



Bringing together patient and specialists: the first Birdshot Day

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ABSTRACT

Background The importance of patient and public involvement (PPI) in healthcare decisions and research is increasingly recognised. This paper describes the aims, delivery, evaluation and impact of a 'Birdshot Day' organised for patients with birdshot uveitis, their carers and healthcare professionals.

Methods Delivery of this event involved the close collaboration of patients with a large number of different healthcare professionals. The event's evaluation used established social research methods including qualitative questionnaires pre, post and 6 months following the event. The results were statistically analysed.

Results Results indicated that this event significantly educated both patients and professionals. The sense of isolation felt by patients was reduced and networking was developed among all attendees. Patient priorities for research were recorded and invaluable insight into patients' needs for a better quality of life was gained.

Conclusions The first undertaking of this novel PPI event achieved all its aims. It became even clearer that fundamental questions remain about birdshot uveitis, including aetiology, pathogenesis, practical clinical issues and impact on quality of life. These questions can only be addressed in partnership with patients. To this end, patients and professionals came together under the banner 'Team Birdshot' and the National Birdshot Research Network was launched.

INTRODUCTION

Patient and public involvement

Involvement of patients in their care, in defining health priorities and research questions is a key tenet of healthcare in the new century.^{1 2} The UK government liberating the NHS claims to 'strengthen the collective voice of patients and the public'³ and the National Institute for Health Research in their *Research for Patient Benefit Programme* have confirmed the importance of involving patients in choosing research priorities.⁴

It is already clear that what is important to clinicians and researchers may not be the most important to patients with eye disease² and yet in October 2011 Tarpey *et al* revealed that only 19% of studies submitted via National Research Ethics Service (NRES) demonstrated patient involvement with a further 43% describing engagement, not involvement.⁵

The emphasis on patient and public involvement (PPI) in health research in the UK has emerged over the last decade, gaining strength, recognition and reflecting the increasing international focus on research in this area.⁶

There is a growing call for greater public involvement in establishing science and technology policy in line with democratic ideals.⁷ Funders are increasingly building PPI into the systems for commissioning and funding research.⁸

It is generally recognised that evaluation in the higher educational sector is a complex undertaking. There is no standard or agreed approach to PPI evaluation and a scarcity of such reports exist in the literature, which mostly concentrate on the setting-up and delivery of such schemes and not on their impact or legacy.

Considerable confusion exists as to the appropriate benchmarks for evaluation and the definition of 'quality' is highly context dependant.⁷

Our paper aims to contribute an effective quality evaluation of PPI and describe the lasting impact of such initiatives for a rare disease.

Birdshot uveitis

Accounting for only 6%–7.9% of cases of posterior uveitis, birdshot uveitis may in the absence of prompt diagnosis and adequate immunosuppression result in irreversible loss of visual function.⁹ Most specialists will have cared for someone with birdshot. Few investigators, however, have access to a large enough patient cohort with which to study the condition in detail. Birdshot is characterised by multiple, distinctive, hypopigmented choroidal lesions,¹⁰ which may not be seen clinically until several years post onset. The mean age at presentation is 53–56 years^{11 12} but the disease affects patients of all ages with adverse effects on quality of life and the ability to undertake activities of daily living.^{9 13} The fact that central visual acuity is often preserved until late in the condition's natural history (when significant loss of visual function may have already occurred) further results in many patients not receiving adequate or prompt immunosuppressive treatment.

Birdshot uveitis from a patient's perspective

Prior to the formation of the Birdshot Uveitis Society (BUS), most people in the UK diagnosed with birdshot had never met anyone else with the condition. They experienced a long, lonely path to finding out about the disease and learning to manage both the disease and the medication side effects.

There have been no publications to date describing the prevalence of birdshot in the general population, internationally or in the UK. Estimates from our UK-based patient support group (by means of a

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UK consultants' survey-2008) suggested that approximately 300–400 patients with birdshot might exist in the UK.¹⁴

Aims of the Birdshot Day

The Birdshot Patient Day had five aims based on semistructured interviews with patients and professionals. It was recognised that principles of PPI in research do not traditionally include the processes of patient support or education.¹⁵ Nevertheless, based on the strongly held beliefs of our patient experts it was deemed important to include education and support covering both clinical and research areas. These five aims were therefore defined as: (1) to reduce the sense of isolation of patients with birdshot, (2) to raise the profile of the disease, (3) to allow a two-way exchange of information between patients and professionals, (4) to obtain better visual outcomes and (5) to provide a base for research.

