

VOICE: 'Science for Advocates' Residential Study Week
2nd – 7th September 2018
Barts Cancer Institute, Charterhouse Square, London
Course Report and Evaluation

2018 Attendees

10 students attended the 2018 VOICE course. 9 were cancer patients and 1 was a staff member of Breast Cancer Now. All students attending the course completed evaluation forms. This report represents all of the feedback received:

The course began with sessions on basic cancer biology. These sessions were designed to give the students an introduction to cell biology based on the assumption that they had no prior knowledge in this field. Morning lectures were followed up each day with practical sessions in the laboratory, with additional support from some of the PHD students at Barts.

Day 1

Theory: 'Basic Cancer Biology 1 – What cancer cells do'

Practical session: Solutions and dilutions

Here are some of the highlights the students described:

'John's lectures did make me realise how incredible the processes are that protect our cells from cancer and how it's almost a miracle that we are alive.'

'The 'highlight' for me was some revision of the biology I had learned at school many years ago!'

And things they felt they'd learned:

'...the difference between DNA and RNA.'

'Senescent' cells can pop up and can cause cancer elsewhere in the body.'

One or two of the students appeared to find the first day's lectures quite daunting:

'For the first day the presentation felt a bit heavy. Feel that we needed to hear something a bit lighter to start off with.'

But the style of presentation and the presenters' understanding that they were teaching patients and non-academics meant that the students were able to 'settle in', ask questions and really begin to learn:

'John presented an almost overwhelming amount of information but with such clarity that it wasn't daunting.'



As with previous VOICE courses, the students were actively encouraged to ask questions throughout the day. This enhances their opportunity to learn:

'Enjoyable way of understanding cancer biology. I'm really glad of having the opportunity of asking so many questions and having an answer for them Thanks!'

Day 2

Theory: Basic Cancer Biology 2 – How cancer cells do it **Practical session: How do we study DNA?**

Here are some of the highlights the students described:

'The highlight for me has been to know about the PEACE trial. I think this is a promising starting for a new way of making science.'

'Cancer is a wound that never heals'. How true that sentiment is.'

And things they felt they'd learned:

'The concept of cells needing to 'talk' to each other.'

'...grasping the construction of chromosomes and DNA.'

'...the importance of cell's receptors and signalling and the different types of cell behaviour.'

As with day 1, some of the students found the lectures quite challenging and the pace too fast at times:

'Found today's content on how cells communicate much more challenging and will need more time to look back over slides and notes together, to help with understanding on today's lectures.'

'The presentations were far too fast with too many diagrams/slides.'

But the patience of the lecturers and lab technicians was greatly appreciated:

'The level of detail in which everything is explained is fantastic, the passion and interest in Richard's explanations gives an idea of the way he works. I think that is what we want to see in scientific people.'

'Mike didn't make me feel like a failure – very grateful for that!'

In particular, students noticed and appreciated the passion the lecturers exhibited so clearly in the teaching of their subjects:

'It was nice to experience again the enthusiastic talks from Richard who seems as much passionate from his work as was John yesterday.'

'Richard was incredibly passionate about his subject and he clearly enjoyed explaining the intricacies of cell signalling, we might need another week on this!'



The afternoon practical session was very much enjoyed by all of the students and really helped them to gain an understanding of how scientific research is carried out:

'Once again the lab practice was fun and useful. We felt more confident to use the tools after yesterdays practice and discovered today the complexity of following (strictly) protocols respecting times of incubation and safety procedures.'

'Learning basic lab skills made me realise how much work goes into that side of cancer research and our DNA.'

Day 3

Theory: Introduction to Pathology and the Multi-Disciplinary Team Practical session: Examining cancer cells

Here are some of the highlights the students described:

'To learn about pathology is the highlight of the course for me so far.'

'The highlight of the day was the discussion over breast density and chosen treatment assisted with all the imaging techniques to screen breast cancer.'

And things they felt they'd learned:

'Lesion – thought I knew what it meant! Now do.'

