheme of work potentially. MBP said the rare disease framework for early diagnosis she had saw recently with some blood cancer fitting into that category. CM said she had a recent conversation with NHSE which showed data that BAME groups went down certain pathways with early diagnosis centres. CM asked for any more thoughts. SD asked if there was possibility for international benchmarking for blood cancer to bring to the government. RG said that this could be helpful with a general election approaching. FH & CD2 concurred. AT asked if the group was aware where the UK was tracking globally with no-one knowing. CM asked if CW had anything to add. CW said he was establishing a working group, with each one having an equality strand – he added that the group was working on creating an international comparison on blood cancer survival rates, but they did not have complexity to break the data down by ethnicity but said there was potential in the US, especially in Myeloma. CM said that was something to consider collectively across organisations. CM asked if there were any more comments. The group then went for a break.	
Major Conditions Strategy	CM resumed the meeting and asked CW to explain the Major Conditions Strategy & how BCA was approaching this. CW said that the strategy would cover six major conditions alongside cancer: cardiovascular, coronary, respiratory, dementia, mental health & musculoskeletal disorders – the BCA worked with One Cancer Voice to hand	• BCA policy group to send five-point plan & social cards to members once completed

	in a petition to Downing Street to register BCA's disapproval at the dropping of the ten-year cancer plan. CW said they all felt strongly about it because they had included patient involvement in the ten-year cancer plan after strong encouragement from NHSE & DHSC. CW said they received reassurance about the patient evidence they had already submitted & that it will be used in the new Major Conditions Strategy. CW said they'd be told there will be a call to evidence in the coming weeks with an interim report by the summer with a final report in 2024 but expressed some scepticism. CW added that charities in the cancer and mental health sector were annoyed with the dropping of the national plans, but other charity sectors, with the musculoskeletal being mentioned by CW, were delighted with this move. CW said DHSC was not planning meetings or consultations with charities at one time and said a general concern was that children and young people will be left out of the strategy. CW said BCA would respond when a formal consultation comes out & were concerned about the potential of blood cancer being lost "in the noise" as NHSE & DHSC focus on the four most common cancers. CW handed it back to CM CM thanked CW for his summary and agreed with his concerns. CM said they want to send a five-point plan to DHSE and that they would work on it over the next few weeks with the consultation opening soon. CM opened the floor to questions. RG asked if the five-point plan was still yet to be done. CM confirmed that it was, with the exact wording still yet to be finalised, stating the need to make it shorter and snappier. GG said it would be helpful to see the five-point plan once it was collated so they could reflect the key themes in their submissions to the consultation. GG added that in Scotland the cancer strategy was likely to be published soon and that it was an opportunity to reflect back to DHSC that they missed an opportunity, especially if it was as comprehensive as they hoped. CM said she heard mixed things about how comprehensive the Scottish	

	report could be, but she hoped it mentioned blood cancer. CM asked if there were further thoughts. RG said they would see how it played out and highlighted the relevance of NHSE's long term plan and said he believed it was unlikely to be released before the election but said "all is not lost." CM agreed that it was helpful to have something to work towards, but the blood cancer community hoped the long-term plan could fix gaps, but it looks unlikely now. FH said David Fitzgerald said NHSE was focused on the long-term plan & they did not want the long-term targets to change. SD asked if it was worth focusing on strategically on the timing on the election, instead of an agency's strategy. CM said narrowing it down to the snappier points would make it easier when it comes to an election. MBP asked how the strategy would be structured & if it would go for wider themes and asked what they might be. CM said she hadn't heard anything. KB said she believes there would be nothing new in the five-point plan. GG said she anticipated the plan focusing on prevention and leveraging the cancer diagnosis centres would be as good as they could expect. CM asked if there were any other thoughts. YS said she was struck by the lack of references of inequalities in the strategy and said they should emphasise in our five-point plan. CM agreed.	

