Patient-driven data “can transform clinical trials and drug development”

Advocacy groups have the potential to use the power of patient experiences and preferences to change the way cancer treatments are researched and brought to market.

However, to take their place at the table on equal terms with pharma companies and academic researchers, patients groups must research and use evidence in a more scientific way. Patient bodies could even fund programmes and services by marketing data to decision makers.

This was the powerful message from the 3rd ESO Masterclass in Patient Advocacy in Lisbon (Feb 2018).

Eric Low, former chief executive of Myeloma UK and now chairman of the Amyloidosis Research Consortium UK, told patient advocates that hundreds of millions of dollars invested in clinical trials produce only small benefits for patients. Even when these add up to larger gains, the process is expensive and slow.

There are no licensed treatments at all for 95% of rare diseases and when drugs do come to market “they come with uncertainty and a high price”.

Flaws in the evidence found during HTA assessments often come too late to do anything about it. At the same time, patient preferences and experiences are almost entirely missing from drug development.

“If you have incurable cancer the decisions you make about how to spend the remaining years of your life are critical. Until we better understand what matters most to patients in terms of potential benefits and risks, we cannot know the true value of treatments.”

Payers need data about comparative effectiveness—does a new drug bring greater benefits than current...
Patients groups can use power of data to transform drug development

Continued from Page 1

treatment and what might be displaced as a result? Uncertainty about this leads payers to demand price discounts for new treatments.

“As citizens we should be happy there are systems in place trying to get the best value for money from tax revenue we invest in health.”

But, Eric Low said, what is really needed is better evidence. Patient groups have a golden opportunity to prevent ineffective trials by bringing in the patient perspective, and working with academia and industry to strengthen the evidence.

That means patient groups thinking about the commercial and economic power of data they can collect.

“For too long we have relied on anger and emotion and anecdotes to convey the patient experience to payers and regulatory authorities.

**Economic power**

“Can we be more empirical and evidence based in the way we capture data about the things that matter most to patients and how can we feed that back into the system?

“I think we can go one step further and think about the commercial and economic power and influence that the data we can generate can have because nobody has the access to patients that patient groups do.

“We could make that data available to decision-makers, governments and health care systems to help them better understand.” It could even be used to fund our organisations. “We can generate revenue to help us drive our programmes and services.”

No health system in Europe is increasing health budgets, but resources could be allocated more efficiently if the patient perspective was seen from the start of drug development.

Patient groups need to work together to help define research priorities and hold the research community to account.

“I am making a strong, strong shout for us working together within networks to think about how we can build frameworks and agenda to influence how to generate evidence needed for market access.”

Three key areas are: improving registration studies, collecting additional clinical data and generating patient level data. This includes identifying research gaps and deciding on the types of evidence that need to be collected from patients.

Low called for a move from evidence-based medicine alone to “value-based practice” by taking more account of clinician experience and patient perspectives.

To achieve this, advocacy needs a mini-revolution. “We are taking step-wise approaches to this new world and I think we need to get there quicker. We need to change the way we think. It is not about having millions of pounds for research, it is about using our knowledge, our data, our perspective to influence the research agenda in our favour.

“We are the brokers. We are the ones who can make the biggest difference to changing the system.

“Our currency is our data; it is our perspective. If we can get empirical evidence of what we want, we can align the system in our favour and that is an amazing opportunity.”

‘For too long we have relied on anger and emotion and anecdotes to convey the patient experience to payers and regulatory authorities. Can we be more empirical and evidence based?”

From Anecdote to Evidence-Based Advocacy
Learning to think as lobbyists
Advocates broke into groups to plan campaigns on issues close to their hearts, including the right to return to normal life, affordable medicines, inequities, clinical trials and research, palliative care, working better together and Brexit. Little wonder they ran out of time!

Public interest lawyer urges advocates “learn to lobby effectively”

Civil society groups must learn to lobby more effectively to drive policy changes, a leading European public interest lawyer told patient advocates.

