

Asthma UK Meeting Notes

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Meeting: Cross Party Group on Asthma

Date: 09 March 2016

Chairs: Nanette Milne MSP and Ken Macintosh MSP

Speakers:

- **Ron MacDonald**
- **Professor Andrew Morris, Chief Scientist for Health in Scotland**
- **Professor Aziz Sheikh, Professor of Primary Care Research & Development and Co-Director Centre for Population Health Sciences, University of Edinburgh**
- **Dr Samantha Walker, Deputy Chief Executive, Asthma UK**

Full attendee list below

Discussion

Nanette Milne (NM) gave introductions and thank yous.

- Noted the importance of solutions that can transform how people with asthma are diagnosed and treated, and how asthma is managed.
- Scotland is ideally placed to use its infrastructure to deliver such a revolution in asthma research and innovation
- From our world-leading universities to our ability to link datasets to gain a unique picture of health at a population-level, and our thriving life sciences sector - one of the largest life sciences clusters in Europe - which our colleagues at Scottish Enterprise have supported.
- NM introduced the speakers.
- Elisabeth Ehrlich (EE) commented that she would also like to see the CPG on asthma re-form after April.

Ron MacDonald (RM)

The impact of asthma and the importance of finding new solutions

- RM introduced himself and his wife Linda as fundraisers for AUK and tells the tragic story of the death of their daughter Lydia. Lydia died aged 28 as a result of an asthma attack leaving her son Mason, 3, alone in their house for a number of days.
- In previous asthma attacks Ron noted that Lydia had been allowed to leave hospital care just hours after receiving CPR which he thought needed to change. Since Lydia's death Ron noted the correspondence he had with both people with and without asthma telling him they didn't think asthma could kill.
- Ron believes we really need to raise the profile of asthma to change people's perceptions of it which he was pleased to see forming part of AUK's 2014-2017 strategy.
- He noted that an increase in highly skilled asthma researchers would also be beneficial to finding a cure quicker. Recently he and Linda had visited the AUKCAR and thoroughly enjoyed it. Lastly, he reminded the room that to

improve the lives of people with asthma AUK needed more money to do so.

Professor Andrew Morris (AM), Chief Scientist for Health in Scotland

Scotland's leadership on data informatics

- AM compared general medical care in the late 1980s to what is available now saying that medicine has moved from simple but ineffective care to more complex, effective yet dangerous care as we take more risks.
- He pointed out that a rise in multi-morbidity creates a challenge in the design of research needed to elucidate the underlying cause of these illnesses. AM believes there needs to be a convergence of care and research in Scotland and that everyone needs to participate in research which is necessary to find a cure for common, complex diseases such as asthma.
- AM noted Scotland's rich heritage in health research. Of its ten Nobel Laureates, five were for medicine or related specialities. Graduates of Scottish universities founded five of the seven Ivy League schools. But there is a need to reinvigorate the Scottish reputation for health research.
- AM then noted the Scottish Government's Health and Social Care Research Strategy 'Delivering Innovation through Research' and outlined six guiding principles to maintain Scotland's position at the forefront of health research internationally, and which AM hoped will directly help asthma-related research.
 - 1) Build on the strong science infrastructure that exists across our universities in Scotland. Despite Scotland having only 8.4% of the UK population it receives 12% research funding illustrating its potential and strength in the area.
 - 2) Collaborative partnerships to develop health science systems which support the tripartite mission of education, research and service delivery. AM commented on NHS Research Scotland which is investing £10m to create agile health science environments across Scotland's academic centres.
 - 3) Knowledge through data - use the info that we gather on people living with chronic diseases to tailor people's treatment pathways and inform the research we should be doing. Scotland has unrivalled datasets and there is an opportunity to lead the world in the definition of what it's like to live with a chronic disease. Asthma is a prime candidate to use the information that we have.

4) Reduce the red tape and regulation. Smoothing the pathway to enable health research and partnership with industry.

5) Partnership with patients across the pathway and with the biotechnology, pharmaceutical, informatics and medical devices industries. Effective clusters occur when the service collaborates with academia and industry to drive innovation into the service. Delighted to see Scottish Health Innovations in attendance, who have a remit to drive innovation in the NHS.

6) Positioning Scotland as a single research site to be globally competitive.

- Stressed the importance of enabling primary care for research as 80-90% of health contacts occur in primary care.
- AM expressed that he was confident that Scotland has what it takes to improve the lives of people with asthma and told the Group that there is an open door policy at the Science Office should anyone want to discuss anything further.

