



International Alliance of
Patients' Organizations

A global voice for patients

g #IAPC2016



**'Innovation improving sustainable access:
boosting your reach and impact'**

7th Global Patients Congress

The Report



An introduction

It is my great pleasure to present this Global Patients Congress 2016 report to you. As anticipated, the event turned out to be a great success judging from the comments shared with the Governing Board and I.

This year we hosted a strongly member-led Congress, tapping into the expertise of IAPO members from all fields and locations. The programme was led and shaped by members and supplemented with invited expert speakers, researchers, industry partners, and health authorities bringing cutting edge insight alongside the rich patient experience shared.

The official Congress theme was 'Innovation improving sustainable access: boosting your reach and impact'. Delegates shared their stories, experiences, successes and skills with each other. Many returned home with a greater understanding of the key issues and challenges faced by others, new ideas to apply to their own situations, and a stronger resolve to support each other in the coming years on key issues.

Many delegates formed lasting friendships, contacts and partnerships with other patients' organizations, experts, industry partners and academics too.

This report outlines the main narrative of the Congress: who attended, who spoke, and the four main themes which emerged across the three day event. The themes provide insight into some of the biggest issues facing patients across the globe - we hope they prove useful as you plan for the future.

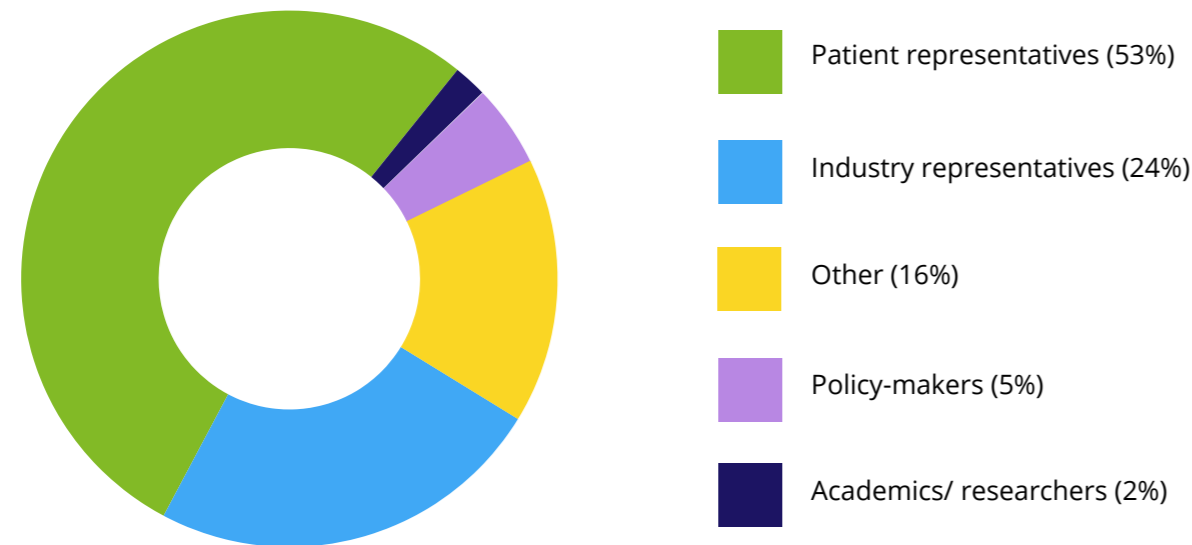
I thank the delegates, board members and IAPO staff, Novus (the logistics and organizer), the hotel staff, and industry partners who supported us generously once again to achieve this great event.

Jolanta Bilińska, IAPO Chair.

Who attended?

