Description and Evaluation of the First National Patient and Public Involvement Day for Thyroid Eye Disease in the United Kingdom

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Background: To ensure appropriate patient-focused outcomes, the National Institute for Health Research (NIHR) in the United Kingdom has made consultation with patients, caregivers, and the public a prerequisite to providing research funding. One method of encouraging engagement with research is through patient and public involvement (PPI) events. We describe the planning and implementation of a PPI day for thyroid eye disease (TED) and evaluate our own event using feedback from delegates.

Methods: The Moorfields NIHR Biomedical Research Centre, in partnership with TED charities, arranged the first national PPI day for TED in the United Kingdom. The event included didactic lectures; pre-event and postevent questionnaires; an exhibition with stalls, posters, and an interactive voting wall to determine research priorities; focus group sessions to explore patient experiences and perceptions of research; and one-on-one interviews recording individual patient stories.

Results: Of 100 attendees, 70 completed questionnaires. When asked whether the day had provided what they wanted, 48 of 52 (92%) said yes; 3 of 52 (6%) said no. Overall 6 of 52 (12%) rated the event as good; 28 of 52 (54%), very good; and 18 of 52 (34%), excellent. Thirty-six patients registered to participate in further research, identifying “finding the cause for TED,” “improving psychological support,” and “achieving a better cosmetic outcome” as key priorities. A poor understanding of TED among medical professionals was a common complaint.

Conclusions: The event received positive feedback and achieved its key objective of engaging patients, researchers, and clinicians in a two-way discussion about research priorities and improved study design. An invaluable insight was gained into patients' needs for a better quality of life, and we have demonstrated that important data can be captured from such events, providing an evidential basis consistent with the NIHR principles of patient-centered research.

Introduction

Patient and public involvement

THE PUBLIC, THE MEDICAL PROFESSION, and the biomedical research community share a common goal in seeking to improve health. Historically, however, research into disease has been driven by doctors, research scientists, and their funding bodies or commissioners and patients often found themselves passive subjects rather than active partners in the process. This is changing rapidly, with the views of patients, caregivers, and the public increasingly central to setting the research agenda, and this group has a role in every area of research including the identification of research priorities, the

planning, funding, running, and evaluating clinical trials, and the dissemination of findings (1,2).

Patients and doctors interact every day in the course of managing medical problems, but these contacts are typically brief and focus on diagnosis and treatment. The need to provide patients, as individuals, with adequate information and proper informed consent for their treatment has long been recognized, and is accepted as central to the patient–doctor relationship (3). Although patient choice is now fundamental on an individual level, the collective views of patients, caregivers, and the public in determining the allocation of limited resources for treatment and research has fallen behind. A major effort is now underway to address this, with the bodies

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who determine provision of National Health Service (NHS) treatments in the United Kingdom (such as the National Institute for Health and Clinical Excellence [NICE]), and those who fund research into diagnosis, prevention, and treatment (such as the National Institute for Health Research [NIHR]) now placing involvement of these groups at the center of decision making under the umbrella of patient and public involvement (PPI) (4).

In 1996 in the United Kingdom a body known as INVOLVE was established. It is now part of the NIHR and is one of the few government-funded programs of its kind in the world. This national advisory group is tasked with supporting active public involvement in every aspect of NHS, public health, and social care research. Based on guidelines supplied by INVOLVE (5), our group planned the first national PPI day for a condition known as thyroid eye disease (TED), coordinated by the NIHR Biomedical Research Centre at Moorfields Eye Hospital and UCL Institute of Ophthalmology (the BMRC). This event was designed to give patients and their caregivers an opportunity to help identify research priorities and improve patient participation in research, as well as provide an update on current research activity and an opportunity for TED sufferers, other family members, doctors, nurses, and researchers to meet and share experiences outside the hospital environment.

