

VOICE: 'Science for Advocates' Residential Study Week Hosted by Warwick Clinical Trials Unit: 19th to 23rd September 2016 Course Report and Evaluation

2016 Attendees

12 students attended the 2016 VOICE course. 8 were cancer patients, 2 were carers and 2 were healthcare researchers. All students attending the course completed evaluation forms. This report represents all of the feedback received:

Pace of the course

Students were asked how they found the overall pace of the course. Responses were mixed, with several students suggesting the pace was fast but necessarily so in order to cover all of the topics in the programme. Half of the students suggested more time should be incorporated for questions and discussion and some felt that too many sessions were scheduled, making them feel too rushed.

Comments included: *'I felt the pace of the course is a bit faster than I could follow but then we had a chance to review the contents of course so it was okay for me in the end'* and *'fast but probably necessary given the short total time of the course'*.

One student felt the pace was right, saying *'I get bored if pace is too slow'*.

Some students would have appreciated more breaks for rest, exploring the local area and exercise.

Course Highlights

Students were asked what they felt was the best thing about the course. Several cited the scientific information and the general organisation of the course: *'The scientific content was highly above my expectations'*, *'scientific information and intellectual stimulation'* and *'Well organised course which made it possible to learn a lot within the short time'*.

The speakers were praised extensively, specifically for their expertise, their ability to explain often difficult scientific concepts and medical aspects of cancer in ways which made them easy to understand. They were also noted without exception, for their generosity with their time and their willingness to answer many questions!

Different sessions particularly appealed to different students but many mentioned Professor John Marshall's session, praising it as an excellent and easy to understand introductory session to the basic biology of cancer.

Specific highlights reported included the following: *'The Pathology tour and learning more about cancer cells'*, *'The science of cancer and information on research'*, *'Trial design/designing a study'* and *'Hearing about the science of cancer which, even though*

included much new terminology, was informative and has given me a good base for further reading’.

One student summed up their VOICE experience as follows: *‘Meeting with the lovely bunch of people and spending time with them – all participants had so much experiences, knowledge, and insight. It was also a joy and a privilege to meet with some health professionals and scientists who are passionate about what they do and who all were willing to talk to us!’*

The students were asked if any particular sessions stood out for them as especially useful or memorable. The anatomy/plastinations session was extremely popular with almost all of the students describing it as an important and valuable session. It gave the students the opportunity to visualise real human anatomy, to touch and feel plastinated specimens and to relate what they could see and touch to the information presented at other course sessions as well as to their own cancer experience. The anatomy demonstrators were attentive and enthusiastic and very keen to make sure that the session delivered exactly what the course was looking for. They were clearly very passionate about the specimens, treating them with respect and ensuring the session was appropriate.

Some comments from the students included the following: *‘The plastination/anatomy afternoon was extraordinary!! And unforgettable (so very useful)’* and *‘the anatomy session was really interactive. The demonstrators were so enthused and conveyed that to us. The opportunity to see and study the specimens was a privilege’.*

The anatomy demonstrators also gave extremely positive feedback: *‘An absolute pleasure to be involved with this session. I hope our new Year 1 students are as keen and enthusiastic!’*

Each individual session on the programme was noted by at least one student to have been particularly useful. Comments included *‘the trial design session - Janet is very good at conveying information’*, *‘Prof John Marshall and his superb illustrations and excellent comprehensible explanations’* and *‘Bill Harris: I found this session very interesting, very educational, mentally challenging and stimulating’.*

Course ‘Lowlights’

Problems encountered on the course seemed to be outweighed by course highlights but around a third of the students felt that the programme was too packed and would have benefited from having more breaks: *‘Schedule too crowded. Needed a gap somewhere’.*

This wasn’t felt by all students but it should be noted that some experience post-treatment fatigue. This should be taken into account when organising future courses - some flexibility would probably be good, perhaps giving students the opportunity to attend extra supplementary sessions or take time out according to their needs.

Half of the students said they would have liked to have more time for questions and discussion at the end of each session. Many said they really value the opportunity to talk informally with the speakers after the sessions. There was a good rapport between students and speakers with a great deal of mutual respect evident.

Some of the students reported disappointment at not having the same level of 'hands-on' laboratory work as there had been at previous VOICE courses.

There was a mix of feelings about the morning review sessions with a lot of the students finding them stressful to prepare and present. Most were not sure that they added anything in particular to their learning and in some cases, they overran, causing issues with the timings of other sessions. This should be reviewed for future courses as there was some value in 'recapping' from a student's perspective.

Course Textbook

The students were each given a copy of a cancer biology textbook: 'The Molecular Biology of Cancer: a bridge from bench to bedside. Second edition; Edited by S. Pelengaris and M. Khan'. The authors met with the students and signed their copies of the textbook. All of the students said they valued having the book – one said *'the wonderful textbook we were given was an additional treat!'* - Some said they would have liked to have received it before the start of the course. Some also felt a pre-course reading list would have been useful.

