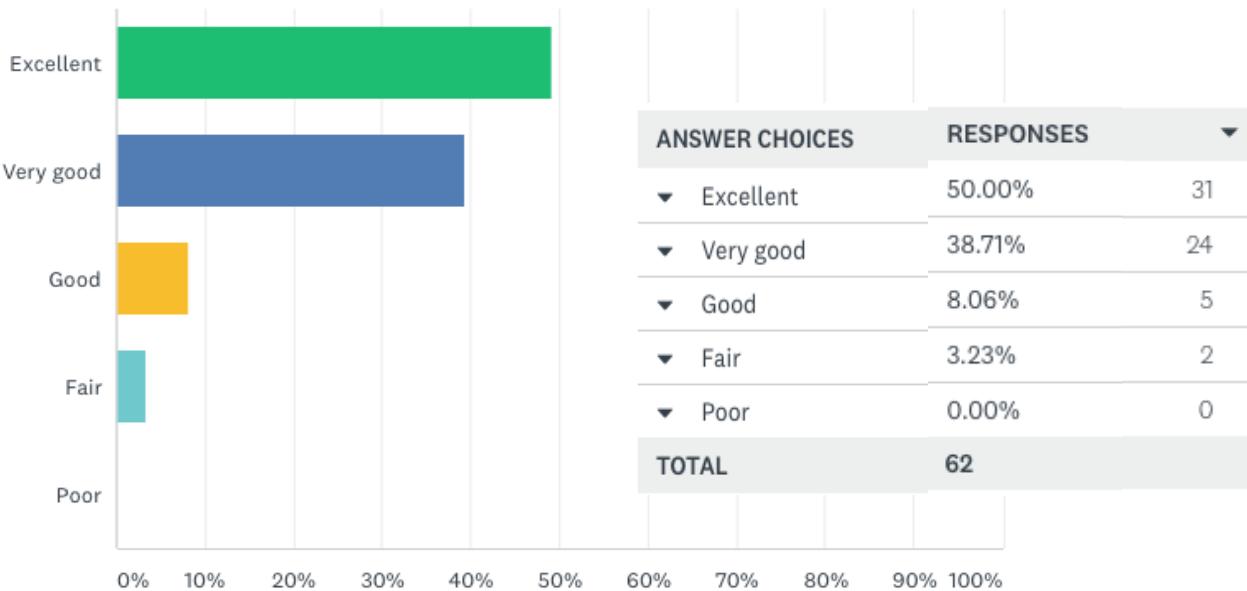


Feedback Report for NIHR 'Think Research' Rare Diseases Patient Day

Held on: Weds 21 March 2018 @ The Friends House, London from: 10:00 to 16:00

Sent out to 140 / Responses so far 62

1. Overall how would you rate the event?



2. What did you like about the event?

Learnt a lot, Liked the interactive system	View respondent's answers
4/11/2018 10:40 AM	
The workshops that we took part in. Communication and data protection.	View respondent's answers
4/5/2018 3:41 PM	
There were people from different charities / organisations sharing all they've been working on. There was much to talk about & we had many questions answered.	View respondent's answers
4/3/2018 8:36 AM	
Good variety of talks and breakout sessions. Good for networking and finding out what has worked/not worked for other patient groups.	View respondent's answers
3/30/2018 10:19 AM	
Range of topics and interaction with presenters	View respondent's answers
3/29/2018 12:16 PM	
Well structured and organised.	View respondent's answers
3/28/2018 3:43 PM	