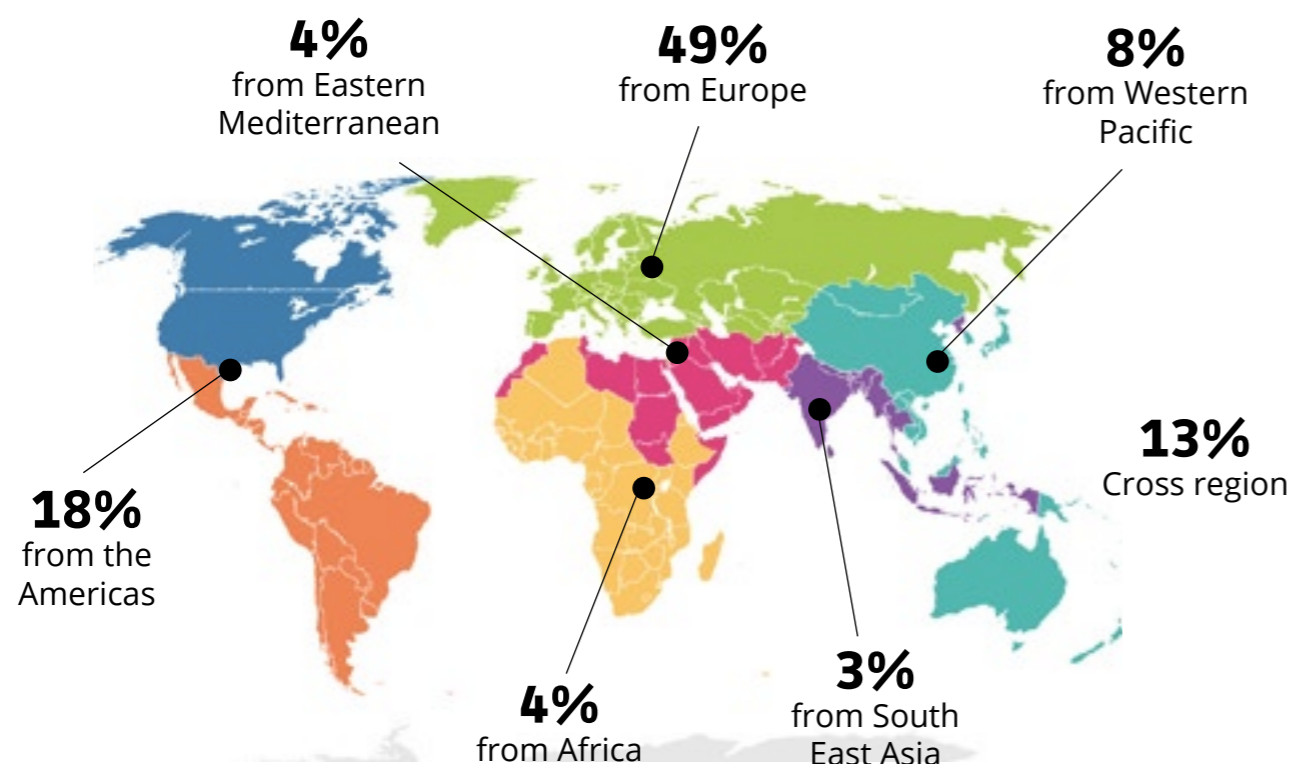
Delegates by field

136 delegates from different backgrounds and groups attended the Congress.



Delegates by region

Delegates came from all over the world. For a full list, please see the handbook at <https://www.iapo.org.uk/gpc-resources-media>



Key themes

1: Patients' role in decision-making processes

Patients' involvement in many forms

The patient's role in decision-making processes consistently came up in presentations, sessions and discussions at Congress. Most of the decisions taken and implemented in the healthcare system end up significantly affecting the lives of patients. Therefore, patients should be actively involved throughout every stage of these decisions.

Patients provide invaluable insight that no other group can provide, and it is essential that decision makers become more aware of what matters to patients. Patients can also play a role in providing the evidence needed to influence practices and policies from the patient point of view.

Creating the conditions for patient involvement in decision-making processes

For patient involvement to be real and effective, several conditions must be met.

- Change can only occur if decision-makers are convinced about the necessity and urgency of undertaking practical actions aimed at fulfilling patient-centredness.
- Patients are urged to speak with a credible voice within the healthcare system in order to be taken seriously by decision-makers. This can only be fulfilled if the causes patients stand for are supported by robust and reliable evidence.

A matter of will

Patient-centredness does not exclusively mean making sure that decision-makers and others develop and implement plans with the patients' best interest in mind. As many of our members have made unequivocally clear, patients should not simply be put at the centre of healthcare. They should be able to actively pursue patient-centredness by taking ownership of their own healthcare.

Too often is it misleadingly assumed that patients need to be persuaded, convinced, or even pulled into working in collaborations with other health partners. Patients do want to be part of the conversation. They want to be involved in research. They want to have a say in policy making. If appropriate and satisfactory guarantees are provided in terms of safety, security, privacy and protection, patients are willing to contribute data to clinical research. They also want to have that data accessed and used by researchers in order to try and improve the lives of patients both today and tomorrow.

Key questions raised during Congress

Congress has posed a number of key questions and concerns. How can patients' voices be made increasingly credible? In what ways can patients speak with one, stronger voice without undermining the variety and plurality of their needs, preferences, and values? And finally, what are the best strategies to maximize patient impact on decision-making mechanisms?

Our members believe that these aspects constitute important cornerstones of a long-term process. Patients will be able to govern and actively guide this process by developing appropriate skills, being part of strong training programmes, and by actively working within high-quality networks.

