

# Asthma UK Meeting Notes

Author: Gordon Brown

Meeting: Cross Party Group on Asthma

Date: 25 March 2015

Attendees: MSPs -Nanette Milne - Conservative; chair of CPG, Ken MacIntosh - Labour; vice chair of CPG, (representative of) Rhoda Grant - Labour, David Stewart - Labour.

Asthma UK - Gordon Brown, Luke Tomlinson, Karen Clough.

Patient representatives - Mike McGregor, Elisabeth Ehrlich, Olivia Fulton

Professor Aziz Sheikh, Professor of Primary Care Research & Development, Edinburgh University; Mome Mukherjee, Senior Data Analyst | Health Services Research Unit (HSRU), eHealth Research Group & Allergy and Respiratory Research Group; Jurgen Schwartze, Chair of Child Life and Health at University of Edinburgh. Henry McSorley, Chancellors Fellow, Child Life and Health, University of Edinburgh; Dr Lynn Morrice, Centre Manager, Asthma UK Centre for Applied Research Research Manager, Allergy and Respiratory Research Group Centre for Population Health Sciences, University of Edinburgh; Trisha Burns, Research Governance Manager, University of Aberdeen/NHS Grampian; Phyllis Murphie, Respiratory Nurse Consultant/Respiratory MCN Clinical Lead, NHS Dumfries and Galloway, Vice-chair, National Advisory Group for Respiratory Managed Clinical Networks James Cant, Head of BLF Scotland.

Alison Culpan, Dir External Affairs, GSK; Mhari Cowan, GSK

Robert Armour, Reporter, Third Force News

Richard Pitt, Public Affairs & Patient Advocacy Mgr | Market Access | Boehringer Ingelheim Ltd.

Tracey Gibson, Io Hui, Eleftheria Vasileiou, Karim Firikh

Discussion	Action	Person to action
<u>The asthma research agenda - making the case for greater investment</u> GB introduced the meeting and explained the importance of increased research		

<p>funding into asthma. It was noted that previous asthma research has had great impact in the past but that it remains a chronically underfunded area. It was also explained that it currently takes 17 years for a new drug to move through the system from research to licencing and that this needs to be halved.</p>		
<p><u>EARIP</u>          Luke gave a presentation on the European Asthma Research and Innovation Partnership, noting that indirect costs of asthma are estimated at 14.4 billion euros per year. It was explained that EARIP brings together 12 partners from 7 countries across research, patient groups and industry and its aim is to identify the research base to cure asthma, and to attract funding and political ambition around asthma research.</p> <p>It was noted by Alison Culpan that it's a crucial time for asthma currently and that the innovation around EARIP can change the landscape for care, as long as it keeps momentum up to the point of getting new medicines and care strategies to patients. Dr Aziz Sheikh queried what is needed from CPG attendees to gain support for EARIP, with LT confirming that support from all stakeholders was needed to push this forward, including political/industry and research sectors.</p>		
<p><u>Asthma UK Applied Centre; the model of a collaborative approach to attract funding - Professor Aziz Sheikh</u></p> <p>Aziz explained the current core programmes of research for asthma and the model for bringing expertise together in a virtual centre. He explained the research model adopted by the applied centre was leading the way in asthma research, noting that its success could change the research landscape for asthma across the UK.</p> <p>He noted the importance of building capacity and expertise in future generations of research via their PHD internships. Alongside this the development of their</p>		

<p>methodology service for asthma trials which is being supported and funded in part by asthma UK to ensure maximum value of secondary uses of data.</p>		
<p>It was noted that the CPG on asthma is high profile and should be used as a tool to encourage funding into asthma research. It was suggested that MEP's could be invited to attend to raise the profile further and an invite coming from Nanette or Ken would add weight. Aziz also noted he was happy to be involved in discussions with SG colleagues.</p> <p>GB asked Aziz if he had a view on what asthma needed to do to try and keep up with the more high profile diseases, such as cancer, in terms of research funding. Aziz noted that there needs to be an understanding of the realities of asthma, although there are asthma related deaths these are nowhere near the level as those from cancer and therefore there will not be the same dedication to funding research into finding a cure as cancer. He believes that instead of asking for 'more of the pie' in terms of funding the size of the pie itself needs to be increased.</p> <p>It was also queried whether the health ministers from across the nations could meet and whether a group of wider stakeholders could be brought together. The importance of events such as the CPG was highlighted to raise these ideas and give strength to current work. Nanette stated that she felt MEP's could be interested in getting involved with the work of the CPG. Luke also explained that the Westminster life sciences minister publically agreed to support EARIP.</p> <p>Nanette mentioned that self management in asthma was like self management in many other conditions, with Aziz agreeing that if we can crack it for asthma then other diseases will follow.</p> <p>GSK raised their asthma app, asking if anyone around the table had experience of</p>		

<p>using it, with Olivia noting she had but that she felt it was too limiting for her but understood the potential issues of making something more like an interactive action plan. The potential of devices such as the apple watch which can monitor your oxygen levels also highlighted.</p>		
<p><u>AOB</u>  The recent publication regarding the over diagnosis of asthma was raised with concern, with Aziz agreeing that it did muddy the water and that the SIGN/BTS guidelines are the most respected in the world and another publication being introduced only causes unnecessary confusion.  GB mentioned that the next CPG would be taking place on May 13<sup>th</sup> and the Health Secretary had been invited to discuss progress on asthma care, a year on from NRAD.  Ken McIntosh updated the group on a response he had received from Scottish government to his question around the inhalers in schools / administration of medicines guidance which stated that due to the hugely complex nature of the situation the guidance continued to be delayed and would be released for consultation in the summer of this year.</p>		