VOICE: 'Science for Advocates' Residential Study Week
3rd – 8th September 2023
Barts Cancer Institute, Charterhouse Square, London
Course Report

Independent Cancer Patients' Voice (ICPV) is a patient advocate group led by patients for patients. We bring the views and experience of cancer patients, their family and carers, to the cancer research community. We believe clinical research is improved by patients being partners with clinicians and researchers, rather than passive recipients of health care

Members of ICPV are actively involved in many areas of research. To facilitate and enhance our role in these activities, we aim to understand the fundamentals of cancer, study design and current areas of controversy and research.

Much of this is gained through experience. For over ten years we have worked with Barts Cancer Institute to develop a tailor-made course which provides intensive training in basic cancer biology, hands-on laboratory experience, an introduction to research terminology and study design, and critical evaluation of research proposals and scientific papers.

This is VOICE - Vision on Information, Confidence and Engagement.

A science course for patient advocates - VOICE is unique, the only course of this type in the UK.

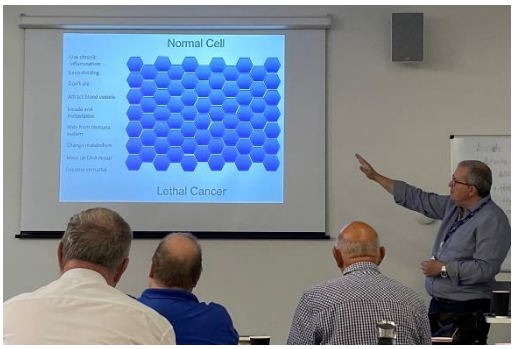
Introduction:

Sixteen students attended the 2023 VOICE course. Seven were members of ICPV, five were sponsored by CRUK and four were self-supported. All of the students had some experience of cancer, either their own diagnosis or experience as a family member or carer, or with a vocational role.

The students became 'real students' for the week, living in University accommodation (Queen Mary's University of London, Mile End), attending morning lectures at Bart's Cancer Institute (Charterhouse Square) and taking part in laboratory practical sessions each afternoon. Evenings were a mixture of organised sessions and some much needed free time. Students had plenty of opportunity for developing new friendships and working relationships with both fellow students and with academic lecturers. The bonds which were formed may be long lasting and productive.

Day 1 - Lectures: Basic Cancer Biology 1: Professor John Marshall.

The course began with an introduction to basic cancer biology. Topics covered included the cell and cell components, DNA, RNA, proteins and specialisation/differentiation of cells. John went on to teach how cancer is caused by mutations in genes and talked about oncogenes and tumour suppressor genes.



Students really enjoyed this start to the course. Some had studied biology to O or A level and one or two to degree level, but for all of them, this had been a long time ago! John set an easy and interactive learning environment, encouraging questions and discussion as the lecture went on. There was a policy of 'no question is a stupid question'.

Feedback was positive and John's easy teaching style was appreciated:

'John's train of thought and the way he explains step by step is fantastic. As the lecture was advancing, I truly felt like I understood more and more and also dusted off memories of biology from middle school.'

'A very good day - hardly Basic Cancer Biology but I did manage to keep up! John's slides were very clear. He was very honest when he didn't know the answer to a question. He answered all questions extremely well and very clearly.'

Day 1 – Laboratory: Solutions and dilutions: Professor John Marshall.

In the afternoon the students were introduced to the laboratory! This really is the Unique Selling Point (USP) of the course, with 'ordinary lay people' given access to the labs and expert tuition in laboratory techniques – the patient advocates become scientists for a week!

This afternoon saw the students learning basic lab techniques including measuring, weighing and pipetting. They wore lab coats and gloves and began to learn what it would be like to be a scientist. Some of the PhD and Masters students from Barts came along to help teach and supervise the students. This proved to be invaluable with some of the VOICE students struggling with the lab techniques. The Barts students were patient and enthusiastic, keen to help everyone to learn. In return, the VOICE students could share their experiences of cancer – diagnosis, treatment and caring roles. Learning for everyone!

'Great explanation and help from John and the rest of the lab experts. It's great to have the opportunity to meet early career researchers too!'

'What a fantastic privilege to learn about and use laboratory tools and measure such small volumes of liquid.'