Professor Aziz Sheikh (AS), Professor of Primary Care Research & Development and Co-Director Centre for Population Health Sciences, University of Edinburgh

The opportunity for asthma data research in Scotland

- AS explained that asthma is one of the most common long term conditions in the UK with high rates of morbidity and mortality. Despite this he noted that it has been proven again and again that asthma deaths are preventable with the correct care.
- Frustratingly AS thought that despite this little progress has been made in asthma and revealed that there were still close to 100 asthma deaths per year in Scotland.
- AS believes collaboration between academics and the third sector would bring the prediction of asthma attack technology closer to fruition, allowing us to reduce the number of asthma deaths. AS outlined the goals of the Asthma UK Centre for Applied Research to achieve a step-change in asthma outcomes: better identifying asthma

attacks, intervening appropriately to reduce the risk of hospitalisation, and to drive down asthma attacks.

- AS noted the important opportunity to harness Scotland's informatics capability - through leadership by the Farr @ Scotland - to allow data to be presented in near real-time to inform decision-making at the front line. This would allow us to understand who will have an attack, which general practices are doing well on asthma outcomes, and which practices need help.
- Scotland proudly produces the BTS/SIGN Asthma Guidelines and we should 'liquify' data assets to see which criteria are being met so that we can support people on the frontline.
- AS explained the importance of creating a Learning Healthcare System which would connect health data to drive improvements in health outcomes and reduce costs. The idea has been developed in the USA by the Institute of Medicine (renamed the Health and Medicine Division of the National Academies of Sciences, Engineering and Medicine, as of Mar 15, 2016), and is already being done in parts of the USA.
- The rest of the world's eyes are already on Scotland for its data assets and there is an opportunity to develop a Learning Healthcare System for an entire nation in Scotland.
- AS believes asthma could be an exemplar for the introduction of such technology; and if it could be made to work for asthma, it could be done for a range of long-term conditions.
- AS emphasises the need to pull together to achieve this ambitious goal.

Dr Samantha Walker (SW), Deputy Chief Executive, Asthma UK

The most promising areas of research that can deliver breakthroughs for people with asthma in Scotland

- SW thanked RM for his speech, which reminds us of why the CPG convenes - to ensure that tragedies such as theirs do not happen.
- SW noted Asthma UK's funding of the Centre for Applied Research, a multi-million pound investment co-led by Aziz, based in Edinburgh.

- SW noted that Scotsman Sir David Jack from Fife led the development of salbutamol - the key asthma drug in the blue reliever inhaler - a visible sign of asthma treatment. But there have been few breakthroughs for people with asthma in the last few decades.
- There are over 368,000 people with asthma in Scotland, and every year there are over 5700 emergency admissions, a third of which are children.
- Asthma is poorly funded - asthma and COPD research makes up just 0.5% of the EU's 6 billion-Euro health research budget. This means that there is still no definitive diagnosis for asthma. There are no systems to spot deterioration in asthma symptoms. And there are an estimated 15,000 people with asthma in Scotland for whom conventional treatments do not work.
- Asthma UK has invested over £5.3 million into asthma research by Scottish universities in the past 20 years. That included research led by Professor Neil Thomson from the University of Glasgow on the reduced effectiveness of inhaled corticosteroids - the mainstay of asthma treatment - in people with mild persistent asthma who smoke.
- But to realise a vision of stopping asthma attacks and curing asthma requires us to work together to achieve a step-change in asthma research investment.
- Asthma UK we've been leading a pan-European project to work out where the next breakthroughs in asthma will come from. After almost three years, this 12-strong consortium of experts has produced a detailed roadmap that - investment pending - can help us to stop asthma attacks and ultimately find a cure. There are essentially three areas where the research could have a transformative impact:
 - o Developing new diagnostic tools
 - o Developing new treatments for severe asthma
 - o And much better use of technology to manage asthma
- The prevalence of asthma is expected to grow from 300 to 400 million globally in the next decade. That means

millions of people of all ages in need of solutions. It will also mean a global market for asthma drugs expanding to £14 billion in 2017.

