



Roadmap for Scottish Asthma Observatory

Real-time monitoring of asthma data to improve patient care



A key stakeholder gathering of asthma patients, clinicians, policy makers, asthma charities plus industry and university researchers has charted a roadmap to create a Scottish Asthma Observatory that provides real-time monitoring of the impact this life threatening condition is having on individual patients and the population at large.

"This was a fantastic opportunity to improve asthma outcomes for patients across Scotland. We now look forward to working with the Scottish Government, Farr Scotland, NHS Information Services, Asthma UK, our patient and public involvement group, and clinical and academic colleagues across Scotland to turn this into a reality," said Professor Aziz Sheikh, Director of Asthma UK Centre for Applied Research and Co-Director of the Centre of Medical Informatics at the University of Edinburgh's Usher Institute.



The Open Innovation Workshop - at Farr@Scotland, Edinburgh BioQuarter on 27th October 2015 – brainstormed on how to use the wealth of routine data produced across Scotland to work on solutions that would improve clinical outcomes and support inward investment from industry in technologies.

Professor Aziz explained that Scotland has one of the highest prevalence of asthma in the world with potentially avoidable morbidity and deaths. He proposed the establishment of a centre of excellence that would harness expertise from across the UK to plug gaps in data and create data streams designed to support improvements in patient care and inform government policies on asthma.



In a wide ranging discussion, Dr Hester Ward, Consultant in Public Health Medicine with NHS National Services Scotland said, "The meeting gave us the opportunity to share understanding of the real potential for improving health outcomes of those people in Scotland with asthma through the rich data we have in Scotland." She also highlighted the importance of patient generated data in any future informatics strategy.

Samantha Walker, Director of Research and Policy at the charity Asthma UK, reminded stakeholders that 180 people are admitted to hospital every day having suffered a severe asthma attack with 3 dying. She argued that a Scottish Asthma Observatory could help recognize where asthma standards are not being met and identify knowledge gaps for further research.



Michael Bang, representing patients on the UK Centre for Applied Asthma Research Advisory Group, discussed the views of asthma sufferers who are broadly supportive of establishing an observatory adding, "You can't know too much about asthma." He also underscored the message that patients want strong assurances about data security. Professor Andrew Morris, Vice Principal Data Science at the University of Edinburgh, recognized the importance of informing the public and working with its consent but cautioned that discussions about data security should not be used "as a smokescreen to prevent change."

Following the meeting a roadmap will be developed by the end of the year and a further meeting of stakeholders will take place in January 2016.