At the end of each day the students were asked for their **'take home message' or their 'lightbulb moment' of the day.** Here are a few from day 1:

'Cells are so complex and so beautiful, I left feeling like I wanted to hug all of my cells! '

'Every cancer cell does not need to be aggressive it just takes one to make a path for others to follow.'

'P53 causes cells to die! The video of the cells invading was terrific!'

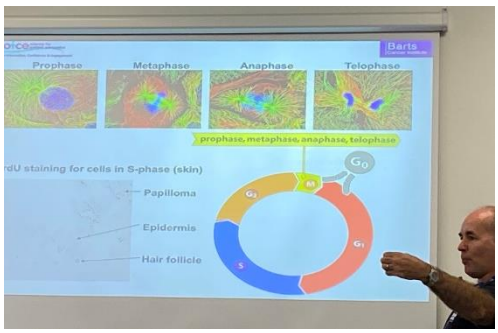
'Just how complicated the human body is. Who would have thought so many 'things' are inside a cell and how much activity takes place.'

Day 1 – Recap:

At the beginning of each day, two of the students presented a brief round-up of the previous day, explaining their own understanding of what they'd learnt. This put some out of their comfort zone, but everyone took a turn. This gave them all a chance to think through what they had learnt and to discuss it over dinner.

Day 2 – Lectures: Basic Cancer Biology 2 – How cancer cells do it: Professor Richard Grose

Day 2's lectures were delivered by Richard Grose. He helped the students to build on the knowledge gained about the cell cycle. He taught them about the signalling of messages to cells, how cells grow and how they die. As with day 1, there was a relaxed and informal atmosphere of learning with questions and discussions encouraged throughout the morning.



Feedback was again positive with students realising just how much there was to learn!

> *'Excellent explanations of the ways cells communicate, live/die and reproduce.'*
>
> *'Amazing session, linking in & expanding on yesterday's class work. He was easy to listen to, the pace was just right & he took time to answer questions & build on people's comments.'*
>
> *'Excellent session which conveyed an enormous volume of information to us in an appropriate way.'*

Day 2 – Laboratory: Conducting PCR to observe changes in cancer oncogenes: Angus Cameron.

The aim of today's practical was to understand how polymerase chain reaction (PCR) can be used to amplify specific fragments of DNA and how PCR can be used to observe changes in cancer causing oncogenes.
Angus led the session with super enthusiasm and energy! The students responded to this well, soaking up the teaching and the help of the Barts students. They were really interested to learn about PCR, having heard so much about it during the COVID pandemic.




> *'Fun, fun, fun afternoon and to actually see results! Thank you Pasmita, Elise and Angus.'*
>
> *'Brilliant session! Angus was really engaging and gave straightforward information throughout. He was happy to respond to follow up questions and was on hand to check everything as we were progressing. He seemed genuinely happy to see the results of an experiment that must – to him – be the simplest of things. His enthusiasm for teaching us was really clear.'*
>
> *'Amazing time. Fully practical session. Angus and his team outstanding!!! We were all very proud of our first PCR test and we could identify mutant cells.'*

The afternoon was made really special by the announcement that Angus had been promoted to an academic reader! The excitement from everyone was infectious – clearly a lot of love and respect for Angus from his colleagues and now from the VOICE students! Hugely well deserved Angus!

Day 2 – Evening Trip to Centre of the Cell: Stem Pod Show: Professor Frances Balkwill.

On the Tuesday evening students were invited to visit the Blizard Institute at Whitechapel. Prof Frances Balkwill and her team of demonstrators gave an amazing presentation from the 'Stem Pod', usually open to school and college groups. VOICE students learnt more about the cell and were given the opportunity to try some of the interactive games in the pod.
This was a fabulous learning experience, stimulating a lot of discussion.

'A wondrous experience- sheer fun and so impressive as a most mode to explain science to the young and engage them.'

'Wonderful experience. Very informative and interactive. You finish and you would like to start all over again. Thank you for that!'

Day 2 'Take home message' or 'lightbulb moments': (Note the scientific language 😊)

'DNA analytics is complex but PCR is a very efficient technique for fast testing!'

'Why certain drugs are used in combination to target various parts of the cell cycle and cell signalling in order to destroy the cancerous cells.'