- Scotland is well-placed to deliver the breakthroughs in asthma research. There is a strong appetite to be at the leading edge of medical science with ground-breaking partnerships in genomics studies, health informatics and imaging technologies. As we heard earlier from Andrew Morris, Scotland is positioning itself as a global leader in life sciences and eHealth.
- The CSO's strategy calls for everyone to be able to live longer healthier lives supported by sustainable high-quality health and social care services in Scotland.
- But to achieve this, Scotland cannot ignore people with asthma. As Sir John Bell recently mentioned: the best example of precision medicine comes from asthma.
- Asthma presents an exemplar condition for the development of the UK's life sciences capability as there is substantial unmet need and a big opportunity to improve health and drive wealth.
- To deliver a leap forward in asthma research investment, Asthma UK calls for support for our campaign:
 - To increase asthma research investment from Scottish and UK-wide funding bodies
 - To have a dedicated asthma-management technology research collaboration
 - To have a themed call for asthma research issued by a major EU funding body

Q&A - chaired by Ken Macintosh MSP

Q. Ken Macintosh (KM) asks AS why there is a gap between BTS guidelines and poor results?

- AS suggests that it's due to the implementation of guidelines which in its self is challenging. He also suggests that many documents that aid asthma care and provide guidelines cannot be integrated into GP's systems. In addition AS believes there needs to be an innovation in treatments such as precision medicine which will offer tailored care.
- SW added that the emerging understanding of basic science telling us that as much as 50% of people with asthma don't respond to only treatment available and so he opportunity for new treatments are immense which if

explored would bring about better results.

- EE commented that from her experience of being a school teacher more than two children in every classroom have asthma. She also revealed that frequently if you suggest you have asthma it's seen as a psychological condition rather than a physical one and thus is associated with negative connotations.
- SW explained that the number of children in a classroom was an average: the number of children in the UK divided by the average size of a UK classroom. She then went on to say in some areas it will be higher numbers of children with asthma. SW noted that changing the perception of asthma was something Asthma UK was trying to combat.

Q. AM asked if AUK had any celebrity ambassadors as he thought Angelia Jolie had probably had the most effect in raising the profile of breast cancer.

- SW replied that most of our informal ambassadors are those from the sports world. Unfortunately, it would seem that extremely high profile sports personalities/professionals, for example, David Beckham, don't want to be affiliated with AUK.

Q. Bettina Sizeland (BS) asked what type of information and technology would make a real difference to asthma care.

- AS answered that self-management was paramount as people with asthma generally have few and far between face-to-face time with medical professionals. He said technology to remind people to take their medication and predict attacks would be the most important noting that prediction algorithms would need to be personalised. These could range from monitoring coughing at night to the pace of walk which would require wearables. In addition to this the information collected could also be relayed to the health care professional via the cloud for example.
- Olivia Fulton (OF) comments that she uses an app to remind her to take her medication and that it's annoying but effective.
- Hilary Pinnock (HP) agrees that a self-management app is so important and that having an asthma action plan is vital. However, HP notes that an action plan is a piece of paper and that we need to integrate it into technology. She continues that an app should offer a prompting service as well as monitoring service. However, this prompting service then turns it into a medical device and that's where support is needed from technology companies to

enable apps to make this leap.

- EE comments that as many as 32% of the population don't have smart phones and so although she sees the benefit of apps they won't solve everyone's problems.
- Prof Sir Lewis Ritchie (LR) contributed that he thinks we need to move away from simple databases and need more continuity available through the use of electronic records that can compensate for human inconsistency and be the glue to hold everything together.
- KM commented that the history of the government and IT is a disaster and although he recognised the importance of self-management he doesn't think an app is the single solution.
- AM believed that the first step needs to be a real time information system within the NHS as currently a lot of information sits on paper. Once this was established then apps could be layered over the top.
- Jurgen Schwarze pointed out that he thought the prevention of asthma was key and that we need to focus research efforts on understanding the pathways that lead to asthma; only then can we effectively manage and treat it.

Q. AM asks if AUK funds research around systematic healthcare?

- SW answers that AUK does not discriminate between the topic of research with its funding.

Q. KM asks if asthma is actually on the rise.

- AS answers that no it isn't but that prevalence isn't decreasing either.
- SL notes that pollution is on the rise and research has showed that pollution has an increased effect on children and does induce asthma.
- AM shared that NERC (Natural Environment Research Council), the Medical Research Council (MRC) and the Scottish Government Chief Scientist Office (CSO) are investing up to £600,000 in projects to identify and fill knowledge gaps about the scope and potential utilisation of environmental data in support of improved health outcomes in the UK. This call will focus specifically on research utilisation of environmental data collected on air

pollution and/or environmental hazards together with health and biomedical data.