MATERIALS AND METHODS

With the goal of reaching every birdshot patient in the UK, the Birdshot Patient Day was organised by the founders of BUS along with a team of 54 healthcare professionals, public-engagement and audio-visual specialists. BUS communicated the agenda to their members; raised funds; provided patient and expert speakers; designed and produced publicity material; and advertised the event and used their network to ensure the presence of a wide range of self-help and low-vision providers.

Informed through a survey of BUS patients, 'What patients wanted' was the focus of the team's efforts. The format and setting were decided based on patient opinion, feasibility and cost issues, given birdshot is a rare disease.

The event was thoroughly publicised nationally and internationally on more than 50 websites as well as in local newspapers. This was done through the distribution of advertising posters (designed by a birdshot patient) to all UK Ophthalmology departments, by communication through scientific literature and online patient support sites. All ophthalmic consultants also received posters and leaflets and were encouraged to inform any birdshot patient under their care.

The Birdshot Day took place in September 2010 in central London, with a large team of volunteers having worked for 10 months in preparation for its delivery.

Medical students were taught by patient experts, physicians, nurses and pharmacists prior to the day and then put in charge of interactive poster boards.

The day's sessions included diverse talks from uveitis specialists, patients and charitable societies. A 'Question and Answer' session followed, with further emphasis placed on the creation of networking opportunities, with ample time spent on informal fora in which individuals were able to learn from each other. Video footage was recorded from all presentations and birdshot sufferers were interviewed about their personal experiences, leading to the creation of an educational DVD.¹⁴

A small art workshop was set up, which was run by a fine-arts research student (author JW). This aimed to elicit and analyse the visual perceptions of all attendees. This is a novel means of using drawing to communicate information about the impact of disease on vision and its effect on the patients' sight and their life experiences.¹⁶

Evaluation

This PPI project's evaluation was developed using qualitative social research methods as applicable to a case-study approach. This involved surveys, questionnaires, interactive poster boards and semistructured interviews, as detailed below.

1. Structured anonymous questionnaires (for patients and carers and separately for professionals). These were completed on three occasions: prior to the event, within 3 weeks after and 6 months (± 3 weeks) following the event.
2. Interactive poster boards were displayed throughout the day allowing all to participate anonymously (using both free text and a 'traffic-light' system of evaluation).
3. Comments were invited for submission on the BUS website forum.
4. Number of 'hits' and new registrations on the BUS website following the event were monitored.
5. The use of questionnaires was the main form of objective, empirical data collection. The researchers, working with statisticians and public-engagement officers, developed the questionnaires which were structured around the aims of the Patient Day. This was then validated with 17 birdshot patients, for content, presentation (readability) and wording.

In parallel to the evaluation process and attempting to promote patient involvement in birdshot research further, interactive poster boards sought answers to two questions. Patients and carers were asked 'What do you think current research should concentrate on?' and patients were asked 'Assuming there is no cure, what would be the single factor that would improve your quality of life the most?'

Research governance

The project's proposal and all documentation including questionnaires and consent forms were submitted to and reviewed by the Moorfields Research Management Committee. An ethics submission was not deemed necessary.

Written consent was gained from all attendees for any information they provided throughout and after the event to be used for research and for images or videos of them to be used for media production purposes.

Statistical analysis

The distribution of responses among patients/carers and healthcare professionals for each questionnaire item was examined.

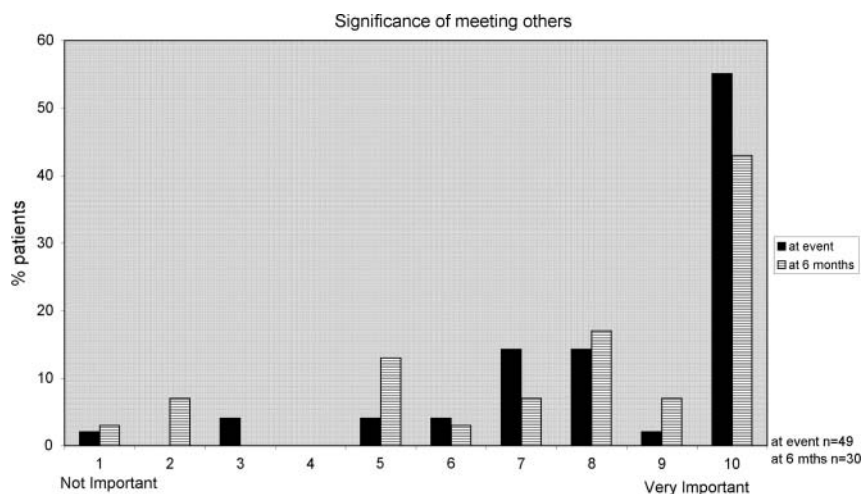
Results were cross-tabulated from one time-point with another to show how responses varied over time. A Wilcoxon Rank sum-test was used to compare knowledge scores in patients premeeting and postmeeting. At this event, questionnaires were completely anonymous, and not matched pre-event and postevent for individuals. All analyses were conducted in Stata statistical software and statistical significance was taken at 0.05 with two tailed values only examined.

