

APPGC Roundtable discussion minutes, Wednesday 22nd March 2017

Attendees:

John Baron MP, APPGC Chairman
Rebecca Harris MP
Nic Dakin MP
Sam Nicholls, Researcher for Sharon Hodgson MP
Deborah Alsina, Bowel Cancer UK
Diana Jupp, Bloodwise
Priyanka Patel, CLIC Sargent
Dr Rebecca-Upton, Kidney Cancer UK
Paula Chadwick, Roy Castle Lung Foundation
Roger Wotton, Tackle Prostate Cancer
Will Jones, Brainstrust
Professor Frank Chinegwundoh MBE, Cancer Black Care
Chris Carrigan, use MY data
James Shield, Macmillan Cancer Support
Angela Culhane, Prostate Cancer UK
Cally Mintern, Breast Cancer Now
Christine Etheridge, Teenage Cancer Trust
Jane Lyons, Cancer52
Emma Greenwood, Cancer Research UK
Athena Lamnisis, The Eve Appeal
Stefano Gortana, PHG Foundation
Louise Bayne, Ovacome
Lindsey Bennister, Sarcoma UK
Simon Butler, Anthony Nolan
Emma Tingley, The Brain Tumour Charity
Rebecca Leech, APPGC Secretariat
Charlotte Nicholls, APPGC Secretariat
Hugh Adams, Brain Tumour Research
Fraser _____

Apologies:

Henry Smith MP
Mark Durkan MP
Annwen Jones, Target Ovarian Cancer
Sophie Gasson, ICPV
Monica Izmajlowicz, Leukaemia Care

- 1. Arrive and welcome**
- 2. Introductory remarks from John Baron MP, APPGC Chairman**

Chairman John Baron MP said that there had been a long campaign by the cancer-related APPGs to try and focus on one year survival figures and that, since April 2015, CCGs had become accountable for their own one year survival figures. John said that one year survival figures are key as a means of driving improvements in early diagnosis and that One in five cancer in England are still diagnosed through an emergency presentation.

John said he believed that we are 'pushing on an open door' and that the importance of one year survival figures had already been recognised and supported by Ministers and Parliamentarians. John suggested that the charitable sector should become more focus of working with CCGs and the cancer community to shine a light on one year survival figures. John asked for organisations to sign up to the letter in support.

John called for a robust debate about whether the cancer community is doing this or not, and how charities can best work together to champion one year survival figures.

- Louise Bayne from Ovacome said that a focus on one year survival figures did not suit ovarian cancer, and suggested that early diagnosis would be improved by increasing access to diagnostics and awareness campaigns. Louise said that the worst one year survival figures are in the elderly population and that the work that was being done around this in partnership with NCIN had been taken away. John acknowledged that different cancers have different characteristics and that CCGs would need to take a holistic approach to improving one year survival figures, that adapted to local populations and local needs.
- Deborah Alsina from Bowel Cancer UK spoke about workforce amidst the complex structures of accountability for cancer. Deborah said that it was already known how to diagnose bowel cancer early, there were national issues such as a lack of endoscopists that prevented this happen. John said that he didn't think a holistic view was a simplistic view and that it would be up to CCGs to identify what the shortfalls are in their area. John expressed a wish that the
- Dr Rebecca Case-Upton from Kidney Cancer UK said that she _____. She felt that putting the focus on CCGs might put pressure on GPs who are already feeling demoralised. John said that
- Lindsey Bennister from Sarcoma UK said she felt there was a reasonable amount of awareness and diagnosis. She said that Sarcoma UK didn't use one year survival figures in its work as the latest figures date back to 2009 since the NCIN sarcoma reference group was lost.
- Chris Carrigan from use MY data said that NCIN used data to rationalise. Chris pointed out that data in the Cancer Registry is there and richer than it has ever been, however is not currently exploited enough. Chris mentioned a new Bowel Cancer Unit (in partnership with CRUK) which is trying to get around the issue of data access. John asked _____ and Chris replied that PHE do not currently have the capacity, time or resources to implement this. It

was agreed that the issue of data access would be picked up outside of the roundtable discussion.

- Rebecca Harris MP expressed her complete support for focussing on one year survival figures as an outcome measure.
- Roger Wotton from Tackle Prostate Cancer (a grassroots group that represents prostate cancer support groups) Roger questioned why Sweden's survival figures were better than the UK's, whether Sweden used prostate cancer screening.
- Angela Culhane from Prostate Cancer UK said that the PSA statement has been very hard fought. Angela expressed concern that focussing on one year survival figures was oversimplifying a very complex issue, suggesting that a nuanced and subtle approach was necessary. Angela also said that a better pathway was needed for those wrongly diagnosed.
- Frank Chinegwundoh MBE from Cancer Black Care said that he felt that progress was being made and that there was very good evidence from Europe that screening works.
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