Although it is not possible to predict how this process will unfold, one thing is for sure. The way in which those concerns will be tackled and those questions answered will be crucial in determining the role patients will play in the healthcare system of the future.

2: Stakeholder Engagement

Understanding stakeholders' needs

Patients do not operate in a vacuum and working with relevant stakeholders in health systems is needed to influence change. IAPO members wanted to better understand the nature and needs of other groups, particularly how patients' organizations can work with the World Health Organization (WHO) and other key decision-makers.

Credibility and access to stakeholders

Many delegates acknowledged that patients' voices need to be credible when making their needs and preferences known. Engagement with others will happen more and more as patients are further equipped and increasingly credible on a range of issues.

Kathy Kovacs Burns from Best Medicines Initiative in Canada emphasized the need to use patient experiences as data to influence decision-makers, but only if it can be crafted and presented as reliable and usable in decision-making processes. By aligning stories and results in this way, decision-makers will pay more attention, and the patient organization will achieve greater influence and impact.

CASE STUDY: European Patient Ambassador Programme

Kerstin Morrison, from the European Lung Foundation, presented the work of the European Patient Ambassador Programme (EPAP). The programme provides an entry-level course for patients and carers with a chronic condition to develop the skills and knowledge for effective patient involvement. This has resulted in empowered and well-informed patients, many of whom have gone on to take part in conferences and meetings, nationally and internationally, as credible patient advocates. ([http://www.europeanlung.org/en/projects-and-research/projects/european-patient-ambassador-programme-\(epap\)/home](http://www.europeanlung.org/en/projects-and-research/projects/european-patient-ambassador-programme-(epap)/home))

Other programmes such as the European Patients' Academy on Therapeutic Innovation (EUPATI) (presented by Tamas Bereczky), are training patients in research and development. The course states that patients should know their bodies best and be equipped to take an active role in all facets of healthcare, moving them towards 'expert patients' empowered by the new information and skills they have gathered.

Consistent communication

Members raised the need to establish consistent communication between patients across different countries and healthcare systems. Flora Raffai from Findacure stressed the value of learning from each other so that patients can make their views better known to new audiences. Her advice was for patients' organizations to properly assess the needs of those they work with, avoid reinventing the wheel, look for help in unusual places, and finally, to think big – big ideas do not need big budgets!



**“Change can only occur if stakeholders and decision-makers are convinced of the need and urgency of taking action”
-- Kathy Kovacs Burns**



“Create an environment for [patients] to contribute, they can bring a lot to the table.”
- Nittita Prasopa-Plaizier

3: Effective advocacy

When patients have the opportunity to speak out, and to work collaboratively with health providers and decision-makers, big changes can happen. Policies, laws and systems can change. This is advocacy.

Communication

Good communication is essential for raising awareness and maximising impact. This can be achieved by promoting campaigns through networks, social media tools, or using well-known figures to generate publicity. Communicating with other patients' organizations or stakeholders with similar aims can be helpful too, even when others have different ideas on how to best generate impact.

Some choose to share best practice while others may deal with organizational and governance issues. 'Skin Deep', created by the Canadian Skin Patient Alliance, was a campaign designed to locate gaps in access to dermatological care and treatment across Canada. The campaign graded each Canadian province on provision of care and and shared the information as report cards, generating awareness and coverage nationwide. Appropriately communicating the impact of projects is essential too.

Collaboration

Collaboration is a key for growing awareness. Working with the media is useful for putting forward and creating support for patients' views in a more credible way. Elena Ruiz de la Torre suggested using key words and messages that specific journalists are interested in and will pick up. Anne Charlet, from Lupus Europe, explained that patients and patient groups must remain in touch with their first goal - 'for the patients, by the patients' - with these acting as the support base. In addition, patients have their own networks (social, professional etc.), and already have an active interest in the issues affecting them and others.

CASE STUDY: The Patient Shouting Café (PSC), South Korea

The Korean Alliance of Patients' Organisations (KAPO) was involved in the Patient Shouting Café (PSC), a programme set up for patients to voice opinions, experiences, and seek solutions from advisory experts. As well as greater visibility of patient issues through media coverage, PSC aims to bridge the gap between patients' issues and the legal system.