Thyroid eye disease

TED is an autoimmune inflammatory condition affecting the tissues around the eyes. It carries an incidence of approximately 4.2 per 100,000 per year (6) and approximately 1.6 per 100,000 individuals are affected to a significant degree (7). It is characterized by a period of inflammation and swelling, particularly of the fat and muscles behind the eyes, followed by a phase of healing and scarring (8). The condition most commonly occurs in association with an overactive thyroid gland, although it can also occur with an underactive thyroid or with apparently normal thyroid function. The involvement of the eyes and thyroid gland can occur simultaneously or many years apart. TED is a diverse condition with a wide range of signs, symptoms, and severity, and these also change over time as the disease moves from the active phase to the healing and inactive phases. The active inflammatory phase is associated with dry eyes, redness, pain, visual disturbance, and disfigurement and unfortunately a patient's eyes often fail to return to normal after the inflammation resolves. The altered appearance typically consists of a "staring" look due to retraction of the eyelids, an "eye popping" appearance due to exophthalmos (the eyes being pushed forward), and the development of a squint with double vision. As a result, it is a condition that has a significant adverse impact on the quality of life of the sufferer and their caregivers (9). Treatment for the active phase consists of symptomatic relief (for example ocular lubricants) for mild disease and oral anti-inflammatories for more severe disease (8). Once the condition has reached the inactive phase, patients may then require surgery to correct the lid malposition, exophthalmos, or squint.

Purpose of the TED patient day

Patients and patient groups were central to the planning of this event, the first national TED day. Patients thought that education should be an important element, updating both

themselves and health care professionals about current areas of research. TED patients and caregivers also saw this as a valuable opportunity to meet and network with fellow sufferers, to tell their stories, and to overcome the sense of isolation that is often inherent to such conditions. While the elements of patient education and support were considered to be very important, the other core objective was to engage TED patients in setting the research agenda, and to allow a two-way exchange of information between patients and professionals.

Materials and Methods

Preparation for the event

A team of 30 organizers planned the event, produced educational material, and arranged and ran the venue on the day; this included 17 members of staff, primarily from the NIHR and clinical faculty at Moorfields Eye Hospital, and 13 medical students from Imperial College, London. This required a significant investment of both time and resources, and we are grateful for financial support provided by the BMRC.

The event was publicized using the Internet, and through leaflets and posters distributed to ophthalmology departments around the United Kingdom specializing in TED. An information and registration page was created on the BMRC website, together with links to this page from other websites (such as Moorfields Eye Hospital and NHS London). The patient support groups for TED (the British Thyroid Foundation and the Thyroid Eye Disease Charitable Trust) also advertised the event on their websites, as well as disseminating information to members by e-mail and post.

Structure of the day

The format of the day was decided after early engagement with patients and patient groups, who wished to have an update on current areas of TED research, and an opportunity to question researchers and clinicians. This aspect of the event was provided by a series of podium sessions and a poster exhibition. Sharing experiences was also a key priority, with a patient panel exploring the impact of diagnosis and treatment on quality of life, employment, and relationships.

The main PPI objectives were achieved through a combination of questionnaires before and after the event, interactive voting posters, focus-group sessions, and one-on-one interviews, as well as podium sessions covering patient involvement in research. These elements were developed using established qualitative research methods to facilitate evaluation after the event.

The event consisted of six major elements.

Questionnaires. All attendees were asked to complete two questionnaires, one on arrival (pre-event), and one prior to departure (postevent). TED patients were also asked to complete a third questionnaire to collect demographic and clinical details relating to their disease and its treatment.

The pre- and postevent questionnaires, developed with statistical advice, were the main method for collection of objective data and were designed to assess the educational value of the event, to record perceptions about TED from all interested groups (including patients, caregivers, exhibitors,

and health care professionals), and to collect feedback with suggestions for improvements.

Exhibition. Throughout the day delegates had access to an exhibition space, an open area with zones set aside for informal discussions over tea and coffee, a series of poster boards with information on topics related to TED (Table 1A), and a number of stands run by charities and organizations with an interest in TED (Table 1B).

Interactive posters. Several posters in the exhibition were interactive, where participants were encouraged to leave short narrative comments on five topics; “My medical care has been.....”; “My understanding of TED.....”; “Doctors please help me with.....”; “One thing that affects me the most about TED.....”; and “If I could improve one thing about TED.....” Messages on these posters were anonymous, although they were staffed by medical students to encourage and assist in the posting of comments. The results of these posters were collated and presented during the last podium session of the day.

Podium sessions. A series of sessions were led from the podium, either as didactic lectures or as more interactive discussions. These sessions were based on four broad themes; meet the researchers (an update on current research), patient panel (sharing experiences), you can help (setting the research agenda), and next steps (getting involved).

