WECAN Academy 2024

WELCOME TO

The leading capacity-building event for cancer patient advocates

11th - 14th July
Barcelona, Spain

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WECAN Academy 2024

Welcome **Message**

We are thrilled to have you join us for this year's event, designed to empower cancer patient advocates across Europe with the knowledge and tools to make a real difference.

The WECAN Academy provides a unique opportunity to combine profound learning with the power of in-person connections. Over the next few days, you'll gain valuable knowledge and tools through a diverse program covering key areas like:

- Advocacy Tools and Skills
- Healthcare Systems, Policy, and Access
- Research and Data

Interactive workshops, insightful presentations, and engaging discussions led by patient experts and fellow advocates will equip you with the latest cancer research and treatment advancements, effective patient advocacy strategies, healthcare system navigation skills, and strategies to connect with your cancer patient community.

We believe that the in-person format fosters an electrifying atmosphere of shared purpose. The next few days will be filled with opportunities to connect with fellow advocates, exchange ideas and experiences, form lasting partnerships, and build a supportive community. Together, we can amplify our collective voices and make a significant impact on the lives of those affected by cancer.

We sincerely hope that you enjoy your time at the WECAN Academy 2024. Your active participation will contribute to growing the next generation of leading patient advocates.

Welcome to a community of shared experiences, learning, and collective action.

Welcome to the WECAN Academy 2024!

WECAN

Workgroup of European
Cancer Patient Advocacy Networks

Our Network

ALAN
Childhood Cancer International EUROPE
CLLAN CLL ADVOCATES NETWORK
CML ADVOCATES NETWORK
DIGESTIVE CANCERS EUROPE
EUROPA DONNA The European Breast Cancer Coalition
EUROPA UOMO The Voice of Men with Prostate Cancer in Europe
EURORDIS RARE DISEASES EUROPE
IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE
IKCC International Kidney Cancer Coalition
THE MDS ALLIANCE
mpnan
MPe Myeloma Patients Europe
MPNE
INCA International Neuroendocrine Cancer Alliance
Lung Cancer Europe
LYMPHOMA COALITION
PANCREATIC CANCER EUROPE
Sarcoma Patient Advocacy Global Network
THYROID CANCER ALLIANCE
World Bladder Cancer Patient COALITION
YOUTH CANCER EUROPE
World UP Alliance
HECADE HEREDITARY CANCER ADVOCATES EUROPE

Building trust, collaboration, and alignment to strengthen cancer patient advocacy across Europe.

Programme **Committee**

We sincerely thank WECAN Academy programme committee members for providing their time to create and design this training event.

- **Anita Kienesberger, WECAN Chair, Childhood Cancer International**
- **Hans Scheurer, WECAN Past Chair, Myeloma Patients Europe**
- **Alex Filicevas, World Bladder Cancer Patient Coalition**
- **Bettina Ryll, Melanoma Patients Network Europe**
- **Gilliosa Spurrier-Bernard, Melanoma Patients Network Europe**
- **Jan Geißler, European Patient Advocacy Institute**
- **Katie Rizvi, Young Cancer Europe**
- **Kathy Oliver, International Brain Tumor Alliance**
- **Michi Geißler, Sarcoma Patient Advocacy Global Network**
- **Sara Dederichs, European Patient Advocacy Institute**
- **Steve Pointon, Action Kidney Cancer**
- **Teodora Koralova, International Neuroendocrine Cancer Alliance**

WECAN Academy 2024

Agenda

Day 1

9:00 - 9:30	Welcome Coffee | SmartStart Registration
ADVOCACY TOOLS AND SKILLS	
9:30 - 10:30	**Setting the Scene | Advocacy principles** Anita Kienesberger, *WECAN Chair, CCIE* and Hans Scheurer, *WECAN Past Chair, MPE*
10:30 - 11:15	Coffee Break / Networking
HEALTHCARE SYSTEMS, POLICY, AND ACCESS	
11:15 - 12:15	**Introduction to Health Economics** Chris McCabe, *QUB*
HEALTHCARE SYSTEMS, POLICY, AND ACCESS	
12:15 - 13:15	**Inequalities Basics: Mapping and Understanding Patients' Rights** Erik Briers, *European Prostate Cancer Coalition Vice-Chairman & US Too Belgium Vice-Chairman*
13:15 - 14:45	LUNCH BREAK
ADVOCACY TOOLS AND SKILLS	
14:45 - 16:15	**The power of Words: Elevating Patient Advocacy through Communication** Alex Filicevas, *WBCPC,* and Lydia Makaroff, *FBC*
16:15 - 17:00	Coffee Break / Networking
ADVOCACY TOOLS AND SKILLS	
17:00 - 17:45	**Communicating to patients: Focus on Risk** Anita Kienesberger, *CCI Europe*, and Gilly Spurrier, *MPNE*
20:00	DINNER: Rustic Restaurant at the hotel - Next to the pool

WECAN Academy 2024

Session 1

Day 1

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

Introduction to Health Economics

Chris McCabe, *QUB* | chrismccabe@qub.com

WECAN SmartStart in Cancer Patient Advocacy

What is it about
This session covers...

This session is designed to introduce the participant to the key components of economic evaluation in health care.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Economic evaluation is one of the key components of the evidence base that underpins coverage and reimbursement decision making. It is essential that advocates understand what it is, its strengths and weaknesses, and why it is used at all, to be effective stakeholders in coverage and reimbursement decision making processes.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

This session will provide participants with answers to the following questions:

- What is an economic evaluation?
- What is cost effectiveness analysis?
- What is the Quality Adjusted Life Year and what are its strengths and weaknesses?
- What is the cost effectiveness threshold and why is it used to inform coverage and reimbursement decision making processes?
- How can equity considerations be incorporated into cost effectiveness analysis?