'After the pandemic, PCR tests weren't on my favourite list, now I've changed my mind. They are pretty cool!'

Day 3 – Lectures:

Introduction to Neoplasia, Breast Cancer and the Future of testing in Cancer (including cancer of unknown primary - CUP - and Sarcoma): Professor Louise Jones.

The lectures in day 3 began to put the knowledge of cells into the reality of cancer diagnoses. As always on the VOICE course, the organisers try to provide teaching relevant to the experiences of the cohort. Students always seem keen to learn about their own cancer or the cancer of those close to them – how did it arise, how was it diagnosed and treated and what will the future look like?

Louise Jones talked about breast cancer – how it is diagnosed, classified and treated. She taught the group about the important role of the pathologist, preparing them for a practical demonstration later that afternoon. Students really enjoyed learning about the role of the pathologist and Louise's style of teaching and gentle explanations were praised:

'Brilliant speaker –I could have listened to her all day!

What an engaging and superbly informative communicator and so self-deprecating. Not only did we learn about the pathological and classification systems, we also learned of developments (and foibles) in the new technologies which will assist with diagnosis and prognosticating in the future.'

'Louise's explanations of the role of pathology; tumour v neoplasm; classification of tumours & tissue of origin were really clear. She was easy to listen to & (like John, Angus & Richard before her) very happy to discuss questions as needed. I'm sure that she's a brilliant role model for her team & for the students she teaches.'

Louise went on to cover 'The Future of testing in Cancer'. Digression in discussion meant that this session wasn't covered as fully as planned. One student had a particular interest in sarcoma so Louise kindly returned later and went through this missed session with her over a lunch break. This was just one example of the dedication of the lecturers which was greatly appreciated by the students:

> *'I saw that Louise gave [name] a talk on this. I think this was the most special moment in the week (and the week was filled with special moments).'*

Colorectal Cancer: Dr Stuart McDonald.

Stuart McDonald gave a comprehensive lecture on colorectal cancer. He began by explaining how colorectal cancer begins in the cells and can sometimes take many years to develop into identifiable cancer. The students found this fascinating with the subject personally relevant to some which they greatly appreciated:

> *'Very informative in regard to the mechanism of development from a single crypt cell over such a long period of time.'*
>
> *'Appreciated the deep dive into specific cancer types – and opportunity to reinforce some of the concepts of day 1 and 2 but also applying them to the specificity of each cancer type and getting a better overview on the organ.'*
>
> *'It was so informative; with my own family history, I learned so much useful information.'*

Day 3 – Laboratory:

Examining cancer cells: Jenny Gomm and Iain Goulding - View cancer cells down a microscope. Remove from growing surface, put in new flask and observe.

Students continued to use their newly developed lab skills to handle cancer cells and to look at them down a microscope. Jenny and Iain led this session with huge enthusiasm 😊 . Once again, some of the PhD students were there to give extra help and supervision.

'This was a very exciting practical that also felt like we were using skills acquired before.'

'Just fabulous fun- put our pipetting into practise and met yet more wonderful researchers who were so enthusiastic to help us understand 'how' and 'why'.'

'Spellbound to see cells moving and growing.'

Pathology: observe tumour being processed: Professor Louise Jones.

Students were given the opportunity to observe this brilliant pathologist at work: Louise was processing tissue from a wide local excision (breast surgery) which had been carried out earlier that day. Students were able to see how a pathologist makes a diagnosis by looking and touching the tissue and then how samples can be taken for use in a tissue bank (this patient had consented to donate their tissue for this purpose).

For many of the students this was a humbling and emotional experience, with m any of them having gone through cancer surgery themselves or supported loved ones through this. Louise showed amazing professionalism and skill as well as a huge amount of respect for the patient. Everyone was in awe of this pathologist at work and greatly valued this experience:

'I am completely in awe of Louise's skill, her dedication & her integrity. The way she handled the specimen, took samples and explained to us what she was doing and why was amazing.'

'Breathtaking session in the Lab. Pathologist working/taking samples from a woman's breast, showing us cancerous area. Very emotional session for all participants. Session I will never forget.'

Day 3 Evening: Baroness Delyth Morgan: CEO Breast Cancer Now: A Lifetime in Breast Cancer Research.