Podium sessions were video-recorded from a fixed-position camera. On arrival at the event all delegates were asked whether they agreed to be videoed and a small number (three) declined. These participants were given a different colored name badge and asked to sit behind the camera during podium sessions. All videos were subsequently checked to ensure that these individuals were not inadvertently filmed.

Focus group session. The focus group session consisted of small group discussions, each chaired and facilitated by a health care professional, and consisting of 8–10 participants (principally patients and caregivers). The seating in the

lecture theatre of the venue was rearranged to provide a series of semicircles around a microphone and flip chart, with medical students directing patients to join one of nine different groups in the room.

The session was primarily aimed at trying to understand how best to engage patients in TED research, and to hear from those patients who did not feel comfortable speaking during podium sessions. An introduction and a series of questions were devised in advance, on three different topics relating to research: Topic A—Making involvement in research a better experience for patients; Topic B—Making research more relevant to patients’ needs; and Topic C—Expanding the role of patients in research. It was planned that each of the nine focus groups would discuss one of these topics (i.e., three discussing Topic A, three Topic B, and three Topic C).

Participants were asked to sign a consent form for audio recording, and each of the groups had their conversation recorded and subsequently transcribed.

One-on-one interviews. Throughout the day, a diary room—with a video camera and an interviewer—was available, in which individuals or small groups were encouraged to discuss their experiences of TED in more depth, and in a more intimate environment. The primary objective was a detailed record of patient experiences in living with TED, its treatment and diagnosis.

Results

Participants were asked to register to attend the event in advance (either online through the institute website or by completing a form attached to the information leaflet). Prior to the event a total of 120 individuals had registered, and on the day of the event 100 people actually attended: 30 event organizers, speakers, and health care professionals from the host organization and 70 patients, supporters, exhibitors, and health care professionals from elsewhere.

Of these 100 participants, 70 completed one or more questionnaires (35 patients, 9 supporters, 4 exhibitors, 15 health care professionals, and 7 other), the number of completed pre-event questionnaires being 64, and the number of postevent questionnaires being 52, with 46 participants completing both. Twenty-nine of the patient questionnaires were completed.

Evaluation of the event

In the pre- and postevent questionnaires patients were asked to rate “How much do you know about TED?” as “nothing,” “a little,” “a moderate amount,” “a lot,” and “I’m an expert.” Of the 46 participants who completed both questionnaires, 13 (28%) reported an increase in their knowledge: 1 went from “nothing” to “a little”; 10 (22%) from “a little” to “a moderate amount”; and 2 (4%) from “a moderate amount” to “a lot.” One of the 46 reported a reduction (from “a moderate amount” to “a little”) and 32 (70%) reported no change.

In the pre-event questionnaire patients were asked, “What would you like to get out of today?” Similar comments were grouped into a series of topics and ranked according to the frequency with which they were mentioned. Patients were free to list as many issues as they wished, with the frequency

TABLE 1. EXHIBITION SPACE

<i>A. Educational Posters Presented at the Meeting</i>
The Combined Immunosuppression and Radiotherapy in TED (CIRTED) Trial
Investigating TED in the Laboratory
Ocular Lubricants
Orbital Decompression Surgery—Questions & Answers
The Psychological Impact of TED Study
Should I Be Taking Selenium?
Why Shouldn’t I Smoke with TED
Treatment Options in TED
<i>B. Exhibitors Represented at the Meeting</i>
The British Thyroid Foundation (BTF)
The Thyroid Eye Disease Charitable Trust (TEDct)
The Royal College of Ophthalmologists
Fight for Sight
Smoking Cessation
The NIHR Biomedical Research Centre

TED, thyroid eye disease.

given as a percentage of the number of respondents who mention that particular issue (Table 2). This question was completed by 63 respondents. The most common responses were: “an improved general understanding of TED” (62%), “a better understanding of my own treatment options” (41%), and “a better understanding of the perspective of others/shared experiences” (37%).

When asked whether the event had provided what they wanted, 48 of 52 (92%) said “yes,” 3 of 52 (6%) said “no,” and 1 person did not specify. Overall, no one rated the day “poor” or “fair,” 6 of 52 (12%) rated it “good,” 28 of 52 (54%) “very good,” and 18 of 52 (34%) “excellent.” Of the 52 respondents, 30 (58%) said it had changed their view of TED, 20 (38%) said that it had not, and 2 (4%) did not specify their view.