WECAN Academy 2024

Session 2

Day 1

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

Inequalities basics: Mapping and understanding patients rights

Erik Briers, *EPCC & US Too Belgium* | erikbriers@telenet.be

WECAN SmartStart in Cancer Patient Advocacy

What is it about
This session covers...

This session will discuss inequalities between and inside countries, based on socio-economic parameters and inequalities between individuals based on differences in learning capacity and digital skills. These inequalities (and others) can be the cause of less quality of treatments and less years in good quality of life.
Inequalities can lead to changes in the treatment of one patient or lead to more important changes in the general healthcare system. Patient rights can be seen as a result of many discrepancies and inequalities.
In the patients' rights are also provided basic reasons for patient advocacy.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Acknowledging discrepancies and inequalities are important for patient advocates as they "should" lead to awareness and calls for action to take care of them. This will lead to better health care and especially to better health care for the underserved who need patient advocates to talk on their behalf to make sure that their rights are upheld.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

Stay alert for discrepancies and inequalities but be careful in the evaluation before going to war. The health care system is a delicate system and balance we should acknowledge and handle with care.

Additional information on the session topic
References

The WHO on Universal Health Coverage

The European Charter of Patients' Rights

Council of Europe: Human Rights and Health

WECAN Academy 2024

Session 3

Day 1

ADVOCACY TOOLS AND SKILLS

The power of Words: Elevating Patient Advocacy through Communication

Alex Filicevas, *WBCPC* | alex.filicevas@worldbladdercancer.org

Lydia Makaroff, *FBC* | lydia@fightbladdercancer.co.uk

WECAN SmartStart in Cancer Patient Advocacy

What is it about
This session covers...

This session is all about the essentials of communication in patient advocacy. We'll explore why good communication is a critical component of our work, share strategic approaches to communications, and look at real-life examples from the community. You'll learn different ways to communicate effectively with various audiences, ensuring your message resonates and makes an impact.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Imagine doing great work, but no one knows about it – like a tree falling in a forest with no one around to hear it. As patient advocates, we often feel like we need to be humble, but it's important to share your positive work for so many reasons. Good communication helps patients find resources, influences changes in laws, helps to find allies and partners, and supports scientists and policymakers. While creating quality printed and digital materials might take time, having them ready saves you time in the long run. Plus, good graphic design can make your organisation look more professional and add to its credibility when engaging with new stakeholders.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

By the end of this session, you'll know how to create a powerful one-page document tailored to your audience, complete with a clear call-to-action and impactful graphics. You'll learn the importance of talking about your impactful work, using free resources to support your communication needs, and considering the different ways people consume information.

- Use the many free resources available to support your communication needs and to brainstorm and develop ideas.
- Remember that people consume information differently; think about your audience and how to reach them.
- Don't hesitate to learn from and borrow ideas from others – we're all working towards the same goal.
- Be proud of your work – it's okay to be humble, but don't be modest about your achievements.

WECAN Academy 2024

Session 4

Day 1

ADVOCACY TOOLS AND SKILLS

Communicating to Patients: Focus on Risk

Anita Kienesberger, CCI Europe | a.kienesberger@ccieurope.eu

Gilly Spurrier-Bernand, MPNE | gilliosa.spurrier-bernard@mpneurope.org

What is it about
This session covers...

Asking about risk is one of the most common questions from patients (and citizens) but it is something that is very hard to communicate well and accurately.
The Science of Uncertainty – Risk in cancer
Understanding the Issues, Language and Terminology around Risk.
Methods of Describing Risk. Good Examples.
Cancer Risk for Citizens and Patients: risk of cancer, risk of treatment strategy, risk of recurrence/progression, Risk of toxicity, Risks for your family,
With Personalization of Cancer - are Polygenic Risk Scores the answer?
Communicating Risk to children – the child patient or the patients' children
Test your ability to communicate risk.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Knowing about Risk helps people to make lifestyle changes, understand the potential course of disease, benefit from relevant screening, select treatment options, predict side effects, prepare their family and generally to help them cope. All stakeholders have a view of risk trade-offs in cancer care, but it is the patients that must live with the consequences of these trade-off decisions.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

As Patient Advocates, we should be able to describe risk TO patients to help them understand, and also FROM patients to other stakeholders who may be making decisions based on their own risk assessment, which can impact patients.

Additional information on the session topic
References

Framing affects the choice

Cancer risk in primary care

Risk Prediction Tools / Clinical Calculators

Clinical Trials Risk presentation

Genetic testing for cancer risk

WECAN Academy 2024

Agenda

Day 2

RESEARCH AND DATA

8:30 - 9:30 **Drug Development Basics**
Jan Geissler, *EPAI*, and Laia Bisbal, *EUPATI*

RESEARCH AND DATA

9:30 - 10:30 **Evidence-Based Advocacy Basics**
Ana Amariutei, *EPAI, Sara Rossi, EPAI*

10:30 - 11:15 Coffee Break / Networking

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

11:15 - 12:15 **Healthcare Ecosystems and Stakeholder Management**
Jan Geissler, *EPAI*

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

12:15 - 13:15 **Policy Stakeholders | How does the EU Work? Who is responsible of what?**
Richard Price, *ECO*

13:15 - 14:45 LUNCH BREAK

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

14:45 - 15:30 **Data Landscape: EHDS federated data and governance**
Teodora Lalova, *EORTC*

ADVOCACY TOOLS AND SKILLS

15:30 - 16:15 **Financial Sustainability of your Organisation**
Katie Joyner, *MPE*

16:15 - 17:00 Coffee Break / Networking

ADVOCACY TOOLS AND SKILLS

17:00 - 17:45 **NGO Governance: To avoid crisis in your organisation, ensuring transparency and integrity**
Ananda Plate, *PV*

20:00 DINNER: Dolce Vita Chiringuito - Castelldefels

WECAN Academy 2024

Session 1

Day 2

RESEARCH AND DATA

Drug Development Basics

Laia Bisbal, *EUPATI* | laia.bisbal@eupati.eu

Jan Geissler, *EPAI* | jan.geissler@patientadvocacy.eu

WECAN SmartStart in Cancer Patient Advocacy

What is it about
This session covers...