Wide ranging but FOCUSSED on patients	View respondent's answers
3/27/2018 6:58 PM	
The chance to network with other support networks/groups. Opportunity to discuss updates & varied subjects relating to Rare Diseases. Good use of internet to put questions to panel & guest speakers.	View respondent's answers
3/26/2018 11:11 PM	
Good venue, informal discussions over lunch, use of Glisser	View respondent's answers
3/26/2018 5:01 PM	
informative	View respondent's answers
3/26/2018 3:13 PM	
The smaller workshop sessions and lunchtime discussion grps particularly - a great chance to ask questions, share experiences and personalise the learning from the day	View respondent's answers
3/26/2018 10:35 AM	
Well organised, great feedback from participants	View respondent's answers
3/26/2018 9:25 AM	
Break out sessions, Morning speakers - great variety, glisser	View respondent's answers
3/24/2018 2:37 PM	
I enjoyed the structure of the day with main hall and smaller presentations.	View respondent's answers
3/24/2018 1:59 PM	
A good venue that was well organised and all the speakers were interesting	View respondent's answers
3/24/2018 12:44 PM	
The patients' perspective. Different rare diseases charities coming together and getting different ideas from them.	View respondent's answers
3/23/2018 7:47 PM	
Good talks, good venue	
Venue. Food. Interaction.	View respondent's answers
3/23/2018 4:16 PM	
Understandable, plenty of interesting content and useful information. the venue and catering were great	View respondent's answers
3/23/2018 4:05 PM	
Breadth of topics, choice of sessions.	View respondent's answers
3/23/2018 4:02 PM	
Breakout sessions	View respondent's answers
3/23/2018 3:55 PM	
Lots of new faces who I hadn't seen before in rare diseases	View respondent's answers
3/23/2018 3:49 PM	

Well organised and run efficiently. All staff very friendly and helpful. Content was excellent and well pitched.	View respondent's answers
3/23/2018 3:40 PM	
Glisser tech and the wide variety of speakers	View respondent's answers
3/23/2018 1:40 PM	
Great professional speaker line up Great location and facilities Fantastic use of technology for social media integration Relevant content on agenda and speaker expertise	View respondent's answers
3/23/2018 1:27 PM	
Information	View respondent's answers
3/23/2018 1:05 PM	
glisser. engaging training	View respondent's answers
3/23/2018 10:57 AM	
 Lots of interesting talks and discussion and the chance to talk to other charities.	
3/23/2018 10:51 AM	View respondent's answers
The opportunity to network and realise that we all have the same problems.	View respondent's answers
3/23/2018 10:38 AM	
The networking opportunities and the workshops. It was difficult to choose which 2 I should attend out of the 4 on offer	View respondent's answers
3/23/2018 10:23 AM	
Finding out about genetics and genomes	View respondent's answers
3/23/2018 10:12 AM	
Interesting and relevant choice of speakers. GDPR featured and particularly topical for most patient groups attending	View respondent's answers
3/23/2018 10:04 AM	
Varied programme & interesting workshop choices	View respondent's answers
3/23/2018 9:02 AM	
Useful networking	View respondent's answers
3/23/2018 8:51 AM	
The short sessions covering a variety of topics and the opportunity to attend workshops.	View respondent's answers
3/23/2018 8:47 AM	
The information was absolutely helpful even though the research people tell us if we're less on disorder we have then they don't go deep to find exactly what we have or given name for our disorders. It will be nice to be identified rather than unknown disorder. All in all the event was nice and well arranged. Thanks for invitation.	View respondent's answers
3/23/2018 8:39 AM	
Speakers, panelists, break out session leaders - all highly experienced and committed, engaging, from whom I learned more. The lunch time discussion leaders included - brilliant session for furthering insights through discussion, 'consciousness raising' to bring back that useful concept. This couldn't happen without the event's being very well and thoughtfully organised. Finally, meeting other participants in this context. One of the best meetings I've been to, and certainly the best on Rare Conditions.	View respondent's answers
 Very clear explanations of the project. Any questions answered.	
3/23/2018 7:53 AM	View respondent's answers
Well organised, welcoming, interesting, glisser, excellent location, excellent speakers	View respondent's answers
3/23/2018 6:53 AM	
High quality throughout with excellent preparation. Highly relevant for us, a small charity. Glisser was brilliant - enhanced it no end for me. I viewed on an iPad and this was much better than my iPhone, since greater visibility and battery life! One of the best meetings of this kind I've been to. The photographic exhibition was great too.	View respondent's answers
3/23/2018 6:50 AM	
Its comprehensivity	View respondent's answers
3/22/2018 11:59 PM	
Everything	View respondent's answers
3/22/2018 11:32 PM	