RESULTS

All 126 attendees were asked to complete questionnaires. This included 50 patients, 26 carers and a multidisciplinary group of

Table 1 Recruitment demographics

| Sample size | Patients and supporters n=76 | Health professionals n=50 |
|-----------------------------|---------------------------------|------------------------------|
| Questionnaire response rate | | |
| Pre | 64.47% (49/76) | 44% (22/50) |
| Post | 67.1% (51/76) | 32% (16/50) |
| 6 months | 39.47% (30/76) | 50% (25/50) |

Figure 1 Evaluating the significance of meeting others.

50 health professionals involved in the care of individuals with birdshot uveitis. The sample size and response rates are summarised in table 1.

Reducing sense of isolation and networking

When asked how many other patients with birdshot they had met prior to the Patient Day, 84% (n=53) of responding patients and carers answered three or fewer. In all, 54% of all patients had never before met another individual with birdshot. Following the event, this had dropped to 4%. In the 6 months following the Birdshot Day, 47% of patients had been in touch with another individual with birdshot.

The vast majority of patients found it 'very important' to have met fellow sufferers (figure 1). This belief was firmly held 6 months after the event.

Overall, 45.45% (n=10) of health professionals had met or cared for 'three or fewer' birdshot patients prior to the Patient Day, while the majority (82%) had cared for no more than 10 patients. In the 6 months following the event, 50% of health professionals had been in touch with at least one other newly acquainted 'Team Birdshot' colleague.

Information and knowledge

When asked 'How much do you know about Birdshot', all patients who had answered 'Nothing' or 'Very little' prior to the event had changed opinion postevent. There was an increase from 42.86% (21/49) to 57% (29/51) in the group who

answered 'Quite a bit'. Patients who found that they knew 'An awful lot' increased from one to 15 patients (30%).

Importantly, patient knowledge at 6 months was still statistically significantly greater than prior to attending the meeting (p=0.015).

Asking professionals 'How much do you know about Birdshot', 42.85% replied with either 'Very little' or 'A little' prior to the Birdshot Day. This dropped to 6.25% following the event. The 'Quite a bit' response was selected by 30.4% more professionals following the event compared with before it. Similarly, the 'A lot' response increased by 23.2%.

Impact on quality of life and choice of future research

Responding to the question 'Assuming there is no cure, what is the single factor that would improve the quality of my life the most?', 55.81% (n=24) of patients selected 'Fewer drug side-effects', 23.26% (n=10) selected 'More frequent and detailed monitoring' and 9.3% (n=4) 'Practical or financial support'; 4.65% (n=2) of patients would have preferred 'Emotional support' and 6.97% (n=3) voted 'Other'.

When patients and their carers were asked what they wished current research would concentrate on, 47.83% (n=33) voted 'Finding out what causes the disease', 31.88% (n=22) voted for 'Better medicines', 13.04% (n=9) for 'Faster and more accurate diagnosis' and 7.25% (n=5) wished research would concentrate on 'Better monitoring' (figure 2).

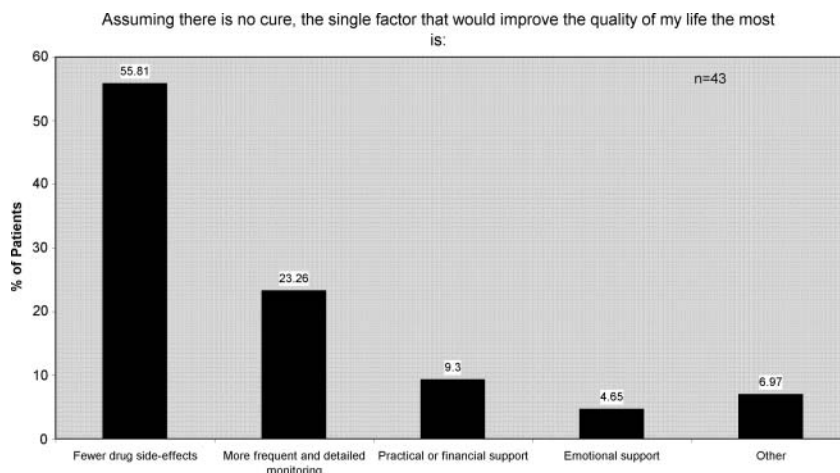
Figure 2 Patients voted for 'fewer drug side-effects' as the factor which if it could be reduced would most improve their quality of life. However, when voting for 'most important research,' they chose 'finding the cause' over 'research into better medicines'.