- How does medicines development work – from Phase I to Phase IV
- Why does patient involvement in clinical research make sense?
- The roadmap on patient involvement in clinical research, and meaningful input in clinical trials
- Digging deeper and further trainings – EUPATI resources

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

- Patient involvement in drug development is crucial for patient advocates as it empowers them to actively contribute to the development of new interventions that address patients' unmet needs and priorities.
- By engaging patients as partners in research, their unique perspectives, experiences, and preferences can be integrated into study design, implementation, and decision-making processes.
- This active collaboration ensures that research aligns with patient needs, promotes patient-centered outcomes, and enhances the relevance and applicability of findings.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

- Patient advocates play a pivotal role in advocating for patient-relevant clinical studies by contributing to the research questions that matter, the design of studies that deliver better and relevant health outcomes.
- The type of input that the patient community can bring in the design, conduct and communication of studies is well described in the "roadmap on patient involvement in clinical R&D".
- Patient advocates need to be informed about the drug development processes to act as research partners on equal eye level. EUPATI provides resources and training for patients and patient representatives

Additional information on the session topic | References

EUPATI Toolbox resources:

- EUPATI Toolbox
- Articles on Basics of Medicines R&D
- Introductory video to clinical research
- Phases of clinical development
- EUPATI Patient Engagement Roadmap

Principles of Successful Patient Engagement in Cancer Research.
Authored by the German Federal Ministry of Education and Research in the framework of the Trio Presidency of the European Council (Germany, Portugal and Slovenia), September 2021

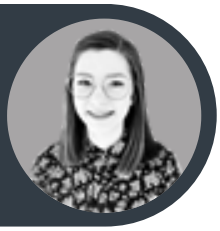
EUPATI Patient Expert Training/Open Classroom Resources:

- EUPATI Open Classroom
- Getting started- online course: Overview of Medicines Research and Development
- Introduction to Medicines R&D Module: online course of Process of Medicines Discovery and Development
- Introduction to Medicines R&D Module: online course of Role of Patients and Patient Organisations in Medicines R&D

WECAN Academy 2024

Day 2

Session 2



RESEARCH AND DATA

Evidence-Based Advocacy Basics

Sara Rossi, *EPAI* | sara.rossi@patientadvocacy.eu

Ana Amariutei, *EPAI* | ana.amariutei@patientadvocacy.eu

WECAN SmartStart in Cancer Patient Advocacy

What is it about
This session covers...

This session focuses on evidence-based advocacy which involves the utilization of research and data to support and promote practices, policies and recommendations that are grounded in evidence. Through this patient representatives and patient organisations influence decision-makers by presenting compelling and factual information.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

The patient community is uniquely positioned to advocate for patient needs, values and preferences. However, individual stories and opinions may lack the efficacy to persuade researchers, healthcare professionals or regulatory decision-makers. To ensure that healthcare truly aligns with the needs of the patients, patient advocates should generate and disseminate robust evidence.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

- Evidence is essential for progress and it enables a variety of stakeholders to build upon existing knowledge and make informed decisions that drive innovation and improvement.
- Implementing evidence-based advocacy leads to better patient outcomes, more efficient use of resources and overall improvements in health.
- Healthcare systems are diverse and dynamic. This means that new evidence can reshape understanding, it aids in staying current with knowledge and allows us to remain open to new findings.

WECAN Academy 2024

Session 3

Day 2

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

Healthcare ecosystems and stakeholder management

Jan Geissler, *EPAI* | jan.geissler@patientadvocacy.eu

WECAN SmartStart in Cancer Patient Advocacy

What is it about
This session covers...

This session will introduce the healthcare ecosystem and its different stakeholders groups, and their interests. It will reflect on the implications for us as patient advocates liaising with different stakeholder groups, also looking at risks and opportunities of the engagement. It also reflects on choosing the right stakeholder group for your advocacy work to avoid barking up the wrong tree.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Healthcare systems are complex systems composed of many different stakeholders, e.g. patients, patient organisations, charities, physicians, clinicians, researchers, insurances, policy makers, hospital administrations, the commercial sector with pharmaceuticals, diagnostics and devices, regulators, HTA, payors etc.

Every stakeholder group, including patients, has legitimate interests that at parts overlap with the interests of other stakeholder groups. No single party fully owns the problem, and solutions can only be found in collaboration and re-alignment.

Understanding the underlying nature of the healthcare ecosystem and its behaviours allows to devise strategies that will work with instead of against the system, increasing chances for success.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

- The ultimate purpose of healthcare is to serve patients; with this, patients have a unique convening power to facilitate cooperation, collaboration and progress between diverse stakeholder groups
- The ultimate purpose of healthcare is to serve patients; with this, patients have a unique convening power to facilitate cooperation, collaboration and progress between diverse stakeholder groups
- Failure to understand the healthcare ecosystem in its complexity means that change measures are unlikely to succeed
- Awareness of overlapping and non-overlapping interests as well as of respective constraints and limitations is essential to formulate win/win/win solutions, the only way for a complex adaptive system to evolve
- Understanding stakeholder groups' interests, concerns and constraints protects against co-option and being taken advantage of
- Collaboration is key
- Bark up the right trees and pick your battles wisely – set priorities and avoid dispersing your resources

WECAN Academy 2024

Session 4

Day 2

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

Policy Stakeholders | How does the EU Work? Who is responsible of what?