Good venue and food, but presentations variable.	View respondent's answers
3/22/2018 11:17 PM	
Variety of topics and breadth of expert speakers from top scientists to patients	View respondent's answers
3/22/2018 10:19 PM	
Pace and sticking to time	View respondent's answers
3/22/2018 9:09 PM	
Well organised, central location, fantastic refreshments, up to the date presentations...	View respondent's answers
3/22/2018 9:07 PM	
Everything...informations,speakers,exciting and promising research..great venue location for transport	View respondent's answers
3/22/2018 8:51 PM	
Content was great, talks informative, location.	
There were a great many useful people to network with and get information from. It was maybe I felt 20 good people that I could've spent a few hours speaking to each to get some relevant information from. The presentations that I managed to attend I felt well very informative and the people were very motivated to impart information and help.	
3/22/2018 7:20 PM	View respondent's answers
A comprehensive day which was excellently managed.	View respondent's answers
3/22/2018 7:18 PM	
Interesting to hear about research	View respondent's answers
3/22/2018 7:15 PM	
Meeting people and the program was very good	View respondent's answers
3/22/2018 7:07 PM	
I enjoyed many things; the event was well organised, in a place convenient to transport links. There was a variety of speakers that delivered accessible information. Also liked the use of interactive technology.	View respondent's answers
3/22/2018 7:01 PM	

3. What did you dislike or could be better?

Less on specific diseases and more on general information for example funding, safe guarding or the option to join additional workshops. Having a chronic illness, my colleague and I didn't join the lunch time discussion as we needed this time to rest our brains a little before the afternoon sessions. Perhaps these could take place instead of talks about specific diseases so the lunch period is kept free to network, eat and rest a little if required. That said, the talks on specific diseases were interesting albeit not relevant to our charity.

4/5/2018 3:41 PM

[View respondent's answers](#)

My brain wasn't working well on the day so I found it hard to follow some of the sessions - I needed more time to take it all in.

3/30/2018 10:19 AM

[View respondent's answers](#)

Better distribution of eg coffee facilities which tend to lead to queuing. Plus side - not as bad as some conferences I have attended.

3/29/2018 12:16 PM

[View respondent's answers](#)

The event app. was a bit cumbersome and had some odd features such as the twitter feed, which didn't seem to be complete.

3/28/2018 3:43 PM

[View respondent's answers](#)

Data consent panel a bit confusing. A bit more on the research path would be good directions

3/27/2018 6:58 PM

[View respondent's answers](#)

I would like to see more time spent on the workshops and maybe a practical class regarding social media - workings & use of. In light of changes to the data protection, maybe a workshop on what the changes entail

3/26/2018 11:11 PM

[View respondent's answers](#)

The last speaker of the day wasn't very engaging; ended things a bit flatly

3/26/2018 5:01 PM

[View respondent's answers](#)

too much time on consent

3/26/2018 3:13 PM

[View respondent's answers](#)

Maybe more time for Q+A questions raised by Glisser to be addressed and more opportunities for interaction and opinion from the audience.

3/26/2018 10:35 AM

[View respondent's answers](#)

Bummer that the tech failed in the first social media session - of all the places! having the second session end at 2.30pm and the talks in the Light commence at 2.30pm meant no turnaround time, which was awkward. Build in 10mins turnaround next time?

3/26/2018 9:25 AM

[View respondent's answers](#)

A bit busy and rushed for me.

3/22/2018 7:18 PM

[View respondent's answers](#)

It lacked relevance to many rare disease groups and Speakers/panelist's seemed to know little about them

3/22/2018 7:15 PM

[View respondent's answers](#)

Some of the Speakers seemed to rush due to having to finish on time

3/22/2018 7:07 PM

[View respondent's answers](#)

I enjoyed the two talks I went to, but it was a shame I couldn't also have attended the other two talks. So for me, it's just that I'd have liked the event to be longer to fit attendance to four talks.