Delyth was the guest speaker for this year's VOICE course. Adrienne's sister and CEO of Breast Cancer Now, Delyth was welcomed by all of the students and lecturers, all eager to hear about her life in breast cancer research. The evening was also a social event with drinks and food and participants talking late into the evening. A fabulous atmosphere of interest and learning.

'I think this session was really enjoyable, it was great to hear more from Delyth and also I loved seeing the dynamic between her and Adrienne.'

'Baroness, a living legend for me. I did not expect such an approachable, genuinely committed person. Wow! On top of that for me personally it was very interesting to learn how the UK system works with charities, trust/trustees.'

'Loved meeting the Baroness, the world needs more strong, caring women like her.'

Day 3 'Take home message' or 'lightbulb moments':

'I am not religious, but this day I felt the utter most respect and need to pray for those women battling breast cancer at the moment, for the many people involved in making sure they are treated well every step of the way.'

'I had to have a bilateral mastectomy. Before cancer I had been both a blood donor and was signed up for organ donation, so I opted to donate both breasts to the Wales Cancer Biobank. Louise's session showed how many researchers my donation could potentially help. To know that I possibly helped researchers by donating my tissue gives me a positive outcome from breast cancer and you don't really get many of those!'

Day 4 – Lectures: Different types of cancer.

Blood Cancers: Joel McCay

Joel took the floor for just over an hour and gave a brilliant, information packed lecture on many types of blood cancers. He completely held everyone's attention, explaining everything in a way which made even the complex parts of blood cancers easy to understand. He drew a superbly entertaining analogy with football teams and leagues, running this theme right through the lecture to bring everything nicely together. Huge lecturing talent from Joel! Too many quotes to include here but just a few to sum it up:

'Extremely informative session. Detailed explanation of leukaemia and lymphoma. HL and NHL. Very patient centred approach. I was absolutely delighted to see that. Well done Joel McCay!'

'Kudos for this session. We always talk about solid tumour, and generically "blood cancers". The explanation was super clear, super useful to navigate the complexity of classification of malignant haematology. Never seen before something SO CLEAR and so clearly summarized.'

'Love the football analogy used to describe the cell biology and roles of the blood calls. Very good and easily understood.'

Great analogy with football. Excellent-very relatable. Made so much sense and clear to understand.

Cancer prevention: Professor Jack Cuzick.

Jack Cuzick is the head of the Cancer Prevention unit at Queen Mary, University of London. His lecture for this course was really enjoyed by many:

'What amazing information to be exposed to-the field seems to be very broad and it was great to have it presented to us so logically and to hear of the new strategies.'

'So interesting and I'm going to look up more of Jack's work. I could have listened to him all day!'

However, some of the students found the lecture quite hard to listen to:

'Not my favourite session, sorry. ☹ *The session was not the content I was expecting, I thought the session would be focused on prevention in terms of public health, lifestyle choices, nutrition etc. Particularly because 40% of cancers may be preventable and during the course the press was reporting that potentially 184000 people will this year have a cancer diagnosis that could have been prevented by lifestyle & diet changes.'*

'This is a session I would propose to modify. I struggle to see the connection with the rest of the course (I thought it was about involvement of research in prevention but it seemed a bit of a commercial promotion). The topic (research in prevention) is very relevant but in this shape it came to me as awkwardly placed.'

Prostate cancer: Mr Ben Lamb.

Continuing the theme of different types of cancer, Ben Lamb delivered a lecture on prostate cancer – diagnosis, treatment and survival.

'A really interesting & well explained session. Really useful to have a clear discussion about the risks of overtreatment of cases that, if left alone, would not progress.'

'Very informative session and it was fascinating to hear of the new sampling techniques and ways of using MRI to identify location and extent of cancerous tumours.'

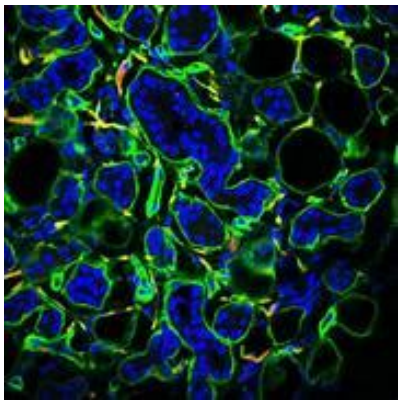
Day 4 – Laboratory:

As with day 2, the students were divided into 2 groups and all took part in at least two different sessions. Some also got to visit the cryo facility on campus.