Alberto Alemanno, Professor of European Union Law and Regulation at HEC Paris, said that many campaigners have been reduced to the role of spectators, demobilised by powerful groups and social media. “We are incredibly specialised in what we do but at the same time we are powerless.”

Alemanno founded the Good Lobby organisation that links civic society groups to 850 professionals who help pro bono. Groups that needed professional help with campaigns should knock on their door. “We want to make sure that we build bridges across communities who usually do not talk to each other.”

Alemanno argued that citizen groups need knowledge and support to use avenues such as formal consultations, Freedom of Information Acts, petitions to the European and national parliaments, Ombudsmen and even the European Courts to bring change. Currently, these avenues are hijacked by powerful groups as influence and money are centralised in ever fewer hands. “You can be the most organised and professional advocate in the world but you will never be able to reach the level of influence that other actors have.”

Liking’ on Facebook and signing online petitions achieves little without follow up. “We remain spectators rather than actors.” Social media promotes an illusion of influence. “We belong in this group of 2 billion citizens around the world who have been hijacked in terms of attention by a few tech companies who are no longer simply targeting us as buyers and consumers of products and services, but they are also trying to shape our lives.

“Most of the forces that drive our lives today are basically driven by algorithms - black boxes – they are not accountable; nobody knows how the data they gather on the internet about us is collected and translated.” Traditional power groups (churches and trade unions) have declined, opening a civic empowerment gap.

10 steps towards effective lobbying
In his handbook “Lobbying for Change: Find your voice to create a better society”, Alberto Alemanno lists ten action points to transform a cause into an effective campaign.
1. Pick your battle
2. Do your homework
3. Map lobbying environment
4. Draw up a lobbying plan
5. Pick your allies
6. Raise money
7. Plan your communication
8. Speak the language of decision-makers In meetings
9. Monitor and implement
10. Obey lobbying rules & laws

The Good Lobby site is at http://www.thegoodlobby.eu/
Video interview with Alberto Alemanno at https://youtu.be/t2wSorlJ4lA

Effective Lobbying by Patient Groups
Patient-led advisory board sets agenda for dialogue with industry

Patient groups are often invited to pharmaceutical advisory boards in November, as companies that promised to engage with patients spend their end-of-year budgets.

Jan Geissler, co-founder of the CML Advocates Network, believes many industry advisory boards have little impact on the direction of medicines research or drug access strategies.

They are seldom attended by top researchers and directors, and internal compliance rules constrain companies from sharing what they have in the pipeline, how they design clinical trials, or their access programmes.

“Some pharma advisory boards are valuable but a lot are not really meaningful or impactful. We still go to maintain good relations. However with very general content and little follow-up, the impact is sometimes questionable.”

Now the CML Advocates Network is turning this process on its head, borrowing an idea started by the HIV patient community in the 1990s.

**Safe harbour**

Instead of waiting to be asked to dance, the Network established its own Community Advisory Board (CAB) and invited senior company staff in clinical development, market access or patient relations to attend.

Patients set the agenda and chair the meetings. Companies are guaranteed confidentiality and a safe harbour for sensitive information.

Patient groups are professional in their approach, with preparatory sessions for patient advocates. “Inviting those who shout the loudest is not always helpful,” says Geissler.

There are also rules for company representatives who must commit to the full meeting—not make a presentation and leave.

One jaw-dropping sign of success is that companies pay to attend these meetings, to cover the expense of preparatory work, travel and venue. Geissler says that this costs companies far less than if they had to host their own advisory boards. However, payments to the patient-led CAB is a huge vote of confidence.

The first CML-CAB in May 2016 focused on the drug development pipeline and global access to medication and monitoring. Later meetings also addressed the quality of patient information and education, patient input into research priorities, clinical and manufacturing practices, access to diagnosis, monitoring, treatment and care and to clinical trials.

Giora Sharf, a co-founder of the CML Advocates Network, says dialogue has become more productive.

“We got tired of flying around the world and when we go into the room we don’t see the results of anything we said or anything implemented.”