3/22/2018 7:01 PM

[View respondent's answers](#)

Afternoon topics covered		
3/24/2018 2:37 PM		View respondent's answers
It would be interesting to have a focus on how small patient groups can affect research. But also the implications for them regarding promoting it.		
3/24/2018 1:59 PM		View respondent's answers
Nothing		
3/23/2018 7:47 PM		View respondent's answers
Some talks were focused on very specific rare diseases, may have been better if it were more generic		
3/23/2018 4:30 PM		View respondent's answers
More time for questions and debate.		
3/23/2018 4:16 PM		View respondent's answers
Some sessions allowed the questioners too much time. Didn't find the length of time on Consent that valuable. Couldn't see all the panel, either		
3/23/2018 4:05 PM		View respondent's answers
Perhaps a more technical/academic talk like the last one could be earlier in the day rather than near the end. The topic was very interesting.		
3/23/2018 4:02 PM		View respondent's answers
Quite short breaks		
3/23/2018 3:55 PM		View respondent's answers
Longer for the workshops		
3/23/2018 3:49 PM		View respondent's answers
Perhaps somewhere to sit down for lunch - it was a little awkward holding food and drink and trying to eat whilst standing!		
3/23/2018 3:40 PM		View respondent's answers
I'd have liked the option to be able to attend all 4 workshops, not just 2		
3/23/2018 1:40 PM		View respondent's answers
Finding the different rooms for breakout sessions could have been signposted a little better		
3/23/2018 1:27 PM		View respondent's answers
More information for charities/support groups		
3/23/2018 1:05 PM		View respondent's answers
More time for the training sessions.		
3/23/2018 10:51 AM		View respondent's answers
I only stayed for part of the session on consent and the GDPR as I was very unimpressed with the solicitor. She did not come across as having a good knowledge of the GDPR.		
3/23/2018 10:38 AM		View respondent's answers

Lack of signage in the corridors made it difficult to know where we were going for each of the rooms (for example, the buildings in situ signage showed that you could access The Light Room upstairs, but we were accessing the room on the ground floor.

3/23/2018 10:23 AM

[View respondent's answers](#)

There was one question asked about GDPR and the amendment from last week which was not answered by the expert panel. The question needed a response at the end of the day.

3/23/2018 10:04 AM

[View respondent's answers](#)

Not enough time spent on each agenda item, particularly the workshops. The workshops were a little simple eg social media aimed at those that don't use any social media - perhaps better to give more information up front on what to expect?

3/23/2018 9:02 AM

[View respondent's answers](#)

I would have liked to attend a word workshop in the afternoon. As the conference was about research, more availability or another research session would have been useful.

3/23/2018 8:47 AM

[View respondent's answers](#)

I find most of things was alright by me. The event was arranged in well manner and professional way. I would love to attend more events like this to k own more about my disorders

3/23/2018 8:39 AM

[View respondent's answers](#)

We covered a lot of ground perhaps at the expense of more discussion allowing comment from participants from the 'floor' during plenaries, but on the other hand I don't know what I would have wanted to 'give up' - always a dilemma. So this isn't a dislike really, just a comment about trade-off of how many talks.

3/23/2018 7:58 AM

[View respondent's answers](#)

Not sure

3/23/2018 7:53 AM

[View respondent's answers](#)

Nothing

3/23/2018 6:53 AM

[View respondent's answers](#)

The sandwiches. The other food was very good.

3/23/2018 6:50 AM

[View respondent's answers](#)

The pace of everything with no room for thought

3/22/2018 11:59 PM

[View respondent's answers](#)

Nothing

3/22/2018 11:32 PM

[View respondent's answers](#)

I felt the day was heavily skewed toward carers of children with rare diseases and certainly not for patients. Insufficient time for questions. Too much reliance on smart phones as a way of communicating. Slides and conclusions of break-out sessions not available for down loading later. Poor time-keeping in afternoon.