Evaluate tumour sections for biomarkers using antibodies: Mike Allen.

The logistics of getting both of these practicals done within the time frame were tricky. This particular session therefore ran over to the following day when the students were then able to look at their slides under the microscope. Despite this, feedback was positive:

> *'Same comments as for the previous practical / lab sessions - these sessions, please preserve them in future [courses]. They are a true pearls in the program….allowing us to do or see something we do not have the opportunity to see in practice anywhere else. We can only read about it, here we could touch and feel. Proceed by trial and error. Fear the mistake and be relieved by the results. And staff: unique.'*
>
> *'Wow, never thought I would do this. The process was shown and then we had a go.'*



Confocal Microscope demonstration: Malgorzata Maksymowicz (Masia).

For the second part of the afternoon, the students were given a talk on the confocal microscope and were then able to take part in a demonstration of it. Unfortunately, Professor Kermorgant had COVID so Masia kindly stepped in to take this session. This was a really unique opportunity for the students to see some great technology in action. Here's what they thought:

> *'The confocal microscope was really special with amazing computer assisted imagery. Very informative.'*
>
> *'Very clever. Aware of the technology but good to see in real life.'*
>
> *'Great tool to see in action, awesome power to see right in a cell and be able to use colours to see what you need to see.'*

Day 4 'Take home message' or 'lightbulb moments':

'The lovely understanding Joel – what a treat he was! I wish he was my consultant!'

'Stage 4 blood is not always a bad thing.'

'There is so much progress in research. I have huge respect for researchers work.'

Day 5 – Lectures: Communicating research - scientific papers: Prof John Marshall and Angus Cameron.

John and Angus delivered a very interactive, final joint presentation about the process of publishing research. They talked about the ownership of research and the difficulties researchers come up against whilst trying to disseminate their findings to other researchers and to the public. There was discussion about how the students as members of the general public could get access to journals and publications.

This session helped to bring together a full circle of research – highlighting the importance of publicising the findings of research in order to shape future research, to improve diagnosis and treatment pathways and ultimately, survival of those diagnosed with cancer.

Students were shocked by some of the laborious processes involved but were also excited to hear of ways in which they could quite easily gain access to current publications – the power of Google! Once again, students recognised and applauded John and Angus's knowledge and delivery style:


On the case

The case of the disappearing teaspoons: longitudinal cohort study of the displacement of teaspoons in an Australian research institute

Megan S C Lim, Margaret E Hellard, Campbell K Aitken

'Very interesting to understand the processes, hurdles but also how things may need to change.'

'John and Angus did a really good of de-mystifying the impenetrability of the traditional (antiquated??) structure of scientific papers.'

John also squeezed in a final session in the laboratory to allow the students to look at the slides they had prepared during the day 4 practical. In addition, he also laid on a surprise visit to the drosophila (fruit-fly) lab!

' I really enjoyed going to the lab to see how the breast and skin cells we worked on looked like. So nice to go and see our work at the end of the week! Also, the drosophila lab was fantastic. Would be fabulous to have a session on it!'

Day 5 'Take home message' or 'lightbulb moments':

'Lecturers really caring about the VOICE course. Time and again going over and above what they'd been asked to do.'

'Peer reviewers powers or the painful peer review process.'

'That Researchers do want patients involved, using their experience as their expertise.'

'New meaning to the fruit flies that fly around the bin, I knew that they were part of research but not how. I loved seeing the drosophila lab and what they do with them!'

And finally! From the whole course - students were asked:

1. Which, if any of the session stood out for you as particularly useful or memorable? If so, which one and why was this?

Day 1 of the course stood out for many of the students. The grounding it gave them was summed up by one:

'The first day of lectures to me is the most valuable. Understanding the basics of cell and cancer functioning is useful for patient advocates and beyond. Everyone that works or has any relation with cancer should have the opportunity to learn it like this. From knowing the basics you can understand much more and make more questions.'

