Following an invitation to join European Cancer Organisation's (ECO)'National & European Parliamentarians for Cancer Action' I joined in May 2024.

The ECO held their annual summit in Brussels in November and invited me to speak at the launch of their 'smartCARE' app – a new app to assist in the treatment and support of cancer patients. I accepted the invitation and attended part of the summit while I was there.

The information I learnt has proven to be extremely informative.

Cancer in War and international learnings

It was 1000 days since Russia invaded Ukraine.

Richard Sullivan explained how 2.4m people currently live in areas of insecure crisis or conflict, with 50 countries in high or extreme levels of conflict, with 50% of sub-Saharan Africa in conflict, coupled with natural disasters and the spread of lethal viruses. By every metric or indicator, he said, things are getting worse.

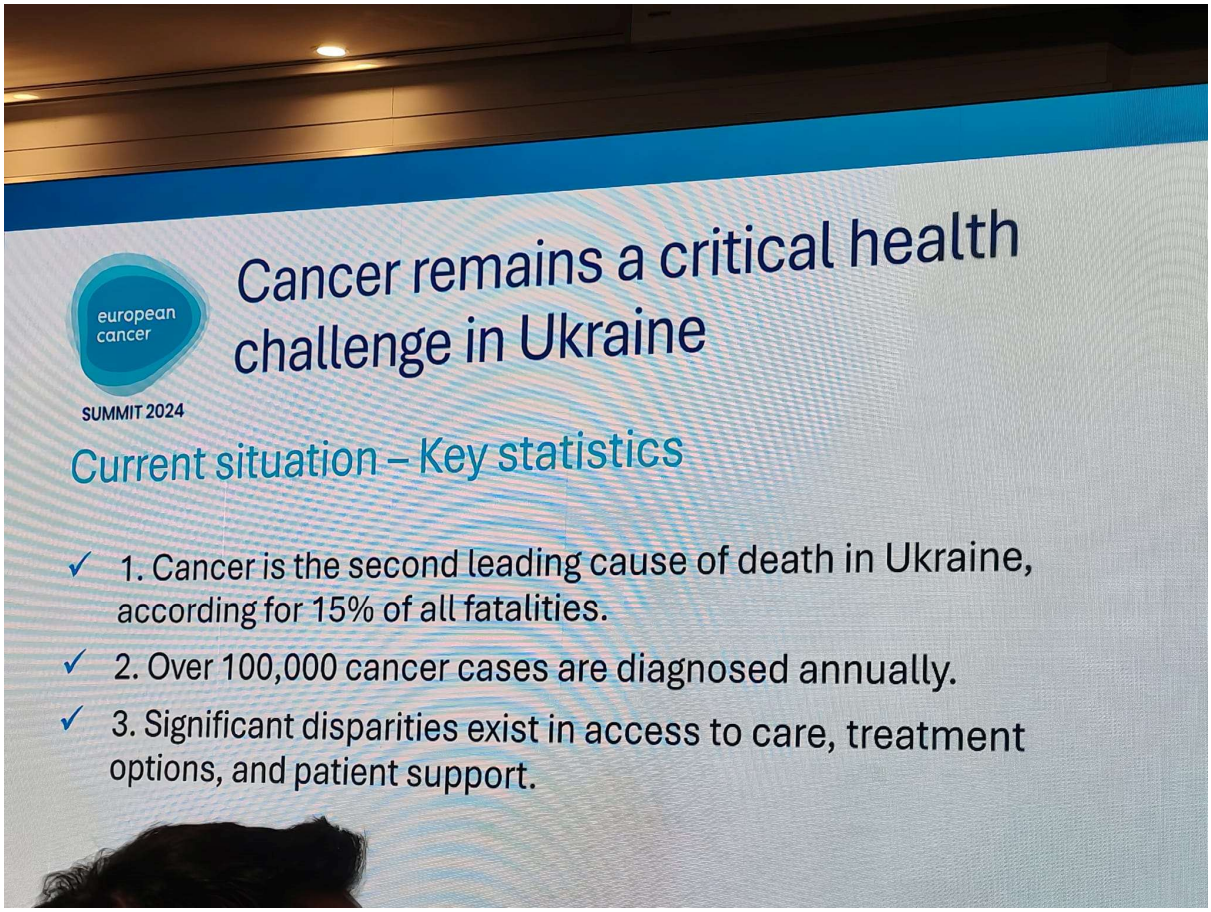
Sullivan explained how in Gaza, Sudan and Ukraine we were seeing the weaponisation of health, and that the violation of international law was becoming the norm.

This, he explained, “completely shattered our ability to provide care”.

Infrastructure which is required from diagnosis or treatment is being destroyed. He referenced Khartoum as an example where there was once a several brilliant cancer centres but had now been destroyed. It would, he told us, take 25 years to be rebuilt.

120m people are displaced, with 60m internally displaced and many more not registered in the system.

Of these some 75% - 80% of refugees living with cancer sought refuge in middle to low income countries, e.g. Chad from Sudan.



He also expressed concern at the push for more money to be spent on ‘defence’, because that money, he argued, would inevitably have to come from health and education budgets.

These patients were denied access to clinical trials because of lack of infrastructure, supply chain issues, and lack of professionals.

E argued that countries needed to maintain clinical trials, but allow cross border trials, and allow patients to access cross border trials.

Adam Jarubas, Chair of the EU's Public Health Committee shared a memorable line, "Health depends on DNA Code but must not depend on Post Code".

Klaus Meier, President, of the European Society of Oncology Pharmacy, explained how procedures had been standardised in 1992, introducing Quality Standards of Oncology, and that today 76 countries had signed up to these. This, it was argued, showed the importance of sharing lessons and teachings across countries.