“In our meetings we see the people we never met—people at the top of the company who want to experience this new model and who want to meet our best advocates worldwide.”

Four sets of meetings have been completed so far, involving separate back-to-back sessions with two, three or four companies, leading to a better understanding of drug development pipelines, dialogue about improving access to drugs, better patient information and better collaboration with the companies.

Geissler emphasises the amount of work involved in setting up, running and following up the CABs, as well as the financial risks, as CML leading advocates attend from Europe, Africa, Asia, Latin America and North America.

At the ESO Masterclass In Lisbon, patient groups expressed concern at lack of opportunities for younger advocates to learn and develop. The CML-CAB is also helping to develop future leaders.

Based on this success, the haematology patient community is preparing a broader CAB covering malignant and non-malignant haematology and a wider range of companies.
Fatima Cardoso, director of the Champalimaud Clinical Centre breast unit in Lisbon, made a plea for patient organisations to work together rather than compete.

Some medical colleagues oppose greater involvement of patients in research and policy discussions, because they say that they are too emotional and do not look at the data.

She drew applause when she added: “This is what I have heard from those who do not like patient involvement—you fight amongst yourselves as fiercely as the competition between clinicians and between pharma. Listen to the sceptics and address these points rather than being upset.”

Cardoso has promoted patient involvement, notably in the MINDACT trial and the ABC (advanced breast cancer) initiative where patients are equal partners in creating guidelines. She says that patients need a stronger voice in prioritising outcomes.

There is a need for patient data on the impact of progression-free survival and quality of life for women with advanced breast cancer where a cure is not possible. Cardoso urged patient groups to document and circulate their research results.

“Heated discussions amongst clinicians and pharma and health authorities are not enough. If the outcome is statistically significant but the absolute benefit is a few weeks or months top, does that really matter to you? We need you to tell us.”

Ananda Plate, from Myeloma Patients Europe, said they should avoid just being seen as the angry voice in the room. “We are trying to create an environment where opinion is replaced by evidence and anecdotes are only used to illustrate the evidence you bring to the table.”

Bettina Ryll, who chairs Melanoma Patient Network Europe, said it was important however, not to lose the power of patient experience. “What drives us is personal experience – we should not discount it or we become as boring as everyone else! Sometimes we will be on one side of the table and sometimes on the other and everyone has to respect that.”

Jan Geissler, founder and chief executive officer of Patvocates, said that patient-led research can have impact without needing extensive resources. The CML Advocates Network changed physicians’ understanding of patient adherence using data from a relatively simple survey.

Video interview with Fatima Cardoso at https://youtu.be/KoVunrJtBFk
Is the market price for cancer therapies ‘ethical’—does it reflect the value for patients?

Differing approaches to the pricing of cancer drugs from experts at the Masterclass in Lisbon, led to a vigorous discussion on the realities of access and price.

**Price finding or price taking**
João Carapinha, who runs his own market access consultancy, presented the price finding mechanism as a continuum where patient groups press for access while companies mainly aim to maximise revenue.

Patients play no direct role in price finding today as the role of managing demand has been taken over by governments and insurance companies.

When Gilead Sciences priced the Hepatitis C drug Sovaldi at $1,000 per pill in the USA ($84,000 for a complete treatment) it was correct in technical terms, as this breakthrough treatment is a fraction of the cost of a liver transplant. However, such “entrepreneurial pricing” is a public policy and communications failure.

In 2015, the price of the antiparasitic medication Daraprim rose from $13.50 to $750 a pill, after a hedge fund bought the company that made it. Carapinha said that if the aim was to maximise revenue, the only way that the company messed up was that it should have set the price even higher, as demand was inelastic to price and revenue rose sharply.

The company position “albeit unpalatable from a social perspective was absolutely correct from a price elasticity point of view. Was it acceptable or fair? Absolutely not.”

Gene therapies are setting record prices—but Carapinha argues that if a drug saves someone from going blind then a price of $420,000 per eye is a saving compared to the cost of not being able to work.