The postevent questionnaire included the question “How could we make [the event] better in the future?” with two columns headed “More of.....” and “Less of.....” This section was completed by 21 delegates. The most common suggestions were: “more detailed information about the treatment options,” “more time to hear from patients/professionals,” and complaints that “the scheduling was too tight.” From a logistical point of view there was a problem with the lecture hall being too hot.

TABLE 2. RESULTS FROM THE PRE-EVENT QUESTIONNAIRE

<i>Answers to the pre-event question: “What would you like to get out of today?”</i>	<i>Proportion (%) of respondents</i>
Improve my general understanding of TED	40/63 (63%)
Understand my treatment options	26/63 (41%)
Understand other people’s views/share experiences	23/63 (37%)
Better, more effective research	12/63 (19%)
Understand the cause/prevention of TED	7/63 (11%)
To raise funds/awareness/support others	5/63 (8%)
More help and support for myself	3/63 (5%)
I don’t know	2/63 (3%)
Better psychological support	2/63 (3%)
Better education of doctors	1/63 (2%)
<i>Answers to the pre-event question: “What is the worst thing about TED?”</i>	<i>Proportion (%) of respondents</i>
Effect on appearance	31/63 (50%)
Psychological impact (loss of self-esteem/confidence)	17/63 (27%)
Effect on vision	12/63 (19%)
Uncertainty and fear of the future	11/63 (18%)
Pain/discomfort	11/63 (18%)
Social impact (isolation/stigma)	9/63 (15%)
Adverse effects of medication/surgery	6/63 (10%)
Functional impact (driving/employment)	5/63 (8%)
Poor sleep/tiredness	2/63 (3%)
Poor awareness among doctors	2/63 (3%)
Lack of information	1/63 (2%)

TED, thyroid eye disease.

The last question on the postevent questionnaire was: “Tell us one thing you learned about TED today that you didn’t know before” in order to identify the main take-home messages from the day. Thirty-six delegates completed this question and the most common answers were: “that TED is a more diverse disease than I thought,” “about the cellular basis for TED,” “that it can happen in both hyperthyroidism and hypothyroidism,” and “that it has a big psychological impact.” The full responses are shown in Table 3.

Patient profile

Twenty-nine patients (25 females; 86%) completed the patient questionnaire, they were an average age of 53.3 years old (median, 54 years; range, 32 to 70 years) and an ethnic mix of 23 (79%) white, 3 (10%) Asian, 2 (7%) other, and 1 unspecified. Three patients (10%) described their disease as “very active,” 8 (28%) as “slightly active,” 10 (34%) as “inactive,” 7 (24%) patients were “unsure,” and 1 did not specify. The average duration of disease was 6 years and 3 months (median, 4 years; range, 3 month to 25 years).

Research priorities

The PPI-objectives of the event were measured using the pre- and postevent questionnaires, the interactive voting posters, and the results from the focus groups sessions:

Questionnaires. In the pre-event questionnaire patients were asked “What do you think is the worst thing about TED?” As previously, similar comments were grouped into a series of topics and ranked according the frequency with which they were mentioned, with patients free to list as many

TABLE 3. RESULTS FROM THE POSTEVENT QUESTIONNAIRE

<i>Answers to the postevent question: “One thing I learned about TED....”</i>	<i>Proportion (%) of respondents</i>
It is a more diverse disease than I thought	7/36 (19%)
About the cellular basis for TED	5/36 (14%)
That it can happen in both hyper- and hypothyroidism	5/36 (14%)
How much psychological impact the condition has	3/36 (8%)
There is more research happening than I thought	2/36 (6%)
That there are treatments other than surgery	2/36 (6%)
That many TED patients feel isolated	2/36 (6%)
That TED can cause a squint/double vision	2/36 (6%)
That selenium can be helpful	1/36 (3%)
That it can affect young people	1/36 (3%)
About the CIRTED trial	1/36 (3%)
That an RCT wasn’t just treatment/no treatment	1/36 (3%)
The impact of TED on quality of life	1/36 (3%)
The difficulties of reaching a diagnosis	1/36 (3%)
That I am not alone	1/36 (3%)
About the current areas of TED research	1/36 (3%)

TED, thyroid eye disease; CIRTED, Combined Immunosuppression and Radiotherapy in TED; RCT, randomized controlled trial.

problems as they wished. Again, the frequency given is a percentage of the number of respondents who mention that particular issue (Table 2). This question was completed by 63 respondents, and the most common responses were: “the impact on appearance” (50%), “the impact on psychological well-being” (27%), “the impact on vision” (19%), “pain/discomfort” (18%), and “uncertainty about the future” (18%).