Richard Price, *ECO* | richard.price@europeancancer.org

WECAN SmartStart in Cancer Patient Advocacy

What is it about
This session covers...

This session will cover the who, the what and the why that patient advocates should know when it comes to EU advocacy.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

The European Union exists for its citizens. EU priorities such as Europe's Beating Cancer Plan and the EU Research Mission on Cancer should reach and support advances in cancer care in ALL countries and for ALL tumour types. But that will not necessarily happen by itself. It takes active advocates, including patient advocates, to draw the attention of policy-makers and decision-makers to the real needs and where the biggest impacts in policy can be made.

This session is designed to help support any patient advocate in any part of Europe get more involved in representing their case to the EU, and in helping EU project and policy support reach into their country.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

Important learnings will include:

- Anyone can get involved in EU advocacy
- Make a start
- EU policy matters for cancer, and EU policy can make a difference for your tumour and interest area – if you deploy strategy to make that happen.
- To support a long lasting connection to EU advocacy activity get involved with European and international level organisations active in EU activity.

WECAN Academy 2024

Session 5

Day 2

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

Data landscape: EHDS, federated data and governance

Teodora Lalova, *EORTC* | teodora.spinks@kuleuven.be

WECAN SmartStart in Cancer Patient Advocacy

WECAN MASTERCLASS in Cancer Patient Advocacy

What is it about
This session covers...

- The new data landscape: brief overview of the European Strategy for Data and the new legal acts stemming from it.
- Introduction to the European Health Data Space (EHDS), covering:
  - Its purpose & where are we now in the process of adopting it
  - The key elements of the regulation, particularly:
    - Primary and secondary use of health data: key rules (how, permitted and prohibited purposes…)
    - New roles and responsibilities: what are health data access bodies, data holders, data users, and what are their rights and obligations when it comes to (re)using health data
    - Is there a role for citizen and patient representatives
  - Why patient advocates should know and have an opinion about the new framework

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

The EHDS is an ambitious piece of legislation that will introduce a profound change into the way health data are exchanged and accessed across the EU, for purposes spanning healthcare, research, policy making and regulatory activities, and others. The new rules will have a lasting impact in the years to come, and as such it is of great importance of patient advocates to know what the new frameworks brings, what are the opportunities and risks it brings, and understand where they could play a role in its future implementation.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

- Understanding of what the EHDS is and what its main aims and rules are
- Awareness about both the opportunities and risks it brings for patients with respect to the use and access to their health data

Additional information on the session topic
References

Sources

EHDS regulation – compromise text

European Commission – resources, FAQ, and more about the EHDS

Online

EHDS blogpost series (KU Leuven Centre for IT and IP Law), ongoing.

Literature

Staunton, C., Shabani, M., Mascalzoni, D. et al. Ethical and social reflections on the proposed European Health Data Space. Eur J Hum Genet 32, 498–505 (2024)

Marelli L, Stevens M, Sharon T, et al. The European health data space: Too big to succeed? Health Policy. 2023 Sep;135:104861. doi: 10.1016/j.healthpol.2023.104861. Epub 2023

Lalova-Spinks T, Saesen R, Silva M, Geissler J, Shakhnenko I, Camaradou JC, Huys I. Patients' knowledge, preferences, and perspectives about data protection and data control: an exploratory survey. Front Pharmacol. 2024

WECAN Academy 2024

Session 6

Day 2

ADVOCACY TOOLS AND SKILLS

Financial Sustainability of your organisation

Katie Joyner, *MPE* | joyner@mpeurope.org

WECAN SmartStart in Cancer Patient Advocacy

WECAN MASTERCLASS in Cancer Patient Advocacy

What is it about
This session covers...

Maintaining the Financial sustainability of your patient organisation:

- Fundraising for patient organisations: Basic principles
- Identification and solicitation of funding
- Types of funding
- The importance of transparency

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Financial sustainability is critical to fuel our work. Without funding, and security in that funding and sound financial planning, the work organisations do to support patients, educate, and advocate for better access and treatment, as well as the thousands of other things in between, would not be possible. In order to have a strong advocacy community, we need strong patient organisations and comprehensive financial management is key to achieving that.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

This session will provide an introduction to fundraising, types of funding, budget planning, and key principles on working well with industry.

WECAN Academy 2024

Session 7

Day 2

ADVOCACY TOOLS AND SKILLS

NGO Governance: To avoid crisis in your organisation, ensuring transparency and integrity

Ananda Plate, *Patvocates* | ananda.plate@patvocates.net

WECAN SmartStart in Cancer Patient Advocacy

WECAN MASTERCLASS in Cancer Patient Advocacy

What is it about
This session covers...

- Things that can (and regularly do) go wrong in patient organisations.
- Preventing crisis in patient organisations.
- Crisis as an opportunity of organisational growth.
- Learning from mistakes, prevent them from happening again.
- De-escalating and getting back on track.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Most of us go into cancer patient advocacy with a strong mission. Many of us may have had a personal experience. Many find our way into patient advocacy with feelings of curiosity, anger, fear or sadness. We are driven by good intentions to change the status quo, or by the wish to prevent others from experiencing something similar.

An informal group of well-aligned patients and carers may soon formalise into a patient organisation. Being totally aligned in friendship and a shared mission, as well as full of energy to help others and the urge of getting things done, the establishment of good governance rules seems like a total waste of time or unnecessary bureaucracy. Why invest into something like this when everything is going so well?