- SW commented that to understand the gaps in research we there needs to be an approach from all sides and that AUK intends to obtain a couple hundred million pounds to fund these gaps.
- KM closed meeting by saying thank you and noting it was the last CPG for asthma and hoped that there would be a renewed group after May. He noted that he didn't think it would be hard to find support and attendance for the group in Scotland. He members of the Group to lobby their MSP's to form the group.
- SW commented that AUK are happy to help lobby MSP's as they are dedicated to supporting people with asthma in Scotland.

Attendee list

Title	First name	Surname	Role	Organisation
Ms	Jill	Adams	Respiratory Co-ordinator	Chest Heart and Stroke Scotland
Miss	Derry	Begho	External Affairs Officer	Asthma UK
Mrs	Louise	Bond	Corporate Partnerships Officer	Asthma UK
Ms	Marion	Butchart	Government Affairs Manager Scotland	Novartis
Mr	David	Cline	Chief Operating Officer	The University of Edinburgh (The Usher Institute of Population Health Sciences and Informatics) and FARR
Ms	Alison	Culpan	Director of Government Affairs	GSK
Ms	Elisabeth	Ehrlich	Co PPI-Lead & Patient Representative	AUK Centre
Mr	John	Finnie	MSP	Scottish Parliament
Ms	Olivia	Fulton	Patient Representative	
Mr	Hugh	Henry	MSP- Member of the CPG on Asthma	Scottish Parliament
Mr	Ed	Hutchinson		Scottish Enterprise and Health Science Scotland
Dr	Steff	Lewis	Deputy Director, Edinburgh MRC Hub for Clinical Trials Methodology Research	University of Edinburgh

Ms	Nicola	Mccleary	Researcher	AUK CAR
Mr	Ron	MacDonald	Patient Representative	
Mrs	Linda	MacDonald	Patient Representative	
Mr	Ken	Macintosh	MSP- Deputy Convener of the Asthma CPG	Scottish Parliament
Ms	Ann	McMurray	Asthma Nurse Specialist	NHS Lothian
Mr	Keith	McKellar	CEO	Scottish Health Innovations Ltd
Dr	Henry	McSorley	Senior Postdoctoral Development Award / Asthma UK Fellow	University of Edinburgh
Ms	Nanette	Milne	MSP - Convener of the Asthma CPG	Scottish Parliament
Professor	Andrew	Morris	Chief Scientist for Health	Scottish Government (Chief Scientist Office)
Ms	Phyllis	Murphie	Respiratory Nurse Consultant/MCN Clinical Lead	NHS Dumfries and Galloway
Dr	Hilary	Pinnock	Reader (ex Senior Clinical Research Fellow) Principal in General Practice	University of Edinburgh and Whitstable Medical Practice, Kent
Mr	Richard	Pitt	Corporate Affairs Manager	Boehringer Ingelheim
Mr	Krisnah	Poinasamy	Senior Policy Officer	Asthma UK

Ms	Julie	Ross	Regional Healthcare Account Manager	AstraZeneca
Professor	Aziz	Sheikh	Professor of Primary Care Research & Development; Director - Centre for Population Health Sciences	University of Edinburgh
Professor	Jürgen	Schwarze	Edward Clark Chair of Child Life and Health, MRC Centre for Inflammation Research	University of Edinburgh
Dr	Colin	Simpson	Member of the Asthma UK Centre for Applied Research. Co-lead on the research volunteer database	University of Edinburgh
Ms	Bettina	Sizeland	Head of eHealth Strategy and Policy	Scottish Government (Directorate for Finance, eHealth and Pharmaceuticals)
Dr	Samantha	Walker	Deputy Chief Executive <i>and</i> Executive Director of Research and Policy	Asthma UK
Mr	Charles	Weller	General Manager	NHS Research Scotland
Ms	Julie	Westwood	Asthma Nurse Specialist	Royal Hospital for Sick Children (RHSC) Edinburgh NHS Lothian
Dr	Allison	Worth	Senior Research Fellow/Research Manager, Allergy and Respiratory Research Group. Also Patient and Public Involvement Lead at AUK CAR	University of Edinburgh/ AUK CAR
Dr	Dietmar	Zaiss	Principal Investigator and Chancellor's Fellow, Institute of Immunology and Infection Research	University of Edinburgh