"If the aim was to maximise revenue, the only way that the company messed up was that it should have set the price even higher"

Carapinha introduced the concepts ‘monopsony’ and ‘oligopsony’, where health systems or insurance companies that buy drugs centrally become powerful price finders rather than price takers. In a world market without one dominant large buyer, negotiating power is on the side of innovative product producers. However, a single HTA body for the whole of Europe would boost the monopsony power of buyers and should lead to lower prices for some medicines.

Slowing access to market was another way to reduce costs—but would patient groups accept a 2-3 years delay? “The market would not function and it would mean a great degree of sacrifice amongst patients currently diagnosed.”

**Low-quality evidence**
Jean-Pierre Thierry, senior medical adviser to the French Union of Patients Associations (UNAASS), questioned whether the current pricing mechanisms reflect the true value of drugs being approved by the FDA and EMA at an ever faster rate.

Drugs prices have risen 10-fold since the 1990s, but the quality of evidence has declined, as most drugs are tested on limited population and surrogate end points.

The pharmaceutical industry has become the most profitable industry in the world. The high price paid for mergers and acquisition ($400 billion in 2016) is inflationary. Research done in the public sector is converted into products by the private sector, but the costs are not reimbursed.

*Continued on Page 7*
Finding a better balance between risk and certainty

Tony Hoos, head of medical for Amgen in Europe, called for “end-to-end” collaboration between industry, payers, regulators, health care providers and patients. However, he says it is not enough for industry and patients to work together if outcomes are not accepted by HTA and regulators. “We have to find a common denominator, as the situation we have today is many stakeholders acting in isolation.”

Each stakeholder has different tolerance levels for risk and uncertainty. Patients are important in assessing acceptable levels of uncertainty as well as the benefit/risk ratio for a therapeutic intervention. Different patients are willing to take different levels of risk. For patients with limited time to live, is the priority overall survival or fewer symptoms?

Patient participation is also important when assessing relevant outcomes, meaningful clinical trial designs and endpoints. Reducing uncertainty has a cost in time and money. “If you take one message away from here it is that the longer we wait, the more data and certainty we have but at some point we have spent so much time and money that the public health value is decreasing and patients who need a therapy now may not benefit from it.”

Building trust is important as patient involvement evolves.

Panel discussion on affordable medicine. Jean-Pierre Thierry, adviser to the French UNAASS, Branca Barata, from Roche and market access expert João Carapinha.

Does market price of therapies reflect the value they bring for patients?

Continued from Page 6

Thierry argues that the initial price set in the US effectively sets patterns for Europe and most of the rest of the world. This could cause a new side effect of “financial toxicity” threatening universal coverage and the goal of equal access.

Since industry meets the costs of the regulators and (in the US) pays extra to fast-track approval, there are integrity and transparency issues. The FDA (US) approves almost all new applications while in Europe, the EMA approves about 80%.

Thierry called for greater patient participation in European HTA bodies and a greater participation by patient groups in price negotiations.

Pricing mechanisms need to be redefined based on real-world data for new products.

He suggested it could be more effective to put resources into paying for nurses or palliative care than to pay for all of the most expensive drugs.

**Treatment delays**

Branca Barata from Roche (Portugal) pointed out that medicines make up only 14% of the €139 billion annual economic costs of cancer in Europe. Delays in uptake of new medicines vary significantly between European countries—from five months in the Netherlands to four years in Portugal, meaning that some patients have treatment that can be two to three years behind the times.

There needs to be a way to speed up patient access to treatments and to ensure that HTA processes keep pace with advances in science.

Barata said that prices should be considered as the total cost of treatment—rather than the price per pack of medicines. More has to be done to ensure that the patient voice is heard and patient organisations need to insert themselves into a remodelled European HTA agency.

Better outcome data is also needed “Everybody speaks about it but we don’t find much good data for health. We are not able to read and work on the data as we should.

“Patient advocacy organizations have an essential role to play in explaining to the public how sharing their medical data benefits patients today and tomorrow.”