This session will cover the importance of investing into governance in times when friendship and alignment are strong, as agreeing to governance rules will never be easier than then. These rules will be critical at times of disagreement and conflict, as they arrive in any NGO sooner or later, for example, when new board members bring new expectations or dissent, or when priorities of individuals change.

While governance rules may currently seem like a waste of time and unnecessary bureaucracy, they can ultimately save a patient organisation from internal divisions and potential dissolution in its first and subsequent crisis.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

- Good intentions do not prevent crisis
- Develop good governance rules
- Governance rules prevent/help manage a crisis
- Share your learnings with the community
- Learn from your own mistakes
- Learn from others
- Stay focused during / get back on track after a crisis
- Use crisis to grow

WECAN Academy 2024

Agenda

Day 3

RESEARCH AND DATA

8:30 - 9:30 — **How to ensure Patient Centricity in Clinical Trials**
Bettina Ryll, *MPNE*

RESEARCH AND DATA

9:30 - 10:30 — **Reading and Interpreting Scientific Data | Part I**
Gilly Spurrier, *MPNE*

10:30 - 11:15 — Coffee Break / Networking

RESEARCH AND DATA

11:15 - 11:45 — **Reading and Interpreting Scientific Data | Part II**
Gilly Spurrier, *MPNE*

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

11:45 - 12:30 — **AI, Light and Dark - Risks and reward in the age of the EU AI Act**
Andrew Evans, *MPNE*

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

12:30 - 13:15 — **Regulatory and Access**
Anne-Pierre Pickaert, *ALAN*

13:15 - 14:45 — LUNCH BREAK

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

14:45 - 15:30 — **Longterm Survivorship | Effects on financial, mental and social side**
Steve Pointon, *AKC*, and Tiago Costa, *CCIE*

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

15:30 - 16:15 — **Inequalities Advanced: Tackling and Addressing Inequalities | Diversity, Equity and Inclusion**
Katie Rizvi, *YCE*

16:15 - 17:00 — Coffee Break / Networking | Farewell of SmartStarters

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

17:00 - 17:45 — **EU Projects Landscape**
Norbert Couespel, *ECO*

20:00 — DINNER: PIC NIC Restaurant - Sitges

WECAN Academy 2024

Session 1

Day 3

RESEARCH AND DATA

How to ensure Patient Centricity in Clinical Trials

Bettina Ryll, *MPNE* | bettina.ryll@mpneurope.org

WECAN SmartStart in Cancer Patient Advocacy

WECAN MASTERCLASS in Cancer Patient Advocacy

What is it about
This session covers...

How can we as patient advocates ensure that clinical trials benefit the patients who participate in the trial as well as those outside the trial?

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

There is currently a lot of talk about 'patient-centricity' in clinical trials. However, what makes a trial truly patient-centric? And what can we as patient advocates do to ensure that clinical trials are good for our communities?

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

- Patient-centricity in clinical trials is more than having consulted patients in the trial design process
- The interests of clinical trial participants come first, before other parties' interests
- Patient advocates can directly and indirectly affect the design of clinical trials

Additional information on the session topic
References

Helsinki declaration

No other interest can take precedence- a patient perspective on oncology drug development

No other interest takes precedence

Clinical trials should optimise the chances of beneficial outcomes for all participating patients and reduce potential short-term as well as long-term harm.
Clinical trials should not interfere with a participant's ability to exert his or her rights, most importantly, to leave a clinical trial without fear of repercussions.
Clinical trials should not abuse the desperation and dependency of participating patients financially, time-wise or other unreasonable requests.
Participants should not be punished for participating in a clinical trial.
Clinical trial designs should not only consider internal but also external validity to ensure that results are applicable in a real-world context.
Clinical trial designs should not only address regulatory requirements but also the concerns of later decision-makers, notably Health Technology Assessment, HTA, bodies and payers.
Clinical trials should be registered and results communicated in a timely manner, including in lay- accessible language. Publications should be open access whenever possible to ensure broadest possible access and rapid learning.

WECAN Academy 2024

Session 2 & 3

Day 3

RESEARCH AND DATA

Reading and Interpreting Scientific Data | Part I and II

Gilly Spurrier, *MPNE* | gilliosa.spurrier-bernard@mpneurope.org

WECAN SmartStart in Cancer Patient Advocacy

WECAN MASTERCLASS in Cancer Patient Advocacy

What is it about
This session covers...

Finding and interpreting the latest science and research, reviewing it for your community, and getting into the practice of reading scientific papers. Knowledge is not just power but also protection.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Being up to date on the latest research in your cancer and knowing about upcoming treatments and development is vital for the patient community both to make sure patients are receiving optimum treatment and management and for effective advocacy. As Patient Advocates, this falls to us to know what information is useful, how to read and critique the published research and then to disseminate this effectively to your community.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

The session is in two parts – Part 1 is an Introduction to where to find good, safe scientific information, what it looks like, how to avoid the pitfalls into pseudoscience and how to disseminate back to your community. Part 2 is a workshop to practice these skills on real Scientific Publications from across Cancer Indications, to start the process of Reading Scientific papers and extracting the pertinent information. It is just Practice. At the end you will do an elevator pitch for your Research Paper.

Additional information on the session topic
References

Knowledge is protection - part 1

How to find the resources you need. And why you already have the tool. And it's not a list.

V2A2: A tool to promote patient agency through effective patient information

The Struggle against Cancer Misinformation

Common Terminology Criteria for Adverse Events (CTCAE)

WECAN Academy 2024

Session 4

Day 3

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

AI, Light and Dark - Risks and reward in the age of the EU AI Act

Andrew Evans, *MPNE* | aevans.wv@gmail.com

WECAN SmartStart in Cancer Patient Advocacy

WECAN MASTERCLASS in Cancer Patient Advocacy

What is it about
This session covers...

