

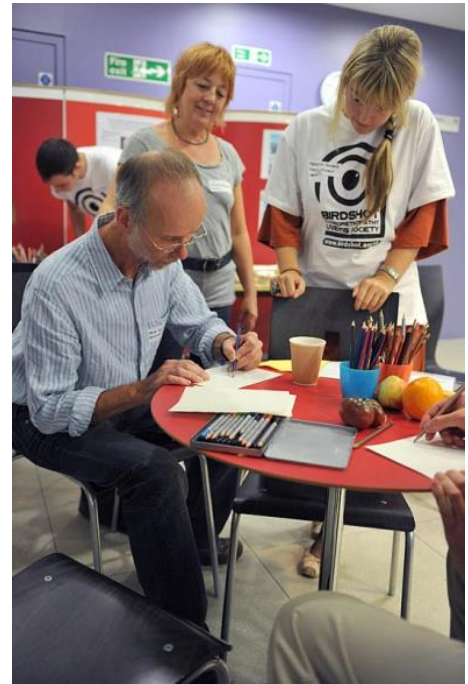
Birdshot Day

Overview and Context

The Birdshot Day was set up to bring together people with Birdshot Chorioretinopathy, their friends and family members, and healthcare professionals with an interest in this area. The first UK Birdshot Day was set up by a team that included an academic member of staff at UCL and staff from Moorfields Eye Hospital in collaboration with the 'Birdshot Uveitis Society' (BUS).

This public engagement project at UCL was a first attempt to have a collective understanding of the disease, and its extent at a national level. On 11th September 2010 an event was held at the UCL campus in order to address issues surrounding the disease.

This case study identifies key findings from the project and highlights learning for any similar projects of this nature.



Background:

Birdshot Chorioretinopathy is a rare, potentially blinding, chronic, auto-immune form of posterior uveitis which affects adults of all ages. It is still relatively little known and often misunderstood. People with Birdshot may never meet another person with the same condition. Healthcare professionals may only see one patient with Birdshot in their entire professional career. It is not known how many have this condition, it is often misdiagnosed or under-diagnosed and many people are suffering, often in isolation without the support they need. The team behind Birdshot Day was a forum to bring together all identified people with Birdshot and all health professionals working in the field of Birdshot to exchange information and learn from each other.



The aims of the Birdshot Patient Day were to:

- Reduce the sense of isolation for patients with this rare disease;
- Raise the profile of the disease in the UK;
- Allow a two-way exchange of information between patients and professionals;
- Help to obtain a better visual outcome for patients, and;
- Provide a base for research.

What happened?

- On 11th September 2010 an event was held at the UCL
- The programme for the day enabled healthcare professionals and people with Birdshot to come face-to-face for the first time, to discuss in an informal setting, the disease and the impact it has on quality of life.
- The event allowed for in-depth engagement, including up-to-date information on government policy to improve services for people with Birdshot, practical exercises such as an art workshop to increase awareness of the disease, and a question and answer session to address concerns.

Facts and Figures

- Although the project set out to attract 100 professionals and people with Birdshot for this one-day event, it far exceeded this target, attracting **126** participants - an equal spread of **50** Birdshotters and **50** healthcare professionals, and an additional **26** supporters or family members;
- The project was funded under the Public Engagement Unit's Beacon Bursary small grants scheme.

Emerging themes from the evaluation

The overall comments and feedback received after the event were testament to its impact both on Birdshotters – many of whom spoke of ‘a new sense of hope for the future,’ and on professionals – who relayed the benefits in terms of a better understanding of Birdshot. Other impacts were as follows:

- A reduced sense of isolation of people with Birdshot. Most Birdshotters had never met another individual with their condition. In the six months following the Birdshot Day, 47% of Birdshotters had been in touch with another individual with Birdshot. As one Birdshotter commented: ‘I am no longer scared of my future and I feel less isolated and powerless.’ Also after six months, 52% of health professionals had been in touch with at least one other newly acquainted Birdshot colleague.
- Raising the profile of the disease. In the 3 weeks following the patient day, the number of ‘hits’ on the BUS website more than doubled to 67,000. Six months after the event, all health professionals who responded to the evaluation stated they would recommend a similar event to people with Birdshot and 96% of them stated they would recommend it to other health –care professionals. An educational DVD about the event has also been created by BUS, the Biomedical Research Centre, and the NIHR (National Institute for Health Research) and circulated to all eye departments in the UK.
- A two-way exchange of information between people with Birdshot and professionals. When people with Birdshot were asked prior to the event how much they knew about Birdshot, 100% of those that answered ‘nothing’ or ‘very little’ had stated they had learnt something by the end of the day. Similarly, when professionals were asked the same question, 43% stated they had ‘very little’ or ‘a little’ knowledge before the event, and this percentage fell to 6% at the end of the day.
- Providing a base for research. People with Birdshot voted for their priorities for medical research. Nearly half of the patients wanted research to focus firstly on the causes of Birdshot. This is because they want to prevent the next generation from experiencing what they have suffered. Birdshotters’ commitment to this research was also very apparent in the fact that on the day, every single one of them was willing to give a blood sample as part of a research project.
- New partnerships. The Birdshot Day project led to the creation of new and lasting partnerships between the UCL Institute of Ophthalmology, NIHR Biomedical Centre for Ophthalmology at Moorfields Eye Hospital and the Birdshot Uveitis Society. Other partnering organisations were:

Further information is available at:

Birdshot Uveitis Society (BUS)
www.birdshot.org.uk

Learning from the Process

What worked well?

- The programme for the day was based on a survey of Birdshotters and their needs. The day included talks about Birdshot (from both healthcare practitioners and those suffering with Birdshot), networking events, practical exercises and question and answer sessions to allow essential two-way learning, communication and feedback.
- The Birdshot Day and the constructive discussions held throughout the day led to the creation of the Birdshot National Research Network. This is supported by the NIHR Biomedical Research Centre for Ophthalmology based at Moorfields and UCL Institute of Ophthalmology.
- The organising team undertook a rigorous evaluation of the day, using a range of methods including pre and post questionnaires. The team were able to write up the findings from the evaluation of the day into a research paper for publication.

What could be done differently?

- The success of this day has led to many other opportunities for the organising team in terms of further research and training opportunities surrounding Patient and Public Involvement. This is great, but it is time consuming and the team have needed to ensure that they have to capacity to respond to the interest generated.

Contact:

Dr Narciss Okhravi
 UCL Institute of Ophthalmology
n.okhravi@ucl.ac.uk