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Video interview with João Carapinha at [https://youtu.be/rgcqODj_P0w](https://youtu.be/rgcqODj_P0w) and with Jean-Pierre Thierry at [https://youtu.be/We0uhgN7IJE](https://youtu.be/We0uhgN7IJE)
Being the boss is lonely and stressful so be kind to yourself

Being the boss is lonely and stressful, as became evident when patient advocates described their experiences in a workshop on preventing burnout. Almost all had experienced or come close to collapse.

One described the stress of working as a doctor in the morning and running a cancer group in the afternoon.

Another—in a disease area where half the patients die—has to switch from dealing with grief and bereavement to managing staff while “riddled with self-doubt”.

The leader of a small group did every job in the organisation for seven years from patient advocacy to crawling under desks to fix computers. Only at the point of collapse was someone hired to ease the load.

Another found dealing with finances alongside their caring role impossible. “Something happened and I could not put my foot in the office.”

A cancer survivor described running a patient organisation as more stressful than being a cancer patient.

And so on. Luzia Travado, head of psycho-oncology at the Champalimaud Clinical Centre, in Lisbon, says this is typical. Leaders cannot survive simply on passion and commitment.

“One of the things that make us burn out is because we are passionate for what we do.” She defines burnout as “a psychological syndrome involving emotional exhaustion, depersonalisation, and a diminished sense of personal accomplishment”.

A period of illness or unbearable workload may lead to physical and emotional exhaustion, cynicism and detachment and feelings of ineffectiveness and lack of accomplishment. Symptoms range from chronic fatigue, insomnia and forgetfulness to loss of appetite, anxiety depression and anger. Little wonder that it undermines attention to clients.

“If we do not pay attention to ourselves we lose the opportunity to take care of the people we are supposed to care for.”

“Knowledge of these symptoms – impaired concentration and attention, not sleeping well or taking exercise, everything goes downhill. Your body talks to you… if you are falling asleep all over the place pay close attention.”

Air stewards tell passengers to put on their own oxygen masks before helping children. Travado agrees. “If we do not bring our attention to ourselves we not only damage ourselves but lose the opportunity to take care of the people we are supposed to care for. Be nice to yourselves. It is a very lonely place to be—a chief.”

Participants filled in a “Maslach Burnout Inventory” which measures exhaustion (“I feel I’m at the end of my rope”) and its effect on the ability to care. Some participants were already showing a burnout red light while others were in the amber zone.

Travado advised leaders to ask for feedback at work and to foster well-being by socialising with people who don’t talk about cancer.

She uses the acronym SELERS as a guide: Sleep, Eat, Laugh, Exercise, Recreate, Socialise. Coping skills also include mindfulness. She advises: “Focus on the present moment. Don’t think about the workload waiting for you on Monday!”

Luzia Travado’s recommendation


3 minute interview with Luzia Travado on preventing burnout https://youtu.be/h17jpoLpUcw

Clinical health psychologist Luzia Travado leads a workshop in Lisbon
The enthusiasm and commitment that see patient groups through their early years are not enough to secure the future as they start to grow. At some point their governance needs an overhaul—and this may mean a new structure and board.

Mike Hudson, Director of the Compass Partnership, told the ESO Masterclass in Cancer Patient Advocacy that critical points arise when a small group hires its first staff member and later when it appoints a paid director. It can also be traumatic when the founder and original inspiration for the group has to hand over the reins.

Governance is seen as a system of structures, processes, meetings and behaviours that set an organisation’s direction, ensure effectiveness and provide accountability.

**Supportive behaviour**

As organisations grow, boards should separate from day-to-day management to focus on “insight and wise judgement” and oversight tasks such as setting objectives and strategy, ensuring financial viability and legal compliance and managing conflicts of interests.

Hudson says that voluntary groups can survive a “wonky” structure but boards must display collaborative and supportive behaviour.

“Behaviour is first of all about sharing a common purpose of an organisation, being clear about what is expected and respectful. It means reading the papers before the board meeting, making challenges in a constructive way, celebrating success and making sure everyone feels good about what you have done.”