3/22/2018 11:17 PM

[View respondent's answers](#)

an aerate consider for such a "day event" - less formal presentations and more time for workshops with a capture of KEY discussion points

3/22/2018 10:19 PM

[View respondent's answers](#)

Rare disease conversation are often about childrens diseases and whilst the important I feel we don't talk enough about adult onset rare disease

3/22/2018 9:09 PM

[View respondent's answers](#)

Originally told registration was 9:30? Arrived and it changed to 10?

3/22/2018 9:07 PM

[View respondent's answers](#)

?

3/22/2018 8:51 PM

[View respondent's answers](#)

Poor choice of vegetarian food

3/22/2018 8:43 PM

[View respondent's answers](#)

Social media talk pre-prep to ensure videos worked

3/22/2018 8:26 PM

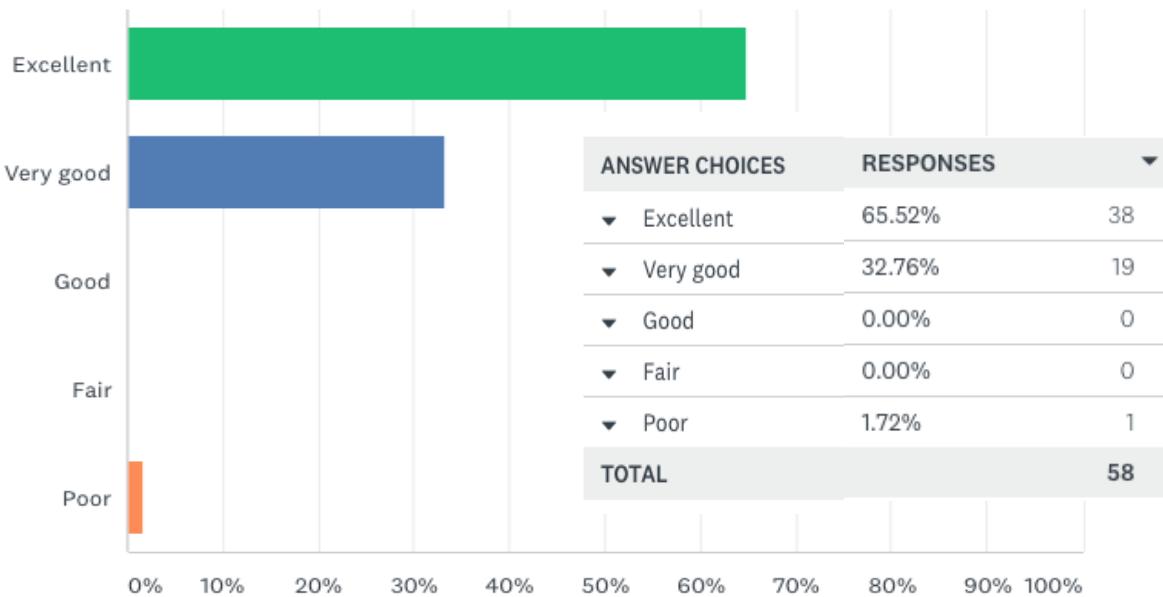
[View respondent's answers](#)

You didn't give the presenters enough time to go through information they had to give out a present. With the NIHR 'Think Research' Rare Diseases Patient Day. I would say that the one problem was the lack of time in the end. I felt like it should have more likely been two or three days. Unfortunately, I missed out on some of the presentations at the end which was very frustrating because I was speaking to people to get details and information from them.