Interactive voting posters. The voting posters consisted of a series of blank columns with the following subject headings: “My medical care has been....”; “My understanding of TED....”; “Doctors please help me with....”; “One thing that affected me the most about TED....”; and “If I could improve one thing about TED....” The number of respondents to each of these questions was 16, 13, 13, 15, and 15, respectively.

A summary of the responses is provided in Table 4. Fifty percent of patients said their care had been “good” or “excellent.” The remainder complained of “poor knowledge

by the general practitioner (GP),” “slow referral,” and “a lack of continuity of care.” The most common problems for which patients wanted help from their doctor were “quicker tertiary referral,” “more information about the disease,” and “advice about driving.” The symptoms that bothered patients most were “double vision” and “pain”; “psychological impact” was also important. The things patients would most like to improve about TED were “cosmetic impact,” “double vision,” and “results from treatment.”

Focus-group sessions. A slightly lower number than was anticipated during planning (48 delegates) participated in the focus-group sessions; this was due to the lower number of attendees compared with registrants and because not all delegates wished to take part in the focus-group session. For this reason, seven of the planned nine focus groups were run (with two groups discussing Topic A, three discussing Topic B, and two discussing Topic C).

Five facilitators chose to make use of the flip charts provided, and transcriptions from the audio recordings were available for six of seven sessions. Facilitators were also asked to “minute” the conclusion of their group’s discussion. A summary of the key points from the focus group session was generated from the flip charts, transcripts, and minutes.

The main motivation for participating in research was “a wish to help future generations,” with a “desire to establish the cause for TED, and to improve diagnosis and treatment.” Recruitment could be aided by “better information and more proactive communication,” for example “using social media, advertising, and patient support groups” to reach potential participants. Patients wanted to “feel involved” in research with regular updates about study conclusions, and to know which arm they had been randomly assigned. The main obstacles to participating in research were the “time commitment and expense,” and it was suggested that “more evening and weekend clinics, joint clinics with endocrinologists and more research done by phone or the Internet” would be helpful. There was a fear of “loss of control” from the process of randomization, with a concern that treatment might be “delayed,” or that you might be randomized to receive “NO treatment at all.” The “fatigue and disfigurement” associated with TED made some reluctant to consider taking on extra hospital visits. It was felt that a third party should be used for recruitment to “avoid the perception of pressure or bias” from clinicians who were also members of the research team. “Early diagnosis and a screening test” were the key research priorities, along with “better treatments for sight loss, disfigurement, and pain (particularly at night).” However, a major concern was the “psychological impact of TED,” “both as cause and effect.” Research was suggested into “the value of cognitive behavioral therapy and peer group discussions” in helping to cope with the disease. In terms of improving care for TED sufferers, a “poor understanding of TED among GPs” was a common complaint—as well as among some ophthalmologists and endocrinologists—an “awareness campaign” was suggested. A source of “reliable, high-quality information” was required, and rapid recognition and referral of the condition was essential.

Discussion

We conducted the first national TED patient day, providing patients, caregivers, researchers, and clinicians with