If we ran a league table for the lectures based on their clarity, educational value, style of the lecturer and also entertainment level, Joel McCay's lecture on haematological cancers would be top of that league! Very fitting given the football analogy running through his lecture 😊 Here are some comments from his 'admirers' (and a pic of Joel with his baby daughter!):

'Joel McCay has such a fresh approach to explaining what sometimes can be difficult to understand.'

'What a tremendous communicator obviously coupled with passion, knowledge and phenomenal intellect. Joel - you are a wonderful example of the adage that a sign of intelligence is how well you can explain different difficult concepts not only how much you know about it.'

'The lecture on blood cancers by Joel McKay was great and tapped into my love of football – everything suddenly made sense! (Play up Pompey!)'

As in previous VOICE courses, Louise's pathology demonstration was outstanding, with students humbled and in awe of her skills and her reverence:

'Together with day one, for me this session was simply the best. Understanding cancer from the point of view of pathologists, understanding their role, how crucial they are.'

'Observing the breast biopsy. It was humbling and portrayed the reality of cancer. The practical with Louise – so respectful and yet so informative.'

The afternoon practical sessions in the laboratory were a hit with all of the students:

'Going to the lab and the increments in which we were discovering more and more is also very useful. It allows you to understand how researchers do it, how they bring theory into practice to then arrive towards possible treatments.'

'The lab work will always be the most memorable.'

2. What were your main take home messages?

'In some ways cancer can be considered a 'normal' process in our bodies. It is when the cell goes truly rogue that we end up with a disease requiring treatment and now we know why and how they work.'

'I have realised even more how important role cancer patients advocates are playing in the communication between cancer patients and researchers. I have also realised how we can make changes by engaging , sharing our knowledge, upskilling, and helping each other.'

'Cancer research is so complex and that there loads being done but still lots to be done.'

'How important understanding of cell biology is for the treatment of the different cancers.'

'How accurate you need to be when working in cell biology.'

'How important it is to have good researchers working in the field of cancer research.'

'The strength of this patient voice is so powerful – aptly demonstrated by this group that had so much lived experience. This willingness and enthusiasm of the institutes lecturers, students and staff was so good.'

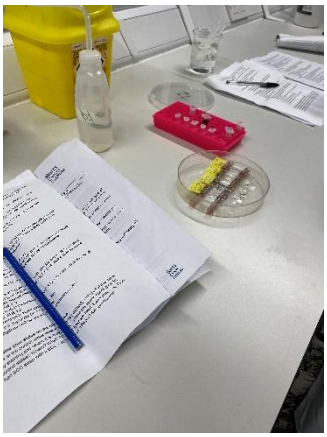
3. What things will be most useful to you?

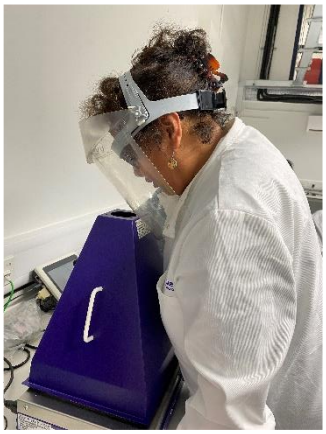
'The lectures on cells and how they behave in cancer was of great value – I enjoyed it the most.'

'The theory of cell biology – so many great lectures and the slides were easy to follow. I understand now more about my own cancer journey.'

'Everything will be useful, patient advocates are now embedded in research more than ever before.'

'The way the lecturers broke down & demystified the science was amazing. It will be invaluable to me when I support researchers in future.'





4. **Will you do anything extra or differently in terms of patient and public involvement (either getting involved yourself or involving others) as a result of attending this course?**