We are witnessing the dawn of a new technological era on par with the sweeping change brought about by the Internet itself - and maybe even more profound. It is happening very fast - 5-10x faster than Moore's Law (the rate of advancement in computer speed). It is also bringing forth very powerful - and potentially harmful - capabilities that offer both fantastic opportunities and dire risks at the same time.

What do we really mean by "AI"? What is it useful for and what are its limitations?

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Most information about the world of AI lags behind what is actually happening because of this dizzying rate of advancement. In this talk, I will attempt to give you a glimpse into what is happening right now, where it is likely going, what it means for patient care (and society at large). I will also illustrate some of the stark dangers we must watch out for - and how the EU is grappling with regulating them.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

The session will combine a slide talk with an extensive audience Q&A session, because our experience is that this topic generates a lot of questions!

WECAN Academy 2024

Session 5

Day 3

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

Regulatory and Access

Anne-Pierre Pickaert, *ALAN* | anne-pierre@care4access.fr

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What is it about
This session covers...

An introduction and overview of how cancer medicines are assessed in Europe, with a specific focus on the European Union. It will focus on the topics and following questions:

- Basics of the marketing authorization process. How is this done in Europe?
- How are national decisions made on access to medicines? (i.e., health technology assessment and reimbursement decisions)

Why do patient advocates need to know about these processes? How are patients involved in decision-making?

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Medicines regulation, marketing authorization and national access processes are essential to patients, as this is how medicines are made available and accessible to them. As advocates, we want to campaign for the best access to medicines for patients and, to do this, it is important to understand how these processes work and how to get involved in decision-making. There are also inequalities in access to healthcare and medicines across Europe, which patient advocates often aim to address. Knowing how drugs are bought to market in Europe can help advocates understand the root causes of these inequalities and begin to strategize on how to address them.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

Participants will gain:

- A general understanding of how the European Medicines Agency (EMA) assesses the safety and effectiveness of medicines for use in Europe and the role of national regulatory bodies.
- Information on reimbursement and health technology assessment processes and how this differs to the role of the EMA.
- Ideas for getting involved in access from a patient advocacy perspective.

Additional information on the session topic
References

European Medicines Agency resources on patient and consumer involvement

EUPATI Guidance for Patient Involvement in HTA

European Capacity Building for Patients – EUCAPA

HTA4Patients

Patient involvement in HTA in Europe

WECAN Academy 2024

Session 6

Day 3

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

Longterm Survivorship | Effects on financial, mental and social side

Tiago Pinto da Costa, *CCIE* | t.costa@ccieurope.eu

Steve Pointon, *AKC* | steve@actionkidneycancer.org

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What is it about
This session covers...

Psychosocial Challenges in Long Term Survivorship

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

You will hear some contributions of daily life survivors' challenges and to see how important it is to estimate psychosocial support beyond cancer. You will also learn some recommendations based on personal experiences of patient advocacy work.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

The oncological disease can change us and affect our social dimension.
Not only the physical aspects should be considered in the survivorship process. It is important to reflect on psychological and social aspects such as financial, employment and mental health issues.
Nevertheless, we should look for the best possible quality of life after cancer.
Creating the right message and identifying the right gatekeepers, such as other patient advocates or health professionals, can help us in the patient advocacy journey.

WECAN Academy 2024

Session 7

Day 3

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

Inequalities Advanced: Tackling and Addressing Inequalities | Diversity, Equity and Inclusion

Katie Rizvi, *YCE* | katie@youthcancereurope.org

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WECAN MASTERCLASS in Cancer Patient Advocacy

What is it about
This session covers...

This session covers the critical aspects of addressing inequalities in cancer care with a focus on Diversity, Equity, and Inclusion (DEI). We will explore strategies and recommendations to ensure fairness and inclusivity for marginalized and underserved populations, including racial, ethnic, and cultural minorities, refugees, migrants, LGBTQ+ individuals, and people from various socioeconomic backgrounds. The session will provide insights into improving patient data collection, fostering diverse representation in care teams, and promoting culturally sensitive care.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Cancer care must be equitable and inclusive to serve all patients effectively. Disparities in care can lead to poorer health outcomes for minority and vulnerable groups. By addressing these inequalities, we can enhance the quality of care, improve patient experiences, and ensure that all individuals receive the support they need. For patient advocates, understanding and tackling these issues is crucial in their day-to-day work to advocate for comprehensive and inclusive healthcare policies and practices.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

The key take-home message of this session is the importance of integrating Equity, Diversity, and Inclusion principles into all aspects of cancer care. Attendees will learn practical strategies to address inequalities, including improving data collection, fostering diversity in care teams, and providing culturally sensitive care. By implementing these strategies, patient advocates can help ensure that all cancer patients, regardless of their background, receive equitable and high-quality care. This session aims to empower attendees with the knowledge and tools to advocate for more inclusive cancer care practices and policies.

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Session 8

Day 3

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

EU Projects Landscape

Norbert Couespel, *ECO* | norbert.couespel@europeancancer.org

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What is it about
This session covers...

Cancer has received unprecedented policy attention at European level in the last 5 years, including through the launch of Europe's Beating Cancer Plan and the EU Cancer Mission. EU funding has been a critical vehicle for the implementation of these initiatives, leading to the launch of multiple calls and funding of numerous projects under the EU4Health and Horizon Europe. This session will aim at providing key elements of information on the EU funding process, the landscape of presently funded projects in the cancer space and the opportunities for future engagement.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Involvement of patients, patient advocates and patient representatives is crucial to ensure that cancer policy ambitions can turn into meaningful change in health systems, including via EU-funded projects. In this regard, a number of EU funding calls require the involvement of patient organisations in funding proposals, illustrating the recognition of the value of patient involvement by the EU.