It is also important for boards to review their own behaviour and performance and see where they have to improve. Members must be totally committed to the development of the organisation and accept collective responsibility for decisions.

The best boards have a short written description of their roles and responsibilities. The chair plays a critical role in the development of new board members.

People living with cancer sometimes object to board appointees from outside the patient ‘family’, but Hudson said that appointing people from different backgrounds brings new energy and ideas and can be hugely liberating for organisations.

During the discussion it became clear that many patient organisations struggle to attract board members with time and skills, especially in patient run groups where alternate board members may be needed to cover periods of illness. Many patient groups are still run by their original founders because of difficulties in finding a successor.

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**Guidelines for Governance of Patient Groups**
Monitoring and evaluation are important but patient advocate groups should be realistic about what it is possible to measure. The primary aims should be to help an organisation learn from what it is doing and to improve effectiveness.

Rosie McLeod, deputy head of evaluation and measurement at the NPC think tank and consultancy, told advocates, “What you do needs to be proportionate, feasible, meaningful to you and used to inform the decisions you take.”

Evaluation helps organisations to work more effectively and share their learning. In an ideal world, campaign groups can show how activities achieve impact and test their “theory of change”—the links they believe lead from activities to improvements in patient outcomes.

According to research conducted by NPC, most evaluation is driven by funders who want evidence that they are spending their money to good effect. A quarter of charities that conducted impact assessment had been able to improve services as a result while one in five felt better able to demonstrate results.

Evaluation must start from the vision of an organisation. Teams develop a shared understanding by deciding what changes can be measured to assess progress towards that vision.

It is important to measure outcomes as well as activities and outputs. The final aim may be too distant to be achieved by one organisation, and so an intermediate outcome is measured. Useful tools include interviews with policy makers and ‘influencers’, and media and social media monitoring to show changing attitudes. Complex methodologies such as process tracing, are used to show what made the difference.

Rosie McLeod recommends collecting the minimum data needed: “Getting deep information can take more resources and time. You cannot do it all the time and you do not want to use up your goodwill capital.” She suggests that patient groups can partner up to create a shared evidence base and lighten the load.

It is also better to talk to people rather than just collect data. “To understand how and why something happened you need to get their words not just numbers.”

Advocates at the Masterclass expressed frustration at the time it can take to show results.

Ananda Plate from Myeloma Patients Europe said they were putting a huge effort into training member groups in each country. After three years it was difficult to see improvements in knowledge levels at national level. While she is sure the approach is right, it is a struggle to demonstrate that it is working.

Questions were raised how to interpret results. If you are not seeing positive change, is your hypothesis wrong, or have you not done enough? Moreover, change can be slow and then happen suddenly. Kathy Oliver from the International Brain Tumour Alliance, said: “You can have assumptions about why change happens, then something unexpected comes along and throws everything into disarray.”

For NPC resources on theory of change and evaluation go to: https://www.thinknpc.org/publications
Interview with Rosie McLeod at https://youtu.be/PDw5FZN0ifk

Evaluate, but be realistic about what to measure

How your activities and external factors can lead to change. Source NPC.

Rosie McLeod
Learning to stay cool in the eye of a media storm

What happens when the treasurer runs off with the money? When you are accused of being in the pocket of a pharma company? When you close a patient service because you can no longer fund it?

If people object to what you are doing, your organisation can quickly find itself in the eye of a media storm. Sandra Bull, from 360 training, gave guidance on how to use planning and emotional intelligence to deal with challenging situations that may create a crisis.

In a fast-moving situation, it is essential to gather facts and create clarity, making sure the right people are in the room—including legal advice and a communication specialist. Managing your own emotions and those of people around you is also vital to avoiding chaos and confusion.

Your leadership team needs to stay cool and manage its emotional response, to create a sense of harmony out of conflict and find the best that could come out of it.

The first step is to define the problem—are financial controls up to the job? Have you been open about your funding? Was nobody inside the organisation listening before the whistle-blower went public? If nothing else, a crisis provides an opportunity to resolve issues like these.