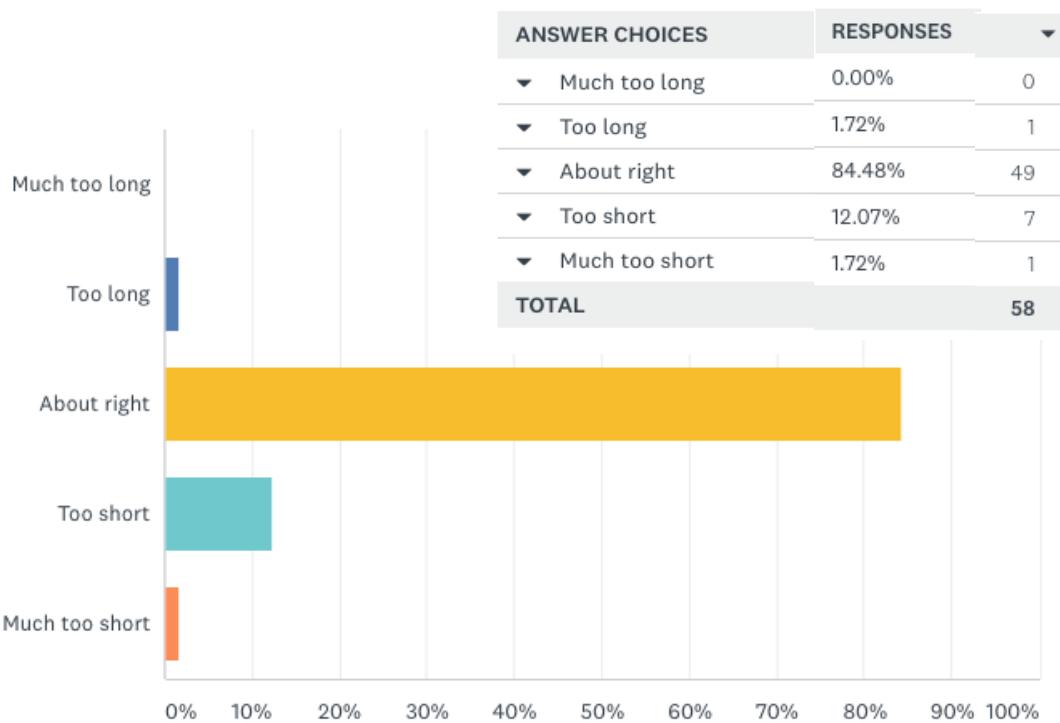
3/22/2018 7:20 PM

[View respondent's answers](#)

4. How would you rate the venue/location?



5. Do you think the event was too long, too short, or about right?



6. Is there anything else you'd like to share about the event?

Fabulous day. Thank you for putting the event on, very informative. Great food, catered for all dietary requirements.	View respondent's answers
4/5/2018 3:41 PM	
6 hours didn't seem long enough, as there was so much to talk about, But finishing at 4pm is good for those who have a long journey home. The venue did not have parking. My suggestion would be, maybe hold the next event outside of London with a place that has parking. [For those who can't go as far as London & need to be able to park outside a building]. Over all it was an amazing day.	View respondent's answers
4/3/2018 8:36 AM	
Georgina was very helpful with the booking process so it was easy for another member of our patient group to participate. All in all a very useful and informative day - many thanks :)	View respondent's answers
3/30/2018 10:19 AM	
Getting there from towns outside London for the start time is a problem. eg train fare increases by £100+ peak/off peak. For me it would be better time delayed by approx. 1 hour.	View respondent's answers
3/29/2018 12:16 PM	
Looking forward to more, great day and great networking. I'm sharing my insights and learning on twitter using the #MedLearn & the event hashtag	View respondent's answers
3/28/2018 3:43 PM	
Directions could be more specific as very difficult road to cross from tube (probably due to impaired vision)	View respondent's answers
3/27/2018 6:58 PM	
Appreciate there is a lot to cram in on one day, regardless a very valuable conference, which I believe everyone attending took something away to consider or implement. Venue was excellently placed for people to attend.	View respondent's answers
3/26/2018 11:11 PM	
I felt a bit out of my depth at some stages.	View respondent's answers
3/26/2018 3:13 PM	
Some great speakers and very useful and engaging workshops - very well organised and a wonderful venue.	View respondent's answers
3/26/2018 10:35 AM	
Great venue, very easy to circulate, very accessible. Would recommend!	View respondent's answers
3/26/2018 9:25 AM	
It was great. Perhaps other topics covered next time and not just research.	View respondent's answers
3/24/2018 2:37 PM	
It's always nice to have more options than just sandwiches!	View respondent's answers
3/23/2018 7:47 PM	
I enjoyed it	View respondent's answers
3/23/2018 4:30 PM	
Liked the technology but it wasn't used as much as it could have been.	View respondent's answers
3/23/2018 4:05 PM	
I really enjoyed the whole event. Great way to meet new people and learn new things!	View respondent's answers
3/23/2018 3:49 PM	
The use of glisser technology and details within the pre-promotional materials and agenda were excellent	View respondent's answers
3/23/2018 1:27 PM	
more chance for open debate would be good. be more strict on presenters to keep to time.	View respondent's answers
3/23/2018 10:57 AM	
The social media breakout session was excellent	View respondent's answers
3/23/2018 10:38 AM	
I enjoyed the event and found it very interesting. It is good to know that all of us, no matter what disease we are affected by are all working towards the same goal, to get a quicker/better diagnosis and an effective treatment/cure.	View respondent's answers
3/23/2018 10:23 AM	
The mix of subjects and participants was very good. Speakers were well chosen with fascinating subjects. I learned a great deal and found the advances in research most exciting. A special word of thanks to the various staff members, both NIHR and Friends House, for their efficient and caring service.	View respondent's answers
3/22/2018 7:18 PM	
Helpful staff	View respondent's answers
3/22/2018 7:07 PM	