- *I will involve myself with other opportunities and encourage others to get involved too.*
- *Absolutely, I want all the patient advocates that I work with to be able to attend this course in the future. I will advocate within my organisation to find more funds to be able to do this.*
- *This has inspired me to put together materials that we already have to share with our patient advocates, although not the same as this course still a start.*
- *I also now see cancer researchers differently (and although I know that each one is different). I can see how some of them sometimes feel detached from patients, since they are in the lab with cells that are cultivated then and there. I will look for a bridge between those researchers and the patients, guided by patient's experience and knowledge.*
- *I will put special attention on the role of pathologists and advocate for them given the important work they do – I understood the risk we are running when people say we have already a shortage in that profession.*
- *Increase advocacy on importance of patient engagement in early research (not just or not only in design of clinical trials)*
- *Keep advocating for the open access for publications.*
- *I will definitely engage more in terms of engaging cancer patients to participate in different research programmes, surveys etc. I want to make their voice heard and counted. This course has showed me how important it is in future progress of cancer treatments.*
- *Yes! I am already more confident in my participation in discussions as a patient advocate. The need for patient advocates, especially expert patient advocates is rising rapidly. It has made me think more about better ways to recruit and how to make training/education available.*
- *Absolutely yes! Already led to more involvement and involving other trusts withing the NHS Sussex system. Expanding after this course to the Brighton/Sussex Health Research Partnership and research champions from our acute trust and community trust. I look forward to a pathway to encourage cancer advocacy.*
- *I will think about this particular question every time I'm involved in PPI projects & I will try to be a PPI person that everyone else on the course would be 'proud' of.*



Future VOICE Courses.

Feedback from the students is really important when it comes to planning future VOICE courses. We therefore asked the group the following questions:

1. **What did you enjoy most about the course?**

- *Learning about cells and the biology aspects of cancer.*
- *Pathology and the explanations.*
- *The connection between theory and practice.*
- *Being able to be in many different labs.*
- *I felt honoured that the researchers were prepared to give their time to our group.*
- *Meeting other patient advocates.*
- *Networking with other patients on the course was great – from all parts of the UK, Canada, Australia, Ireland.*
- *I enjoyed the mix of lectures in the morning and lab activities in the afternoon.*
- *I liked the variety of topics and the friendly environment.*
- *I also liked a lot the exchange with the other participants, the warm inclusive environment they created.*
- *And last but not least the logistic (location, residence, etc) was super (in the green, close to the underground, happy to see so many students around).*
- *The interaction of all of the attendees, so many views and expertise on patient advocacy meant ideas were bouncing about all of the time, during the day as well as in the evening.*
- *EVERYTHING. The generosity of everyone to share knowledge and experiences. The fact it was a safe place for us all to ask questions and not be afraid to say" please explain again as I don't understand".*
- *An inspiring atmosphere of joint enterprise – on both sides.*
- *Just everything but the relationship building, support and just everybody's lived experiences.*

2. Was there anything we didn't cover which you would like to have learnt about?

- *Maybe more about different gynaecological cancers.*
- *What advocacy is and what it is not.*
- *A follow up course on drug and therapies development and approval.*
- *Imaging advances.*
- *The relation with other organs, like nerves and the signals coming from the brain due to mental health or other triggers.*
- *Biomarkers.*
- *Artificial Intelligence (AI).*
- *Research on social/behavioural science applied to cancer care and on mental health.*
- *Mini lectures from participants on the work they do within their patient organizations.*
- *The impact a cancer diagnosis can have on mental health.*
- *More detail on the Tissue Bank.*
- *Metastatic cancers and any progress that has been made in ways of identifying patients most at risk.*
- *Treatments to delay progress and improve quality of life for those people living with metastatic cancers.*

3. How did you find the overall pace of the course?

- *At first I thought it was fast paced but because we were allowed to ask questions as we went along I managed to keep up.*
- *The pace of the course was fine but the interactive nature of mature students with presenters meant that if side conversations took off the presenter couldn't complete their session. You cannot make the course longer but perhaps put Q & A at the end of the session with one question each to give all attendees a chance.*
- *Hard work but I coped!*
- *I think it was intense, mainly because some labs the first few afternoons felt a bit like too basic. I then understood at the end of the week that we actually learned in increments which was great. Perhaps a timeline or a sentence or two on this at the beginning would be good to share with the participants.*
- *The days were full on but I didn't mind this and kept up. I would probably have to go back and look up the information covered again – that's ok, good that the lecturers shared their slides.*
- *It would have been easier if we were able to be in accommodation closer to Bart's Cancer Institute. Having said that, the staff on the Mile End site, were very friendly and helpful. The people in the Curve couldn't have been nicer.*
- *Intense but manageable.*
- *It was fast paced but it had to be to cram everything in.*
- *Course was intense but so interesting that I didn't mind. Enjoyed every minute!*
- *Tough but enjoyable. Good to break it up in the way it was delivered.*