Theory/Practical Mix

The afternoon course sessions were mainly practical, held either in the CTU or at the hospital. Students were asked to give their views on the practical sessions and the mix of the two. Generally the students reported being happy with the theory/practical mix. The afternoon practical sessions were described as useful and interesting. One student was disappointed not to actually conduct any practical laboratory work as students had done on previous courses. One student commented *'The practical sessions were extremely useful/interesting for me, but I was quite conscious of interrupting people's work or being in the way of extremely busy people. I am not sure how this issue could be resolved to be honest but perhaps we could visit in less busy time of the day and we could inform members of staff when we will be around so that they know?'*.

Others said *'the hospital and CTU visits were extremely useful and interesting to see what happens to samples to make a diagnosis'* and *'I enjoyed the sessions with a clear link to real life – seeing DNA, slides, human forms.'*

One student declared that *'full days in the classroom would have been tiring'*.

Networking Opportunities

On the subject of networking with other students on the course and also with the speakers and practical demonstrators, all were extremely positive. Feedback included *'Extremely helpful – I learnt a lot from other students!'*, *'useful to compare cancers and different treatment plans'* and *'all lecturers were amenable and open to answering questions'*.

Hospitality and Catering

This was the first VOICE course to use a hotel for accommodation and catering. This made the logistics of the course organisation much easier. Students were generally positive about the hospitality with just the catering not as good as expected: *'Catering was disappointing – poor selection of menu choices for dinner'*. One student felt she would have felt more comfortable with simpler accommodation: *'It was a lovely hotel but I have felt a little uncomfortable with the level of food/spa hotel as I was being sponsored by a charity'* and one suggested *'Could have sandwich lunch rather than 'sit down' lunch'*.

Conference Dinner

This took place at Warwick Castle where attendees enjoyed a tour of parts of the Castle and the Kingmaker attraction before sitting down to a castle banquet with entertainment from a knight and a magician! Most gave positive feedback: *'The visit to Warwick Castle for dinner was very good. Relaxing end to the course'* and *'superb! Enjoyed myself immensely (and I didn't think I would very much)'*. One or two felt something lower key might have been just as good: *'Enjoyable but I'd have also enjoyed chilling out at a restaurant which might have saved money?'*

Future Courses

Students were asked for their thoughts on future VOICE courses, whether they thought anything should be done differently or whether the content should be altered or added to. As previously noted, many felt that the programme was good but too packed. Longer spaces between sessions would allow time for questions and discussion as well as networking between students and lecturers. The timings of talks could be stricter to enable each day's programme to run to time.

There was great enthusiasm for the current content of the course but also many suggestions for content of future courses. There was a suggestion that *'a longer course could be considered'* or that the course could be extended but divided into different modules which could be run several months apart. Separate certification could be provided for each module.

Some student suggested that a panel of specialists could be invited to take part in a question and answer session. The panel could include consultants, nurses, pathologists and researchers.

There was a lot of feedback about the order of the programme with one student suggesting *'moving from the context of cancer to more detailed biology'*. Many students really enjoyed and valued the session on trial development and felt it was extremely relevant to their work in Patient and Public Involvement (PPI) in research. Several felt this session should be scheduled early in the week and also be extended with instruction on how to read and understand research papers.

Other suggestions for future course content were as follows:

- Extend the introductory session so that all can understand role of ICPV
- With the Da Vinci Robot – if students aren't able to see it working, maybe a video could be shown, with questions/discussion?
- Have some quizzes to test knowledge throughout the week.
- Stem cells - students were fascinated by this
- Integrative/natural therapies
- Liquid biopsies
- Lectures about interventional radiologists
- Consider certification/exam for those who want it
- Produce a biography sheet of participants for the speakers
- More emphasis on taking theory into practice – share the results of wonderful work for patient benefit
- What about following a patient pathway, from symptoms to investigations to scans to treatment to side effects to recovery? Include quality of life aspects.

Impact of the VOICE Course

Students were asked whether they would do anything extra or differently as a result of attending the course. Many responded positively: *'Yes – I will look up more YouTube video to advance my knowledge on cancer biology' and 'I am very keen to consolidate my learning and feel very much better able to be an effective lay researcher with TOC'.*

One student declared *'with the increased knowledge, I will be able to discuss research with professional members of research teams and steering groups on an equal footing'.*

Others were inspired to get more active in PPI and also with ICPV (current members).

Final Comments

Final comments included the following:

- No technical problems with the IT throughout the week – well done!
- Some closed social media group could be created for students including from other years.
- Thanks to Sophie, Janet and everyone else who helped to make this a successful and enjoyable week.



Thank you to everyone for your valuable feedback 😊