

ARVO Outreach Tools

How to prepare for a patient engagement day



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Introduction

This guide describes how to organize a small patient engagement day in which scientists and patients can come together to share their stories and perspectives.

Prerequisites

To run a patient engagement day, organizers will need the following:

1. A budget ranging from a few hundred to one thousand British pounds. Expenses primarily originate from catering, printing and speaker travel costs.
2. Approximately ten to fifteen research staff working in the ocular field of interest that will be happy to volunteer at the event. These volunteers will likely be from the group and department you work in.
3. Event space that is suitable and accessible for the visually impaired, preferably in the department where you work.
4. Contacts within the patient community that you would like to invite.

1. Six months before the event

1.1 Apply for funding

Your institute might have specific funding for public engagement events. Decide whether you have suitable event space available to you at your institute. If not, you might need to apply for more funding to rent a meeting space.

1.2 Contact patient support groups to determine interest

It is useful to join the patient support group that you are interested in inviting in order to determine the kind of interest there is about coming to the event. Check if there is a patient support group meeting that you can attend so that you can talk to individuals and gauge how popular the event might be. Tell them about the day and what you are planning. It is also useful to ask for their input in terms of event planning and what they would like out of the experience.

2. Five months before the event

2.1 Set a date

Consider the time of year if planning an even for partially sighted people. The middle of winter might not be suitable for them to get around easily. Leave yourself enough time to organize the event and consider any clashes with room use if using space in your institute.

2.2 Decide scientist to patient ratio

The number of patients to invite depends on the ratio of scientists to patients that you would like at the event. A ratio of 2:3 scientists/helpers to patients is a good starting point, as this will facilitate a good dialog during networking and also provides plenty of helpers throughout the day.

2.3 Recruit volunteers

Ask your coworkers in your group, department, and institute if they would like to participate in the event. Send out emails describing the various roles available (see 5.2). Share the fact that the number of volunteers will dictate the number of patients that will be able to attend.

2.4 Select and alert invitees

Decide on the different patient groups you would like to invite, for example aniridia patients only or aniridia and Fuch's dystrophy patients. A mix of people with different ocular disorders can be an advantage in that they can share their experiences with a wider audience. Send a save the date email.

2.5 Find and book venue

If you have a suitable venue in your institute, determine the capacity and layout of the room and whether it will be appropriate for your event. It might be that you can use 2 rooms, one arranged for talks and lunch, and the other set up with science information posters and stalls for demonstration of experiments. It is especially useful to have the event in your institute if you would like to provide lab tours for visitors.

Considerations to take in mind for the visually impaired:

- a. Check if the route to the event space is free of stairs.
- b. Check if the route is free of delivery items and boxes.
- c. Check if the event space is close to the main entrance.
- d. Think about guide dog facilities.

Book the room/rooms for the anticipated time plus 1-2 hours before and after the event so there will be no potential conflict with other events.

2.6 Build event website

Make a page on your research website describing the event and providing all relevant information. Create a Facebook page describing the event and invite people to like.

3. Four months before the event

3.1 Decide on event format

Decide on the structure of the day and whether you want formal sessions or a mixture of formal and informal sessions. It is useful to break up the day with a formal session of talks in the morning and an informal interactive session in the afternoon, with posters and tables set up showing simple scientific techniques (see Appendix 1). That way patients and scientists have a good opportunity to interact and discuss their experiences. Laboratory tours can also take place during the afternoon session (Appendix 2).

Decide how many coffee breaks there will be and what time lunch will be. An arrival period of about 30 minutes at the start of the day is usually a good idea, with time for coffee and registration. For an example program, see Appendix 3.

3.2 Invite guest speakers

Invite a mixture of scientists and patients to give their accounts of the disease discussed. This will mean that both patients and scientists learn something new from the day.

4. Three months before the event

4.1 Publicize event

Send out invites by contacting the patient support groups that you have already made contact with (section 1.2). Create a document with all the relevant information about the day and ask if it can be posted on the patient support forum. Tweet about the event and post about it on the event Facebook page. Send out reminders to your volunteers, and post flyers in the hallways of your department encouraging additional volunteers to sign up.

4.2 Start planning print material

Start preparing programs, name badges, venue signage, large signs for what sandwiches are at lunch, and introductory and intermediate presentation slides for the day.