Sandra Bull recommends writing down the challenges you face and your preferred outcomes. Advocates had a chance to plan and practise media interviews—demonstrating active listening, clear messaging and assertiveness. They learned to use language, tone and body language and to understand that saying too much can be as dangerous as saying nothing at all.

Learning to make a bridge between the questions you are asked and two or three key points you need to make is a skill that can be learnt. Self-awareness, self-management, social awareness and social skills are all needed for successful communication.

With good planning and emotional intelligence it is possible to strengthen the organisation by sorting out problems where your critics have a point, or where a complaint is unfair to “nail the lie”.

Guide gives Swedish men vital information on prostate cancer medicine options

Many of the 100,000 men living with prostate cancer in Sweden have little knowledge of what treatment is available.

Stig Lindahl vice chairman of Europa Uomo pointed out that only around 10,000 of these men are members of the Swedish Prostate Cancer Association. Many of the others never talk about their disease and are unaware of the wide variations in access to drugs and of unequal care.

Guidelines for treatment and access to medicines are implemented in different ways by six regional cancer centres and 20 self governed county councils.

Following EMA approval, it takes up to eight months for Swedish medical boards to approve the use of a prostate cancer drug, and several more months for approval by each county council, which even then may not have a budget to pay for it.

The Association has produced a booklet with up-to-date advice about medicines and how to access them. The booklet is available online and will be regularly updated.

Lindahl told the Masterclass that it is crucial to provide information in plain language for patients who are not experts in their disease.
With your 725 years of experience, can you tell us the difference between being ill and being a patient and what is the best route towards sustainable cancer care?

What’s the difference between feeling ill and being a patient? Are do afraid of the dentist? Do you get enough sleep? Random questions make advocates think on their feet. While forming a daisy chain timeline across the room, they estimate they had 725 years of advocacy experience between them.

They identified feelings of frustration, fear, anger, hope, opportunity, resilience, empathy, love, optimism and impotence.

They used assets such as information, knowledge, courage, motivation, listening, acknowledging rights, representation, experience, perseverance, communication skills, integrity and sense of justice to open channels to sustainable cancer care.

Tomas Bereczky of the European Patients’ Academy for Therapeutic Innovation, provided facilitation.

Tomas, whose background is in advocacy for people with HIV, doubted that advocates pay enough attention to the power of emotions in a field where many patients are terrified of dying. “Feelings are there whether you talk about them or not. Unless you acknowledge death and grief and you work with love and resilience, it is not going to work.”

Call to Action over Europe’s lung cancer inequalities

Lung Cancer Europe (LuCE) launched an online Call to Action about unequal access to diagnosis, care and treatment across Europe.

LuCE surveyed healthcare professionals and advocates in 16 countries, including face-to-face interviews and a survey of pharmaceutical companies. Their report highlights how lung cancer clinical trials are clustered in a few European countries, and disparities in access to radiotherapy. The biggest gaps are in Eastern Europe.

The survey also looked at the availability of lung cancer drugs and at reimbursement for molecular tests.

Slovenian MEP Alojz Peterle hosted an event in the European Parliament to launch the report, which is being used for advocacy and education.

Mirjami Tran Minh of Lung Cancer Europe said that follow-up campaigns at national level are needed to increase impact. Download the report at: www.lungcancereurope.eu/2017/11/07/disparities-in-diagnosis-care-and-treatment-access/
Patients take MRI scan appeal to Scottish Parliament

Patients have protested to the Scottish Parliament over a decision of the Chief Medical Officer in Scotland not to offer ocular melanoma patients an MRI scan after their primary diagnosis. About half diagnosed with Ocular Melanoma develop metastases in the liver which can be more readily treated if discovered early.

Iain Galloway, who chairs the Ocular/Rare group within Melanoma Patient Network Europe, told the Masterclass that MRI scans are offered to patients in England and Wales routinely in many centres and usually made available if requested.

Scottish patient Jennifer Lewis gathered enough signatures for a hearing at the Public Petitions Committee of the Scottish Parliament.