TABLE 4. RESULTS FROM THE INTERACTIVE VOTING POSTERS

<i>Answers to the statement:</i> <i>“My medical care has been....”</i>	<i>Proportion (%)</i> <i>of respondents</i>
Excellent	8/16 (50%)
Poor until referred to specialist	3/16 (19%)
Poor knowledge by GP	2/16 (13%)
Slow diagnosis and referral	2/16 (13%)
Poor continuity of care	1/16 (6%)
<i>“My understanding of TED....”</i>	
Good	5/13 (38%)
Fair	3/13 (23%)
Explained well by consultants	2/13 (15%)
Poor knowledge by GP	2/13 (15%)
Conflicting advice received	1/13 (8%)
<i>“Doctors please help me with....”</i>	
Quicker tertiary referral	2/13 (15%)
More information about TED	2/13 (15%)
Advice about driving	2/13 (15%)
Reading	1/13 (8%)
Better continuity of care	1/13 (8%)
Meeting other TED sufferers	1/13 (8%)
Coping with double vision	1/13 (8%)
Quicker diagnosis	1/13 (8%)
Quicker treatment	1/13 (8%)
Dealing with the long-term effects	1/13 (8%)
<i>“One thing that affected me the most about TED....”</i>	
Double vision	4/15 (27%)
Discomfort (gritty eyes, night pain)	3/15 (20%)
Psychological impact (social anxiety, stigma)	3/15 (20%)
Difficulty with steps	2/15 (13%)
Difficulty driving	1/15 (7%)
Difficulty reading	1/15 (7%)
Tiredness	1/15 (7%)
<i>“If I could improve one thing about TED....”</i>	
Cosmetic appearance	7/15 (47%)
Double vision	3/15 (20%)
Better treatments (medical/surgical)	2/15 (13%)
Prevention	1/15 (7%)
Better information	1/15 (7%)
Relieve discomfort	1/15 (7%)

GP, general practitioner; TED, thyroid eye disease.

an opportunity to engage in a two-way discussion about the current state of TED research and the direction of research going forward. The event received very positive feedback, with most participants finding it both informative and enjoyable. Many delegates changed their opinions about future research priorities, and the researchers themselves received a lot of useful information about how patient engagement in research could be improved. An opportunity to meet fellow sufferers and to tell their stories was appreciated by many of the patients.

The key components of the day—didactic lectures, patient panels, pre- and postevent questionnaires, an exhibition with posters and stalls, interactive voting posters, focus-groups sessions, and one-on-one interviews—provided a range of opportunities to both educate and communicate.

The setting of research priorities in ophthalmology is a particularly pertinent issue, in light of recent scrutiny from the Sight Loss and Vision Priority Setting Partnership (PSP). This recently convened group has been given the task of identifying research priorities in the field of prevention, diagnosis, and treatment of eye disease and sight loss, “giving equal weight to the views of patients, caregivers, and health professionals.” The project is overseen by the James Lind Alliance, an independent, not-for-profit organization specializing in collaboration and consensus building between clinicians, researchers, and patients, and is funded by the NIHR. The stated objective of the James Lind Alliance is to “ensure that those who fund health research are aware of what matters to both patients and health professionals.” In 2012 the Sight Loss and Vision PSP surveyed patients, caregivers, and eye professionals to identify key unanswered questions, receiving 4461 questions from 2200 respondents. These questions were grouped into 12 different eye disease categories, with each category discussed at a workshop of interest groups chaired by the James Lind Alliance. TED was part of the Ocular Inflammatory Diseases category, and TED featured highly in the “top 10 priorities” of this group. The full list of questions is shown in Table 5.

The priorities for TED research, as determined by the Sight Loss and Vision PSP were for improved treatments and a

better understand of the causes of TED. These correspond well with results from our own event, where the cosmetic and visual impacts of the disease were the major concerns. However, our findings also suggest that addressing the psychological aspects of TED (both as a cause and effect) was an issue of great importance to patients, although only biomedical research questions were considered by the PSP, with quality of life and other psychosocial research specifically excluded. Other important lessons have been the problems of pain and fatigue in TED, a widespread perception that knowledge of TED among GPs and other health professionals is poor, and that referral is often slow. The impact of TED on work and driving are also of considerable concern to patients.

The questionnaires worked well as a tool for obtaining information from the majority of delegates, with easily interpreted data. The voting posters were arguably less useful in this respect, tending to attract a more vocal minority. We found the focus groups most useful in bringing unexpected issues to the attention of researchers, such as the problems of fatigue among TED sufferers considering participation in research, rather than in providing a representative cross-section of opinion. The role of the facilitator in the focus-group session was an essential task in keeping the conversation targeted on the core topic. There was a tendency for particularly strong characters in each group to dominate discussions, and the natural “thirst for information” among many participants meant that facilitators who were clinicians often found themselves answering a lot of questions.

When asked how the event could be improved in the future, we received requests to “hear more from the professionals” and to “hear less from the professionals,” to “hear more from the patients” and to “hear less from the patients,” and to have “more in the event” and “less in the event” all in roughly equal measure. This may suggest that the overall balance struck in this event was broadly correct. However, there was a widespread desire among the delegates for more detailed information about the treatment options available to them, and we are planning to revise our patient information resources in the light of this demand.