Early Diagnosis	CM highlighted the recent research regarding Early Diagnosis. CM mention members having conversation with NHSE regarding the blood cancer campaign they had suggested they were going to run in the next calendar year. CM said that the challenge around symptoms & the variety of symptoms had made it more of a vigilance campaign. CM said there was an ongoing conversation with NHSE about blood cancer & raising awareness. CM added that Cancer52 were leading the discussions around proxy measures for cancers with BCA involved with hope & positivity in getting the measures, combining the number of GP visits with emergency diagnosis data. CM said they were looking at access to data, with aims of understanding what data is available across all the British nations on blood cancer. CM said they wanted to understand the levels of accessibility of data across the UK, hopefully encouraging better access to this data. CM asked if there were any questions. RG mentioned that the blood cancer dashboard was useful. RG added that Janssen has been unable to succeed in gaining access to data across the UK, with different organisations having different timeframes for data releases, making it challenging to collate the data. CM said the blood cancer dashboard was important and hoped it would be useful for members. CM asked if there were any questions & asked leadership & AP if they wanted to add anything.	
VPAS	CM said BCA had published a statement last October with their initial thoughts on VPAS pricing. Since December, there had been some coverage in Pink Sheet & had joined with the Charity Members Access Coalition & Cancer52 to issue a joint statement which was broad ranging & covered issues around life sciences and research, as well as problems at NICE. CM added that BCA had done well in terms of getting their views out there. CM said that they tried to a roundtable with DHSC and NHSE refusing to participate but BCA have met with NHSE in April.	• AT, LH & MBP to send severity modifier examples to KB

	KB said this was with Claire Foreman, which was positive & they were open to receiving evidence. CM added that YS attended this meeting, but it was a big meeting with all patient groups. CM mentioned that they had written to Hugh Taylor but there had not been a response. CM said there would be further opportunities to meet but the meeting with NHSE did give the impression that they would provide progress so far at the next meeting which is not what BCA were hoping for. CM added that the other challenge is there was an impression that they were “getting by” at NICE and that BCA didn’t have access to the necessary data. KB added that NHSE wanted definitive proof, which is challenging to attain. KB said that they said we could send them what we could, and they would take a look. CM invited YS to comment further. YS concurred with what had been said and signalled her frustration as well. CM opened the floor to questions. LH asked if there had been any questions on the severity modifier. KB said they brought it up and said they were taking a holistic approach to reviewing access issues across the board, saying it was a positive that VPAS wasn’t seen as the end of the opportunity issues to be addressed. KB added that YS and CM mentioned during the meeting that the recent implementation of the makes it difficult to provide tangible examples showing how it is working, but NICE was open to receiving examples. LH wondered how it would pan out in the future, given they have a submission ongoing yet the end-of-life criteria in Scotland has higher threshold than the severity modifier in England, meaning healthcare access in Scotland is more appealing than in England with the potential to causing “postcode prescribing.”	

	AT said they submitted that very case to VPAS at the end of the last year & the president of Novartis spoke to the Financial Times to outline the case, meaning they have examples they are willing to share. KB thanked AT for this and said they (NICE) were willing to listen to this. LH offered to send examples to KB and KB accepted. MBP also offered to help. GG said the negotiations would explore the issues surrounding access & if that a twenty percent payment rate in options around access was the result, that would not be their priority, as they would want to see a reduction in percentages and having a more sustainable payment scheme which was internationally competitive was more important. GG added that she was keen to see NICE incorporate pricing. MBP said that VPAS was not designed to resolve every issue in the commercial and that it would be better off there was not compromising language in VPAS that could constrain what they could do. RG said that if they put too much into VPAS, it becomes too contingent on that and that having broader access discussions outside of VPAS allows them to make more progress. RG encouraged members to continue talking about the issues already raised in the discussion. CM added that they aren't looking for solutions but commitments & took away from the meeting how language could constrain. CM asked if there were any other thoughts. GG flagged that there was a Westminster Hall Debate today on VPAS & one in the House of Lords on the 23rd of May.	
Secretariat update & close	KB asked if anyone had any reflections on items they hadn't heard which they would like to hear & opened the floor to feedback. RG mentioned the new formation of the CIO & said it was good that BCA	

	wanted them involved. FH said that they wanted to have further engagement with Janssen & the next meeting would hopefully come by the end of the year. CM said it was useful to hear about the research from RG and that any members should flag research for future meetings. CM invited feedback from those dialling in. CM thanked members for attending and ended the meeting.	