One student in particular described how much she'd learnt about pathology and how this would help her to contribute more effectively in a research project:

'Learning more about the precision of pathology and how this translates to the diagnosis of cancer. No other setting in which I would have had the opportunity to learn about this. Going forward, the learning and knowledge I have gained today will better prepare me for the research project that I will be involved in with the NI Biobank.'

Again students recognised the efforts the lecturers went to in order to deliver understandable sessions and greatly appreciated the extra efforts they made to have further discussion and answer questions:

'The presentation of Louise Jones was impressively clear and meaningful to us/me. I particularly appreciated that she stayed over for lunch to answer our questions in an open and informal discussion. I would change nothing to the day. Perfect! So grateful!'

'Louise is a fantastic communicator. She's able to transmit all the passion she put in her work. I loved camera explanations. The time at the lab was fantastic, to see the cells...Ian was really helpful and patient with us.'

'There is a skill in adapting the language to which a professional is immured and translating it for the layperson's understanding. [Louise Jones] managed this effortlessly. I found the lecture completely absorbing.'



By day 3 the students were clearly becoming more confident with working in the labs and were enjoying the experience of translating theory into practice:

'The lab practice was also fascinating as we could observe, study primary cells ER+, such as my breast cancer cells.'

'The lab session was especially good and moved from slides to the real thing.'

There was more praise for the lab staff with appreciation of their skilful teaching and support:

'Linda led us through the processes involved with great patience and encouragement. It was fascinating to have first-hand experience of passaging cancer cells and to observe our work under the microscope. Looking forward to seeing the results of our efforts. Gained new insight into the methodical, sterile approach to lab research and deep appreciation for the painstaking work involved.'



Day 4

Theory: Different types of cancer

Practical session: Bedside to bench, tissues & biomarkers

Day 4 was the standout day for most of the course students. The experience of observing the tissue dissection in the pathology lab was identified as the highlight of the day by most of the students and in fact as the highlight of the whole course for many:

'The highlight was certainly the fresh tissue dissection done by Louise Jones, done in such a respectful way. This unique chance to see a pathologist proceed really helps me to grasp the purpose of each procedure I underwent at the time of surgery.'

'Louise managed to convey her obvious passion for her work alongside a sincere patient focus. To borrow a term from biology I think the association is 'symbiotic' - each benefits by association with the other.'



Other highlights of day 4 included the following:

'Process of fixing slides: positive result!'

'Looking at the biological therapies...'

And things they felt they'd learned:

'The new advances in detection of less invasive surgery for oesophageal cancer was particularly eye-opening for me.'

With more praise for the style of teaching:

'I loved the structure of what we know and what we don't know. And the explanations about the areas of research.'

One student expressed how the course structure with lab sessions following on from theory sessions, really helped to consolidate their learning experience:

'...continuing it going to the lab to dye the tissue and look at the cells....the full week made sense!'

Day 5

Translational Research – From Bench to Bedside

This was the final day of the course and with a change of content from previous courses the lecturers taught the students about translational research – how the results of research are applied to practice.

Here are some of the highlights the students described:

'I liked learning more about the landmark papers. I understand better what are the challenges of scientists writing papers and succeeding in being published. Very interesting!'

'The immunotherapy just because it is new and complicated.'

And things they felt they'd learned:

'Role of T cells.' *'Structure of research reports.'*

The students valued learning about research papers and this seemed to be an area of relevance to a lot of their work in research and PPI:

'John's presentation on how to appraise research papers was so worthwhile and I will definitely take this learning back to my work with NICRCF and NI Biobank.'

'Found the critical appraisal of research papers especially useful and will be better equipped to practice this skill both in my day to day work and in my partnerships with research and academic staff in Belfast.'