4. When we run this course again is there anything you think we should do differently?

- *Make sure handouts are more accessible.*
- *I think that sending out the glossary a week earlier may help.*
- *I think outlines or one slide timelines of how each session or the whole set of sessions work would be a great visual way of ensuring accessibility and understanding of it all.*
- *I would also have the schedule sent sooner, this would give participants more time to get to grips with what they will be doing.*
- *I think that a paragraph on "what to expect" would be a nice addition to future paperwork.*
- *What to expect in terms of the course but also and more importantly in terms of the intensity.*
- *It would be good to consider a code of conduct - some characters in the group needed to be reminded that it was not 'their show'.*
- *Guest speakers – maybe consider inviting a politician or a policy maker? Maybe somebody from the European setting (also an umbrella patient organization for example) for an exchange of view?*
- *It would be nice to have amongst participants (or maybe as testimonials) young cancer patients as they can bring a variety of other issue they encounter (from fertility to financial discrimination, survivorship, etc.)*
- *Different venue for the Sunday evening meal* 😊
- *Maybe fewer breaks but slightly longer?*
- *I think the course should be 4 days.*
- *Consider filming some of the sessions for use as patient advocate training and as refreshers for those attending the course. Many sessions would work as completely standalone modules online. Ask Pharma to pay?*

5. Thoughts from this year's organisational team:

For the most part, this year's VOICE course ran smoothly and was an amazing learning experience for both the students and the lecturers. Organisation was good with just a couple of minor coffee delays and some logistical issues with getting students from one part of campus to another in a short space of time. Breaks were made more frequently than in previous years which seemed to work well.

There was some upset among the students which escalated towards the end of the week with a few clashes of personality and learning styles. This was mostly resolved amicably but it raised the question of whether a code of conduct should be developed for subsequent courses. This could be co-written by some of this year's students with the following guide for inclusion:

- Consider what the students will be given by the lecturers/organisers.
- Consider what is expected from the students in return.
- Respect to all.
- Enable everyone to speak and be listened to.
- Ensure quiet during lectures to allow lecturers to concentrate (leave the room as necessary).
- Special importance of respect during the pathology demonstration with Louise. Remember that this is an actual, clinical and diagnostic procedure and that the tissue has been donated to research by a patient currently undergoing surgery and diagnosis.

General wrap up:

This was an amazing group of students and an equally amazing group of academic tutors. Huge thanks must go to the following:

Adrienne Morgan and Chris Finch from ICPV – the drivers and founders of the course.

The team at Barts Cancer Institute, whose unfailing enthusiasm and passion for teaching and learning (it's a 2-way process 😊) is crucial to the success of this course: **Prof John Marshall, Prof Louise Jones, Prof Richard Grose and Angus Cameron.**

All the other lecturers and lab tutors - **Joel McCay, Jenny Gomm, Iain Goulding, Stuart McDonald, Prof Jack Cuzick, Ben Lamb, Mike Allen, Stephanie Kermorgant, Masia Maksymowicz.**

Prof Frances Balkwill and her team at the Centre of the Cell.

Baroness Delyth Morgan for her guest lecture.

All the PhD students who supported the lab sessions. Without them a lot of the VOICE students would have been confused and lost confidence.

Mercedes, Lizzie, Charlotte and Vanessa who worked tirelessly to print and deliver handouts.

Sophie Gasson for facilitating the course and making sure no one got lost between Mile End and Barts Cancer Institute!

Chris Finch and Adrienne Morgan

Some final thoughts from 'The class of 2023':

'I have learned so much from this course! Starting from cancer cells, through different cancer types, diagnostics to treatments. The whole course was very interactive and informative. It was such a productive time.'

'I just wish I had my time all over, this week has been the best learning experience of my life.'

'I will never be able to thank you all enough for the amazing gift of learning and empowerment you have given me. Thank you all from the bottom of my heart.'

'I had a thank-you party recently for everyone who has helped me through my cancer. I took my VOICE certificate as it's my biggest achievement since leaving school.'

Course report written by Sophie Gasson – VOICE 2023 facilitator.