As with these events, great for networking

3/23/2018 10:04 AM

[View respondent's answers](#)

I would like to see more information for the people who not diagnosis or given name for their diseases we have. The information about my rare diseases was not enough as I was expected, I asked the research speaker about why we're not knowing exactly what kind of bleeding disorder we have, but the answer because we few of us it seems the research don't go further deep to recognise us and given name. I just wonder if the medication we're given if is right for us? I understand the coasting if they will go further but it will be nice if I know what I have as this is for me and my generation. Been in limbo is so frustrating and wonder or things so many time. In general the event was absolutely nice and well arranged.

3/23/2018 8:39 AM

[View respondent's answers](#)

We talked about including children and young people, and how best to do that, in our lunchtime session. There are several aspects to that question and not just for a Rare Conditions meeting. Something to consider for next time: creche, attractive sessions for children and young adults, etc. On a more prosaic note perhaps: catering was excellent with much choice for healthy option, but may I go one step further to suggest considering whole food breads and 'treats' (pastry, biscuits and here with a nod towards low sugar).

3/23/2018 7:58 AM

[View respondent's answers](#)

It was very informative.

3/23/2018 7:53 AM

[View respondent's answers](#)

Just my thanks

3/23/2018 6:53 AM

[View respondent's answers](#)

Not really. Just one of the best organised events from start to finish.

3/23/2018 6:50 AM

[View respondent's answers](#)

I think it should focus on one area each time and not try to cover all at once

3/22/2018 11:59 PM

[View respondent's answers](#)

No. This feedback probably not much use to you. It really was a good day, from which I learned a lot, made some important contacts, and so forth. TY. T

3/22/2018 11:32 PM

[View respondent's answers](#)

Overall very enjoyable - we had some valuable discussions in the smaller group work-shops and this could be a bigger focus in the future

3/22/2018 10:19 PM

[View respondent's answers](#)

Background on key subjects needs to go out to people prior to event - too much info given on the day. Loved Glisser it was amazing

3/22/2018 9:09 PM

[View respondent's answers](#)

Timekeeping for the 1st workshop on working with Industry wasn't good - should have been manged better. Workshop on data very good!

3/22/2018 9:07 PM

[View respondent's answers](#)

It was great meeting new people and to share experiences. Felt like close family. Missing you all already.

3/22/2018 8:51 PM

[View respondent's answers](#)

Well managed and great staff

3/22/2018 8:26 PM

[View respondent's answers](#)

Rare diseases have a lot of difficulties getting a message out and being able to speak to other people in similar situations is very useful and this event should be held multiple times. I would very much appreciate if you could put me on your mailing list to be part of any similar events.

Really useful - thank you

4/11/2018 10:40 AM

[View respondent's answers](#)