5. Two month before the event

5.1 Plan catering

Decide what facilities are needed for coffee breaks and who will serve the coffee. Remember partially sighted people might not be able to serve themselves so it would be a good idea to have one of the researchers helping out with coffee.

Select an area for lunch and designate tables for the lunch platters. Large signs will need to be printed out in advance describing the food available so that the partially sighted can read them. Having a few volunteers on hand to offer bringing a plate of lunch to the more visually impaired attendees is also a good idea.

5.2 Plan jobs for the helpers

It's best to have all of the scientists involved in helping with the event. Set up a list of jobs that will need doing and ask volunteers to select their preferred job. Some of the jobs might include:

- a. Meeting and greeting attendees on arrival
- b. Registration desk and handing out programs
- c. Serving coffee at the interval
- d. On standby to help at lunch
- e. Clear up after lunch
- f. Presenting a poster of a scientific technique
- g. Being a lab tour guide

5.3 Organize a photographer

Someone in your department might be able to help with this, or see if your institute has a photographer that can record the event for you.

5.4 Write a risk assessment

Check all risks involved in the day, particularly if you have laboratory tours, and make sure you have it all documented in a risk assessment. Ask your department staff if you need assistance.

5.5 Open registration

Email those who have expressed an interest. Write an article with relevant links to registration and ask patient support groups to post it on their website. Use an online registration service to keep track of the number of patient attendees. Make clear that only registered patients will be able to attend (to ensure the desired scientist:patient ratio).

6. One month before the event

6.1 Lab cleanup

If providing laboratory tours as part of your event, make sure all equipment and boxes are out of the way to avoid tripping hazards. Make sure lab is clean and tidy in areas you plan to show on the tour.

6.2 Prepare the speakers

Email the speakers to ensure they have all the information they need regarding:

- a. Length of talk
- b. Questions during or after
- c. Available equipment, laptop, pointer etc.
- d. Ask for talk titles
- e. Book travel and accommodation for external speakers
- f. Order gifts for speakers (if there is room in your budget and appropriate)

6.5 Plan catering menu

Order lunch platters from your local store/catering service. Order coffee cups, plates, napkins etc. from your local provider. Buy coffee, or sort out how you are going to make it (e.g., instant, filtered, or coffee from a machine).

6.6 Order stationary

Order any pens, notepads and name badge holders you wish to provide and ensure you have everything you need for registration.

7. Two weeks before the event

7.1 Send reminder about event to attendees

Email all attendees with programs and abstracts and to remind them of the event. Check for last minute cancelations. Fill cancelled places with those from the waiting list. Ask attendees if there are any requirements they need (i.e., facilities for guide dogs).

7.2 Send programs to the printers

Have the programs ready for printing with everything finalized.

8. One week before the event

8.1 Print signage and name badges

Print event logos to use as signs to guide people to the right place. Print the names of lunch platters so that it is easy to read for visually impaired attendees. Print out name badges and use different colored card for patients and scientists so that they can easily identify each other.

8.2 Walk through venue

Check 'house-keeping' information such as fire exits, toilets, etc. and pass this information onto the opening speaker for announcement at the beginning of the event.

8.3 Ensure you have all relevant equipment

Laptopschargers/adapters/laser pointers for presentations.

8.4 Produce running order

A running order lists exactly what will be happening at what time, with the name of the person responsible for that process (see Appendix 4 as an example). Give a copy of the running order to everyone involved in helping at the event so that they know where they need to be and when.

9. Day before the event

9.1 Setup venue

Make sure there are wide aisles between chairs in case patients have guides/guide dogs. Set up dedicated space for catering, a reception/registration desk either in the room or just outside the room and any areas for demonstration in the laboratory.

9.2 Print attendee list

Print a complete attendee list for the registration desk.

9.3 Send reminder and tickets to attendees

Use this opportunity to give clear directions of how to get to the venue.

10. After the Event

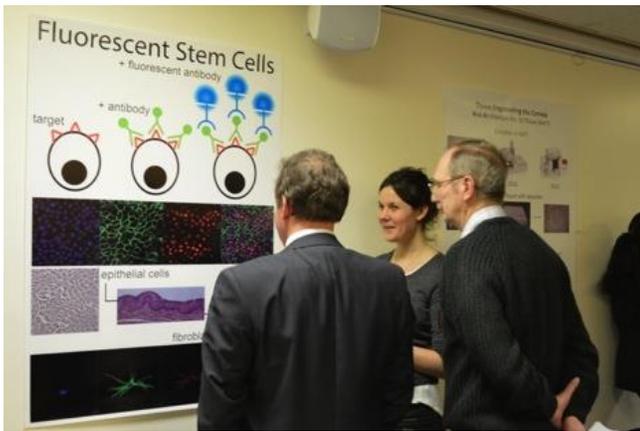
10.1 Thank you and feedback

Send thank you emails to speakers, staff, sponsors, and all attendees and ask for feedback from the day.