When I asked for examples of good practice I was referred to: Tit Albrecht in Slovenia, who was their lead on screening; Portugal was a leader in access to healthcare; Lithuania and Latvia were leaders in preventative action; Estonia was a leader in digitisation; and Sweden was a good example of telemedicine.

Role of clinical trials

Benedikt Westphalen, Member of the EU Cancer Mission Board, put forward the case for the important role of clinical trials, saying that it was not a question of it being a luxury. Without clinical trials, he said, countries had no access to innovation and no furthering of the cause of cancer care. Everything that was on offer today, he explained, was as a consequence of clinical trials.

He set out the difficulties in recruiting and retain quality workforce without clinician trials.

Sarcona, a drug for a rare type of cancer, was not available for clinical trials in Europe, but was available for treatment in Japan and the US. This was due to regulatory regimes not allowing it, and patients were suffering as a consequence.

Ricardo Ferreira, Chair of the EULAR Committee of Health Professionals in Rheumatology introduced the Coalition for Reducing Bureaucracy in Clinical Trials. The BMJ published a piece in 2019, “Bureaucracy is strangling clinical research” which started the movement, which was looking at Safety Reporting, Informed Consent, and Regulation.

In safety they were arguing for the harmonisation and simplification of submissions, with a single online platform, simplified reporting forms, and for it to be paperless.

With ‘informed consent’ they argued that it should be informative and less legalistic, reducing the length of consent forms e.g. greater use of appendices.

In essence, they were calling for the work to be simplified.

Vlad Voiculescu, MEP, Member of the Subcommittee on Public Health and Zsuzsanna Devecseri, Global Head, Medical Affairs Oncology, at Novartis, explained how, in 2022, we saw a decline in clinical trials in the EU.

CT generated an economic value of £1.5bn, but a more attractive environment was needed. Clinical trials had to be run where the patients are, they argued. Gaps should be identified – which patient groups are missing? Sex? Age? Socio economic backgrounds?

Winette van der Graaf, President, European Organisation for Research and Treatment of Cancer (EORTC) & ECO Board Member, explained how clinical research is still young. 85% of clinical trials are Pharma led, with a concern that big Pharma was taking over. Academic research, she said, was losing ground.

She argued that this was not good for cancer patients. There is 15% less chance to survive 5 years with a rare cancer than a common cancer, yet pharma is not conducting trials on rare cancers. This is why we need to see academia step up and governments step in.

Matthias Löhr, President of the United European Gastroenterology (UEG) group explained how pancreatic cancer is the biggest killer, and how work was needed on this particular cancer.

Digital health

In the digital health session it was emphasised that digital is a tool and not a goal, which should facilitate and provide extras.

Annemiek Snoeckx, Co-Chair of the Digital Health Network explained how AI will play a part in radiology, and in fact in every step of the journey. But she cautioned saying that it posed challenges as well., such as safety ad data security. Cross border strategies and frameworks were required to overcome these concerns.

Alex Eniu, also Co-Chair of the Digital Health Network explained how digitisation was not able to hep in all clinical trials, and that real world experience was also required – the data must be entered by someone, he said. However, harnessing AI will help.

Tomi Mäkelä, Flagship Executive Officer at iCAN in Finland explained how Finland had been the pilot country for European health, and it had taken five years to develop legislation.

4000 patients had been recruited and they had developed a BioBank collecting digital data since the 1970s. They had collected it to a single platform, and in 2019 a new secondary healthcare act had been passed to help with the work.

The data in Finland was controlled by the National Health Authority. He explained how there had been challenges, namely how the new act, once passed, had clashed with other existing pieces of legislation leading to a delay in implementation. “Do not overkill with an Act”, he warned.

Tomislav Sokol MEP, Rapporteur for EU law on the European Health Data Space, explained how data was primarily used by professionals, but that there was a secondary use by researchers and policy developers and other similar fields of work.

The primary use was not controversial, as the control of the data was retained by the patient. The patient could restrict access to various things, e.g. mental health records which could be hid from , say, the oncologist or indeed deleted altogether.

But the secondary use posed more of a problem. It needed to be defined clearly in order to give patients trust in the system – e.g. anonymise data.

There was also an issue with GDPR because it is being interpreted differently across all the EU states – this, he argued, needed uniformity.

A contributor referred to the development in London of OneLondon which, he explained, had led to a saving of 1.3m minutes each month and a £44m annual saving.

A concern with developing policy around digitisation and AI which was raised was the fact that diagnostic equipment is made up of two basic parts – hardware and software. The hardware such as magnets, tubes etc, they argued remained pretty much the same, however software required regular updates and changes.

Quality of life

“To heal the patient, first you need to hear the patient”.

In a roundtable event attendees shared their projects in their respective countries.

An innovative oncologist from Bulgaria showed her ‘Life’ app – an app that she had developed herself for hear breast cancer patients to track their symptoms and treatment. She explained how she had to be self-taught to develop the skills and self-fund the project, and how therefore she could not roll it out to iPhones, who had different standards.

In Portugal clinicians had developed the Cinderella app for surgery preparation, and to provide information on breast cancer – e.g. how the body looks after surgery. They had received funding from the European Horizon project.

It was argued that any digital innovation should start with GPs as they already held so much data on each patient.

Smart phone based diagnostics were already rolled out in India and parts of Africa – and it was argued that 'tey were way ahead of us'.

A concern was expressed that no quality assurance programmes were in place for health apps. External audits were in place but no developer assurances. If digital diagnostics eg apps were used and considered a medical device then they would need to reach medical standards.

However the Covid apps that were developed showed that it was a proven technology and ow they could be developed swiftly and rolled out at pace if required.

Figure 1 Mabon ap Gwynfor MS speaking at the SmartCARE showcase event at the European Cancer Summit