She told MSPs that few doctors understood the disease or the importance of early scan of the liver. “My GP told me ‘This is not a life sentence.’ She was told her next scan would be done by ultrasound in a year’s time.

The patients were dismayed by the response of the CMO, who proposed a UK group to start a trial. Iain Galloway said that such a trial would be prohibitively expensive and take years. “This was designed to mask the real issues of cost and capacity.” He felt that there had been an attempt to undermine their case by deleting evidence. “We had cited case series saying MRI was more efficacious but because we were a patient group they had taken it out.”

The Scottish Parliament has now asked the CMO for a new response.

Information about the petition at http://www.parliament.scot/GettingInvolved/Petitions/PE01629

Footage of the Scottish Public Petitions Committee hearing at https://www.youtube.com/watch?v=lA0R92tslLU (start viewing after 55 mins 36 seconds).

Only 1 in 6 NET patients can make informed decisions about their care

A survey by the International Neuroendocrine Cancer Alliance (INCA) has highlighted lack of information for patients.

Teodora Kolarova, INCA Executive Director, said that fewer that 1 in 6 patients felt they could make informed decisions about their care, and 1 in 3 do not know how to manage their condition.

INCA captured input from more than 300 patients and carers, 70 health care professionals and 35 patient leaders. More than half of patients and patient leaders identified gaps in psychological care. A minority of patients knew about relevant clinical trials but only 6% of healthcare professionals understood that there was a problem. Patients and professionals recognise the need for a global standard of access to care. Other priorities are improved information for patients, a greater patient voice in research, better education for health professionals and funding to enable patients to be active partners.

INCA supports 20 patient advocacy and research groups in 17 countries. Because neuroendocrine tumours (NETs) are rare almost half of patients travel more than 300 kilometres to see a specialist and 70% rely on patient groups for information.

Concern over thyroid drug reformulation

Judith Taylor from the Thyroid Cancer Alliance raised concern at the number of patients reporting side effects following changes to levothyroxine, a drug used after removal of the thyroid.

French groups started legal action after 17,000 patients reported palpitations, anxiety and tiredness. Merck has removed lactose from its brand of levothyroxine and the new formula is being introduced in other countries.

Marika Porrey, President of the Thyroid Cancer Alliance said this was also an issue in the Netherlands where Aspen withdrew its levothyroxine, requiring patients to switch to a new brand.

Kathy Redmond suggested that country level organisations give feedback about how patients are being affected.
Lymphoma association in Serbia raises alarm over late diagnosis and poor information

The Lymphoma Patient Association of Serbia (LIPA) surveyed more than 500 people with lymphoma to find out what they know about their disease and how well they are supported. The results were alarming. More than six in ten patients had originally been misdiagnosed and some had to wait months or even years before being referred to a haematologist.

More than four in ten patients did not fully understand their condition and almost one in five were not told they had a cancer.

The survey uncovered high levels of distress with 85% of patients expressing fears of relapse and 65% feeling isolated and depressed.

LIPA has worked with the Haematology Association to create a tool and GP online education course to make family doctors more aware of symptoms and the need for specialist diagnosis.

They have also produced a protocol on essential information that patients should receive when they are first diagnosed.

LIPA is looking at ways to support survivors following treatment. Maja Kocic, president of LIPA and a Board member of the Lymphoma Coalition said: “Normal life before diagnosis may never return. We need to find the new normal.”

Maja Kocic said that although most GPs were willing to collaborate, some older doctors are not used to involving patients in decision making.

There is also a problem with stigma. “Patients suddenly hear the word cancer and they freak out.”

How we were in Lisbon... Ver você de novo

The 3rd ESO Masterclass in Cancer Patient Advocacy included 23 patient networks

The Masterclass was supported by the following companies


A Stronger Voice written & produced for ESO by Peter McIntyre, petermcintyre2013@gmail.com

For comments or queries please contact Corinne Hall at chall@eso.net. For Steering Committee see http://bit.ly/3rdMPA