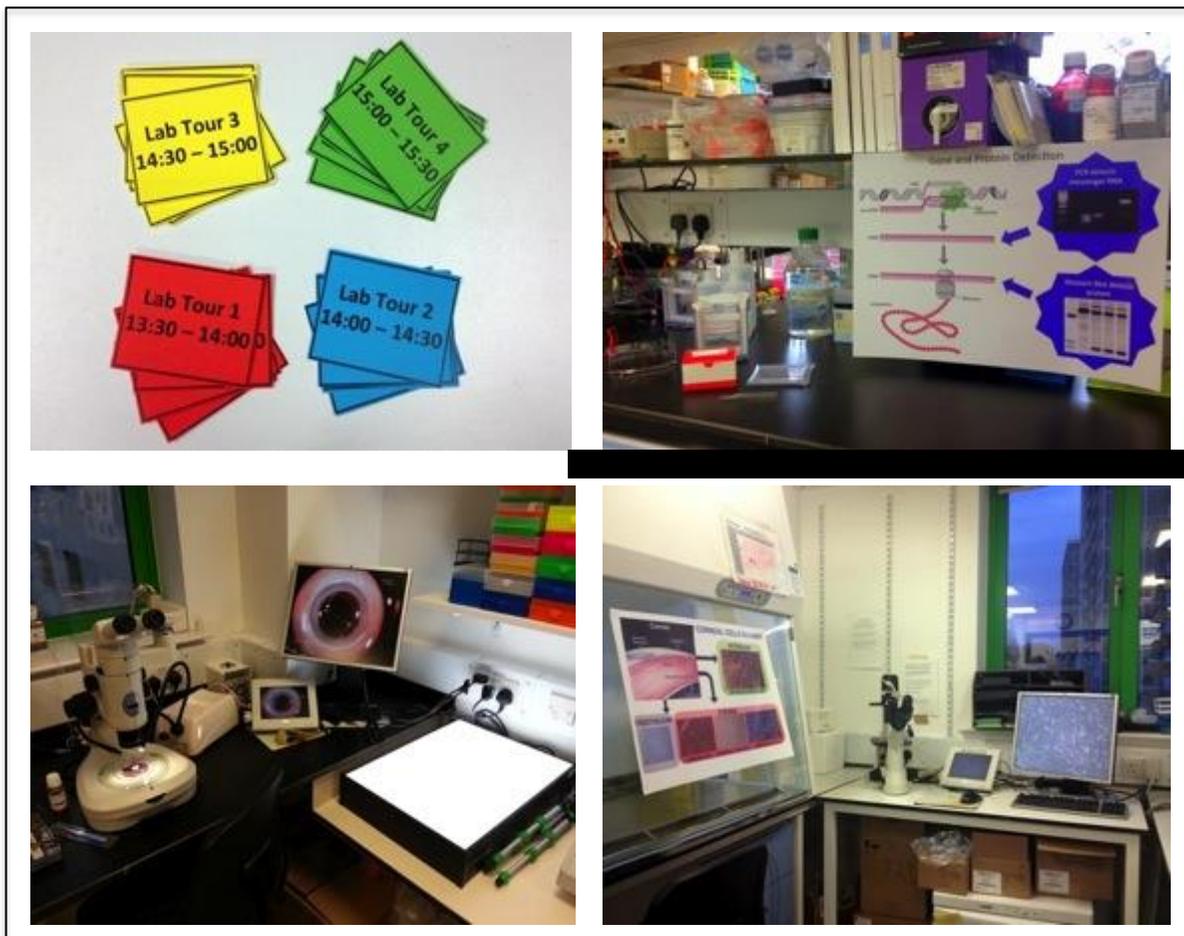
10.2 Pay outstanding bills and reimbursements

Don't forget to claim all expenses back from the project grant.