In conclusion, we conducted the first national TED patient day, providing patients, caregivers, researchers, and clinicians with an opportunity to engage in a two-way discussion about the current state of TED research and the direction of research going forward. The event received positive feedback, with most participants finding it both informative and enjoyable. Many delegates changed their opinions about future research priorities, and the researchers themselves received a great deal of useful information about how patient engagement in research could be improved. An opportunity to meet fellow sufferers and to tell their stories was appreciated by many of the patients, and we have demonstrated that important data can be captured from such events, providing an evidential basis consistent with the NIHR principles of patient-centered research.

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TABLE 5. SIGHT LOSS AND VISION PRIORITY SETTING PARTNERSHIP: OCULAR INFLAMMATORY DISEASE RESEARCH PRIORITIES

1. What are the most effective treatments for ocular and orbital inflammatory diseases?
2. What causes thyroid eye disease?
3. Can the severity of ocular and orbital inflammatory disease in an individual be predicted?
4. Is it possible to prevent further occurrences of retinal damage caused by toxoplasmosis?
5. What causes birdshot retinopathy?
6. Why does disease burn out in patients with ocular and orbital inflammatory diseases?
7. Can early detection methods be developed for ocular and orbital inflammatory disease?
8. What medications best prevent the development of eye disease in Behçet's?
9. What causes scleritis?
10. Can diet or lifestyle changes prevent uveitis from developing?

of arranging a patient day for birdshot uveitis. Our supporting patient groups and charities include: The British Thyroid Foundation (BTF), The Thyroid Eye Disease Charitable Trust (TEDct), and Fight for Sight. Thanks also to the staff at the National Institute for Health Research Biomedical Research Centre at Moorfields Eye Hospital, and in particular; Debbie Bryant, Louise Halfhide, Meike Walcha, Jocelyn Cammack, Maaret Virtanen, Panagiota Founti, Moloy Dey, and Kam Balagan. We thank our speakers and patient panel members: Stan Newman, Maryse Bailly, Carol Lane, Rea Mattocks, Dolores Conroy, and Peter Foley; our focus group facilitators and poster authors: Jo Hancox, Sadie Wickwar, Cornelia Poitelea, Steve Byard, Mohamad Abdullah, Dov Hersh, Caroline Fitchett, and Matt Edmunds; medical students from Imperial College, London; Caroline Fitchett, Matt Edmunds, Mitesh Naik, Lawrence Walker, Zaman Durani, Kavita Aggarwal, Neil Patel, Julia Zhu, William Hickman, Min Zhi Yap, Guy Ratu, Ranjit Samra, and Rob Holliman.

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References

1. Twamley K, Evans J, Wormald R 2011 Why involve consumers in eye health research? *Eye* **25**:969–970.
2. National Institute for Health Research 2013 Research for Patient Benefit (RfPB) Programme Guidance Information for Applicants.
3. Gulland A 2011 Welcome to the century of the patient. *BMJ* **342**:d2057.
4. Department of Health 1999 Patient and Public Involvement in the NHS. Her Majesty's Stationery Office: London.
5. INVOLVE 2012 Briefing notes for researchers: involving the public in NHS, public health and social care research. INVOLVE, Eastleigh.
6. Abraham-Nordling M, Bystrom K, Topping O, Lantz M, Berg G, Calissendorff J, Nystrom HF, Jansson S, Jorreskog G, Karlsson FA, Nystrom E, Ohrling H, Orn T, Hallengren B, Wallin G 2011 The incidence of hyperthyroidism in Sweden. *Eur J Endocrinol* **165**:899–905.
7. Laurberg P, Berman DC, Pedersen IB, Andersen S, Carle A 2012 Incidence and clinical presentation of moderate to severe Graves' orbitopathy in a Danish population before and after iodine fortification of salt. *J Clin Endocrinol Metab* **97**:2325–2332.
8. Cawood T, Moriarty P, O'Shea D 2004 Recent developments in thyroid eye disease. *BMJ* **329**:385–390.
9. Wiersinga WM 2012 Quality of life in Graves' ophthalmopathy. *Best Pract Res Clin Endocrinol Metab* **26**:359–370.

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