Figure 3 Drawings (by patients, carers or professionals) proved a useful and powerful way of depicting the visual symptoms of sufferers of BU.



Raising the profile of birdshot uveitis

In the 3 weeks following the Patient Day, the number of ‘hits’ on the BUS website more than doubled to 67 000. In all, 97% of attending birdshot patients responding at 6 months said that they would ‘come again next time’. From the attending health professionals, 88% would ‘come again next time’. Overall, 100% of professionals responded that they would recommend this day to other birdshot patients and 96% would recommend it to other health professionals.

Since the event, the team has publicised their work at ophthalmic, medical education, art (figure 3) and PPI conferences.¹⁷ A ‘highlights video’ was uploaded online¹⁴ and a DVD of the entire day was sent to all patient participants and UK healthcare professionals involved in the care of birdshot patients.¹⁴

DISCUSSION

The aims of the Birdshot Day reflected the need of both patients and healthcare professionals in developing an approach which would lead to a lasting legacy.

Reducing the sense of isolation felt by patients with this rare condition was one of the main aims of this project. Our data confirmed that the majority had never before met another individual with birdshot. After the day numerous comments suggested patients now felt ‘a lot less alone’. Discussing side-effects of drugs with other cosufferers ‘helped put things in perspective’ and patients reported ‘feeling more positive for the future’.

Since the Birdshot Day, local networks of patients forming self-help groups have spread throughout the UK.¹⁴ Patients have also reported improved levels of awareness of the disease among healthcare professionals, which has increased their satisfaction and confidence in the care received.

Patients reported education being particularly beneficial in the explanation of their drugs’ side-effects. This event’s effect on the knowledge of patients’ condition (both in the short and medium term) measured very comparably with results from similar published non-ophthalmic studies.¹⁸

The educational benefit to health professionals was strongly emphasised in all feedback received. Enabling clinicians to better understand the quality of life of patients was a particular success of the project. Feedback suggested the need for more Q&A sessions and this has been taken into account in the planning of future patient days.

Patients voted to confirm their wish that current research should concentrate on ‘aetiology’ even though ‘fewer drug side-effects’ would have greater impact on their own quality of life. This strong drive to identify the cause of the disease emphasises the concerns of sufferers to ensure that next generations do not have to endure similar life experiences.

When during one of the Q&A sessions patients in the audience were asked if they would be prepared to give a blood sample as part of a research project, the response was unanimously favourable. The enthusiasm and need to be involved in medical research, so prominently displayed by all attendees, led to the creation of the National Birdshot Research Network, a nationwide partnership of patients, uveitis specialists, scientists, physicians and nurses. Funding is now available and research focused on priorities set by patients at the Birdshot Day has commenced.¹⁴ Examples include the collaboration with the International Immunology Consortium in establishing a bio-bank of birdshot specimens (addressing ‘Finding out what causes the disease’)¹⁹ and research in the use of immunosuppressants such as Sirolimus (addressing ‘Research into better medicines’). The drive for involvement in research has also meant our empowered patients have in large numbers contributed to the research priority-setting exercise for vision and sight loss led by the James Lind Alliance.²⁰

The impressive turnout of patients, carers and professionals and the ‘infectious enthusiasm’ apparent throughout the day have been supplemented by the touching and inspiring comments received after the event. The impact produced by this partnership approach to a rare disease has been and remains remarkable.

Albeit positively moved by the enthusiastic display of patient-involvement potential, it is difficult to be sure that this is representative of the birdshot community or a general ophthalmology population. The event’s organisation was heavily time and resource intensive and the lack of ready structure and support was apparent. However, the benefits have been compelling and the legacy long-lasting.

Patient days are an important source of consultation and learning in helping to deliver patient-centred care and research.

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