Appendix 1: Interactive afternoon session at a patient engagement day



Appendix 2: Lab tours for a patient engagement day



Appendix 3: Example program for a patient engagement day

MORNING	TALK/SPEAKER
09:30 – 10:00	Registration and coffee
10:00 – 10:15	Welcome and Introduction to Cornea Connect
10:15 – 10:30	An introduction to the Cells for Sight Programme <i>Speaker: Prof. Julie Daniels</i>
10:30 – 10:45	The impact of living with aniridia <i>Speaker: Mary Cox</i>
10:45 – 11:00	A model for studying Aniridia <i>Speaker: Dr. Victoria Tovell</i>
11:00 – 11:25	BREAK
11:25 – 11:35	Fuchs Dystrophy discussion <i>Speaker: Roger Davison</i>
11:35 – 11:55	Tissue engineering the corneal endothelium <i>Speaker: Dr. Hannah Levis</i>
11:55 – 12:10	Different conditions of Aniridia <i>Speaker: Jenny Langley</i>
12:10 – 12:25	Cells for Sight Transplantation Programme <i>Speaker: Radhika Sheth</i>
12:25 – 12:30	Summary
12:30 – 13:30	Lunch

AFTERNOON	SUBJECT
<i>13:30 – 15:30</i>	<i>Lab Techniques and Tours</i>
Zone 1	The Clean Room Guide: Amanda Vernon
Zone 2	Fluorescent Stem Cells Guide: Isobel Massie
Zone 3	Tissue Engineered Cornea Guide: Alvena Kureshi
Zone 4	3View Imaging Guide: Marc Dziasko
Zone 5 – LAB	Gene and Protein Detection
Zone 6 – LAB	Cornea and the limbus
Zone 7– LAB	Corneal Cells in a Petri Dish
15:30 – 16:00	Final discussion and closing remarks

Appendix 4: Running order for a patient engagement day

Time	Action	Who
08:30 – 09:30	Cells for Sight team arrive and help set up Set up laptop and get slides ready Set up Tea and Coffee Get the juice Put up signage up – common rm x2 seminar room, outside door Set up posters in seminar room Set up activity tables etc Organise Registration table	All
09:30 – 10:00	Bringing people into the Common Room Greet people at reception and bring them through to the registration desk Point out the toilets on route	Hannah Victoria Julie
09:30 – 10:00	Registration Mark people off on the register Give out name badges Give out Programmes and Pens Allocate Lab Tour Times	Amanda Isobel
09:30 – 10:00	Morning Tea and Coffee Serve tea and coffee using the Urn Choices: Instant Coffee, breakfast tea, Flavoured teas and hot chocolate	Louise Alvena
10:00 – 11:00	TALKS	
11:00 – 11:25	BREAK – Serve tea and coffee **Show people where the toilets are if they need assistance**	Anna Amanda All
11:25 – 12:30	TALKS	

12:25 – 12:30	<p>Setting up for lunch Put out M&S lunch onto the high table Drinks/water onto the round tables</p> <p>**Announcement** GROUP PHOTO Whilst lunch is getting set up ask everyone to gather at the front for a group photo</p>	<p>Louise Isobel</p> <p>Victoria</p>
13:00 – 13:30	<p>Lunch Coffee Clear up from previous coffee session Set up and serve Don't forget to eat your lunch though!</p>	<p>Nuria Anna</p>
13:30 – 13:40	<p>After lunch clear up Clear up and throw away used plates, cups etc Consolidate leftovers and place back in fridge</p>	<p>Nuria Marc</p>
13:30	<p>Usher people into the seminar room</p>	<p>Victoria Hannah</p>
13:30 – 15:30	<p>Afternoon session in the seminar room.</p> <p>Posters & Tables: Clean room poster & table Immuno poster RAFT Poster & table Threeview Pipetting Table</p> <p>Lab Tour 1 13:30 Lab Tour 2 14:00 Lab Tour 3 14:30 Lab Tour 4 15:00</p>	<p>Amanda Isobel Alvena Marc Anna</p> <p>Victoria Hannah Victoria Hannah</p>

15:30 – 16:00	Closing Remarks and Question Time **Announcement** Ask people to comment on the feedback poster	Victoria
16:00 – 16:30	IMPORTANT!!! Clearing up Seminar Room There is a booking after us at 16:30 and the porters will need to set it up for drinks.	All possible
16:00 – 16:30	Clear up common room and sort furniture.	All possible – after seminar room is sorted
16:30	PUB! Please join us in the pub for thank you drinks. There will be an area reserved in the eagle from 16:30.	Those who can make it