EU funding processes can however frequently appear complex and the number of existing EU-funded cancer projects can make it difficult to get an overview of the landscape in the field, which has the potential to lead to suboptimal involvement and duplication of efforts. This session will aim at providing patient advocates with key tools to decipher the state-of-play in EU-funded cancer projects and leverage opportunities for engagement.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

While EU-funded cancer projects can appear complex and burdensome, they represent a historic opportunity to transform present EU cancer policy attention into long-standing progress for cancer patients and their families across Europe. Patient advocates are a critical part of the cancer community that are needed to make this happen in a meaningful way.

WECAN Academy 2024

Agenda

Day 4

RESEARCH AND DATA

8:30 - 10:00 **Patient Reported Outcomes and other Patient-Relevant Measures and Endpoints**
Tamas Agh, *SRI*

RESEARCH AND DATA

10:00 - 10:30 **Introduction: Hereditarity in Cancer**
Tamara Hussong, *EC*, and Bettina Ryll, *MPNE*

10:30 - 11:15 Coffee Break / Networking

RESEARCH AND DATA

11:15 - 12:15 **Evidence-Based Advocacy - Advanced: Overcoming hurdles, experience of EB generation**
Ana Amariutei, *EPAI,* and Jan Geissler, *EPAI*

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

12:15 - 13:15 **Pricing: Health Economics Advanced**
Stefan Weber, *AZ,* and Chris McCabe*, QUB*

13:15 - 14:45 LUNCH BREAK

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

14:45 - 15:30 **Workshop on EU Policy and the impact on PA | Role of PO**
Violeta Astratinei, *MPNE*, and Bettina Ryll, *MPNE*

ADVOCACY TOOLS AND SKILLS

15:30 - 16:00 **Not being the Victim of Hidden agendas**
Academy Programme Committee members

16:00 - 16:30 Farewell of Masterclass, End of the Event

WECAN Academy 2024

Session 1

Day 4

RESEARCH AND DATA

Patient Reported Outcomes and other Patient-Relevant Measures and Endpoints

WECAN MASTERCLASS in Cancer Patient Advocacy

Tamas Agh, *SRI* | tamas.agh@syreon.eu

What is it about
This session covers...

The session will focus on patient-reported outcomes (PROs), other patient-relevant measures, and endpoints, all discussed from the perspective of patient advocates. Participants will gain an in-depth understanding of various PRO types and measurement methodologies. We will address the challenges of PRO administration in both research and clinical settings, and explore how to analyze and report PRO results to meaningfully influence future patient care.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

This session explores the integration of patient-relevant measures in patient advocacy, emphasizing their role in enriching our understanding of disease impact and treatment effectiveness from the patient's viewpoint. PROs and other patient-relevant measures are essential in capturing information on patient experiences, functional abilities, and quality of life, providing a necessary complement to clinical outcomes. However, measurement of PROs in clinical trials and clinical practice is still an emerging field. Challenges include the lack of meaningful PRO instruments or their inadequate utilization, hindering their accurate assessment. Incorporating PROs as endpoints in clinical trials supports regulatory decision-making, influences treatment choices, and aids in the development of guidelines, thereby enhancing day-to-day patient advocacy efforts.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

Participants will gain insights into:

- The differences between PROs, measurements of PROs and patient-reported experiences (PROMS, PREMS)
- The difference between quality of life and health related quality of life
- The proper measurement of PROs by exploring various types of PRO tools, including generic, symptom-specific and disease-specific measures
- Cutting-edge methods for collecting PRO data, such as electronic PROs (ePROs)
- Applications of PROs in clinical trials and clinical practice
- Involvement of patient advocates in selecting meaningful PROs, analyzing and disseminating clinical trial results, demonstrating their critical role

WECAN Academy 2024

Day 4

Session 2

RESEARCH AND DATA

Introduction: Hereditarity in Cancer

WECAN MASTERCLASS in Cancer Patient Advocacy

Bettina Ryll, *MPNE* | bettina.ryll@mpneurope.org

Tamara Hussong, *EC* | tamara.milagre@evitacancro.org

What is it about
This session covers...

About 10-15% of all cancers are considered to be hereditary, so can be passed on from one generation to the next, with direct implications for their patients and families. This session will cover the basic concepts underlying hereditarity in cancer and discusses advocacy actions in support of patients with hereditarity cancer.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Hereditarity in cancer concerns all cancer communities as it consistently affects a subgroup of patients. Understanding the basic underlying genetics as well as the implications for patients and their families is therefore important to adequately support affected patients and to inform advocacy actions.

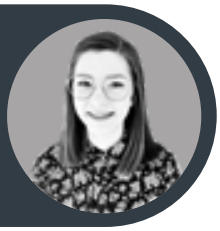
Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

- Understanding the importance of hereditarity in cancer
- Understanding of basic terminology: genotype, phenotype, monogenic, polygenic, penetrance
- Get to know important advocacy topics around hereditarity in cancer

WECAN Academy 2024

Session 3

Day 4



RESEARCH AND DATA

Evidence-Based Advocacy - Advanced Overcoming Hurdles, Experience of EB generation

Jan Geissler, *EPAI* | jan.geissler@patientadvocacy.eu
Ana Amariutei, *EPAI* | ana.amariutei@patientadvocacy.eu

WECAN MASTERCLASS in Cancer Patient Advocacy

What is it about
This session covers...