General Feedback

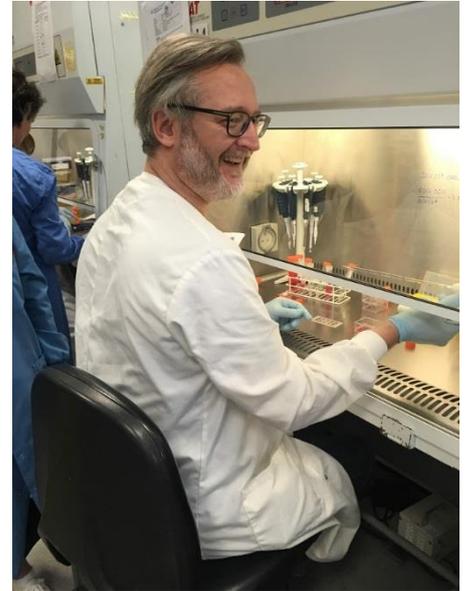
Student feedback was prolific with many describing the course as a huge learning experience and one which will potentially help them to become more effective in research and PPI:

'The molecular biology was the most informative part for me and then being able to apply it and ask questions in the lab.'

'I wanted to be able to understand cancer better and be able to make a sensible work as a PPI. The first point is achieved, the second we'll see....'

Many commented on the humility and passion of the lecturers and scientists:

'The discovery of a very passionate world with very humble doctors and professors who are doing incredible work for patients and have shared this week their knowledge – for us so valuable!'





'There is a great deal of energy, effort and expertise among the medical, scientific, academic and voluntary community devoted to preventing, managing and treating cancer.'

Networking and getting to know the other students was important to many:

'Meeting other patients and hearing about their treatment rather than their story.'

'Good contacts made on this course and lots of potential for collaboration beyond completion of the course.'

Future VOICE Courses

Students were asked if there were things they would have liked to have covered in the programme and if there were things they thought could be done differently if future years. They came up with the following ideas:

'For me it's important to have a full picture from primary research to bedside patient treatment. I'd like to learn more about NICE and those processes.'

'The personal experience of a surgeon and how they can link patients and the research community would be interesting to hear.'

'The epidemiology of cancer, particularly research into genetics.'

'Next steps for a patient advocate in service delivery? How can we help? Opportunities? As an advocate in service delivery it's made me realise that we need that there too?'

Course Highlights

Many of the students identified Louise Jones' session in the pathology lab as their overall course highlight. One student summed it up:

'I don't think I can ever forget Louise's dissection, it brought the reality of the disease home with a sledgehammer, especially for a non-patient. This reality was combined with such respect and compassion that the whole experience was deeply moving.'

Other highlights included:

'The interaction with the group members, facilitators, course leaders and students.'

'Being able to recognise normal cells from cancer cells through microscopic observations and carrying out experiments on cell cultures growing our 'own' cells and see them proliferate....an amazing sight and memorable week.'

Applying the Learning

Students were asked whether they would do anything extra or differently in terms of patient and public involvement as a result of attending the VOICE course. Responses were positive:

'Yes!! That was my main interest.'

'Yes. I am now a much more informed support group leader.'

And finally...

'Thank you so much to the presenters, the lab helpers but also to the wonderful facilitators who looked after us all week with so much care and attention!'

'The course was superb! Throughout the week my confidence went from 0 to 100. I can't believe how many questions I asked. Big thanks to Bec and Jim for looking after us and running the course so professionally – thank you.'

Writing this Report

If all of the positive feedback and the appreciation expressed to the lecturers for their efforts to ensure that the lectures and practical sessions were understandable and enjoyable was included in this report it would span many, many more pages! When subject matter was difficult the lecturers clearly went out of their way to repeat and clarify and then question the students and explain things in a variety of ways to make sure everyone could understand what was being taught. Appreciation for these tireless efforts is evident in all of the feedback forms.

Acknowledgements

Many thanks to Prof John Marshall, Prof Louis Jones, Dr Richard Grose and the rest of the team at Barts for once again making this course happen. Thanks also to guest lecturer Dr Mariam Jamal-Hanjani and to all the ICPV members who worked behind the scenes to organise and run the course, to Bec Hanley and Jim Elliott for expertly facilitating and finally to all of the students for your enthusiasm and desire to learn.



The Class of VOICE 2018!