This session focuses on evidence-based advocacy which involves the utilization of research and data to support and promote practices, policies and recommendations that are grounded in evidence. During this session we will go through how to set-up an evidence generation project and how to use patient data for advocacy.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

The patient community is uniquely positioned to advocate for patient needs, values and preferences. However, individual stories and opinions may lack the efficacy to persuade researchers, healthcare professionals or regulatory decision-makers. To ensure that healthcare truly aligns with the needs of the patients, patient advocates should generate and disseminate robust evidence. We know that evidence-based advocacy is increasing with more and more organisations generating and publishing evidence however, the process is often not well targeted, planned or strategic.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

- Evidence is essential for progress and it enables a variety of stakeholders to build upon existing knowledge and make informed decisions that drive innovation and improvement.
- Evidence-based advocacy integrates research, data and expert analysis into decisions that aim to enhance effectiveness and credibility of advocacy efforts.
- As advocates we should implement evidence generation with a clear and common purpose. The focus of an evidence-based advocacy project should be on the impact you want to have and that will guide the evidence needed to be generated.
- Emerging trends and innovations in evidence-based advocacy, such as big data analytics, digital advocacy tools and different means of engagement are essential for staying informed and updating strategies.

WECAN Academy 2024

Session 4

Day 4

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

Pricing: Health Economics Advanced

Stefan Weber, *AZ* | stefan.weber@astrazeneca.com
Chris McCabe, *QUB* | c.mccabe@qub.ac.uk

WECAN MASTERCLASS in Cancer Patient Advocacy

What is it about
This session covers...

This session considers the challenges that health systems face in providing access to the many new health technologies that are coming to market. It will provide participants with a conceptual model for thinking about what a fair price might look like, explore the roles of risk and uncertainty in price determination, as well as the dynamic effects of prices on investment in future innovation.
We will look at the complex balance between the goal to enable timely access, meet local affordability and willingness to pay while maintaining global equity in funding R&D, and meeting investor expectations.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Media coverage of access to specific drugs often present the issue as one of whether an identified individual's life is not worth price that the company charges for the product. These cases occur when the drug pricing system has failed. A sustainable and fair drug pricing system cannot be founded on individual stories and cannot operate on the front (web)page of newpapers. The processes and considerations that drive drug prices are multi-factorial and complex. Advocates must understand this to be effective partners of both the private and public sector actors in drug price determination processes.
We will investigate the value of cancer medicines but at the same time will portray a critical view of "value-based-pricing" by highlighting systemic issues and internal / external constraints limiting such practice.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

This session will provide participants with answers to the following questions:

- Is it ethical or efficient that prices and access vary between countries and health systems?
- How can we think about a fair price for drugs?
- What is the relationship between current drug prices and future innovation?
- Can health care payers use this relationship more effectively?

WECAN Academy 2024

Session 5

Day 4

HEALTHCARE SYSTEMS, POLICY, AND ACCESS

Workshop on EU Policy and the impact on PA | Role of PO

WECAN MASTERCLASS in Cancer Patient Advocacy

Violeta Astratinei, *MPNE* | violeta.astratinei@mpneurope.org

Bettina Ryll, *MPNE* | bettina.ryll@mpneurope.org

What is it about
This session covers...

Opportunities for patient organisations to participate in European projects are dramatically increasing. What does it take to be a successful consortium partner and what can we as patient organisations concretely contribute? This session will give an introduction with tips& tricks from a patient organisation that has been there, followed by a hands-on task of how to effectively generate patient input for a concrete project.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Patient participation is becoming increasingly sought after but comes with both considerable demands on organisational capacity as well as unique opportunities for patient organisations to define their role within a consortium to ultimately improve outcomes for patients.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

- EU projects are a great opportunity for patient organisations
- EU project participation requires administrative capacity but there are Lessons Learned from colleagues
- Opportunity to find novel ways to improve outcomes for patients

Additional information on the session topic
References

iToBoS seminar on the same topic:

https://www.youtube.com/watch?v=-5vRXfo2g5A

WECAN Academy 2024

Session 6

Day 4

ADVOCACY TOOLS AND SKILLS

Not being the Victim of Hidden agendas

Academy Programme Committee members

WECAN MASTERCLASS in Cancer Patient Advocacy

What is it about
This session covers...

A light-hearted look at the various stakeholders that Advocates must work with to get better outcomes for patients, and some of the hidden agendas you may encounter. This is done as a role play by some experienced WECAN Advocates.

Why is it important
Why this session is necessary and where is the impact for the day-to-day work in patient advocacy

Since this is our final session, we think it is good to leave with a lighthearted look at some of the pitfalls we find dealing with other stakeholders in Cancer Patient Advocacy.

Key take-home message
A brief and to the point explanation of the sessions content and most important learnings

Everyone has a hidden agenda or a vested interest – even patients have a vested interest, all-be-it one of the most valid: they just want to survive their cancer relatively unscathed. Most Stakeholders are decent people with different pressures and constraints on them. The trick is to get a feel for what these are with every stakeholder, attempt to make sure there is a return on engagement for everyone, try to make everyone look good and navigate the Advocacy minefield.

WECAN Academy 2024

Organising **Team**

We are thrilled to introduce you to the dedicated team behind the WECAN Academy 2024. Each member brings a wealth of experience and expertise to ensure your time at the event is as smooth, informative, and enjoyable as possible.

Feel free to approach any of us with your questions or concerns. We are always happy to assist and make your WECAN Academy experience truly exceptional.

Sara Dederichs

Linda Silva

Ana Amariutei

Gina Ubide

Francisco Mena

Rebeca Castiñeira

Paula Capparelli

Sara Rossi

THERE IS
NO SHORTCUT
TO
KNOWLEDGE

WECAN Academy

Thank You

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