The project involves 'shouting, healing and solutions'. Patients or their families share their stories and sufferings, bond emotionally with listeners, and seek solutions with the advisory board's recommendations (composed of lawyers, patient representatives and doctors). Some of these suggestions are implemented by KAPO. One example is the story of Chong-hyun Chung, a boy who died from erroneous medication, told by his mother. After this, through a petition and work with KAPO, the Patient Safety Act was introduced in Korea in 2014. The success of the PSC demonstrates that many patients are willing to personally speak out about the issues they face, and that communicating well and collaborating with others will lead to effective advocacy. (www.koreapatient.com)

4: Patient information

Quality of information for patients

Quality of information for patients was a recurring theme throughout Congress. Ofra Balaban, from CHEN (Patient Fertility Association), said that 'effective patient empowerment relies upon practical advice and information.' Without accurate, accessible information, patients cannot be empowered to take part in or improve healthcare. The responsibility lies with both patients and providers.

The consequences of a lack of information

Lack of patient information can have dire consequences. IAPO members from many countries including Uganda and the Philippines flagged it as one of the biggest challenges in their regions. Millions of people are unaware of dangers and diseases, unaware of their rights, and vulnerable as a result.

Lack of patient information materialises in other ways too. Tamás Bereczky, from the European Patients' Academy on Therapeutic Innovation (EUPATI), commented that many patients lack knowledge on certain aspects of healthcare such as medicine research, clinical trials and drug development. EUPATI is helping to change this and has provided 150+ hours of e-learning and two four-day sessions to two groups of 50 participants, open to patients, carers, patient advocates and volunteers.

The patient's responsibility: moving from passive to active

Patients have a responsibility to become more active in their healthcare. Victoria Pinkney-Atkinson highlights several key areas for this: patients must grow in health literacy (which builds decision-making), communication skills (which builds connection with other stakeholders), and access to information (which improves self-management of condition). Patients should be equipped to function as 'watchdogs, not lapdogs!'

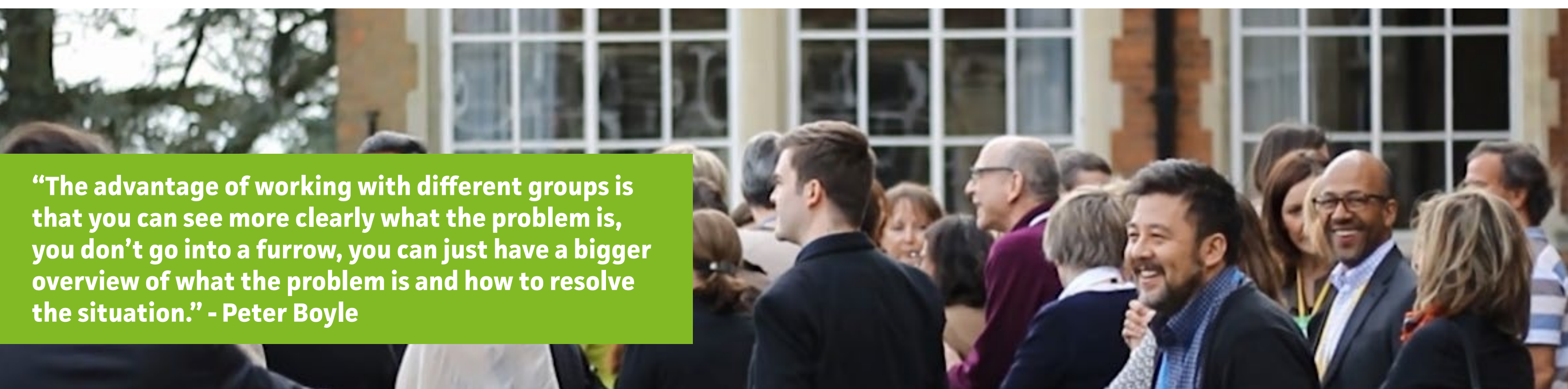
Penney Cowan, from the American Chronic Pain Association (ACPA), explored how patients can be a bigger part of their healthcare team, and use tools to gather their own information – data that can be shared with healthcare professionals to improve quality of life. The ACPA launched a mobile app called 'Live Better with Pain Log', which allows users to track everyday things such as stress levels, sleep and medication that have an impact on pain. The information can then help patients get the most out of limited time with healthcare providers, but give them detailed, useful information. (<https://theacpa.org/painLog/default.aspx>)

The provider's responsibility

Healthcare providers have a responsibility to equip and involve patients in healthcare by providing more user-friendly and accessible information. Professionals at all levels should shape their patient information and health policies on the insight of patients too. Patients' groups can provide unique insight on the 'real needs' of patients including gap analysis in research priorities, clinical trial design and research policy.

During the session on building effective networks, Anne Charlet, Lupus Europe, argued that healthcare providers should pay more attention to discussing the range of methods used to adequately capture patients' perspectives. Regardless of how strongly patients feel about something, many can still be reluctant to share their views if they do not feel comfortable with the method being used to collect this information. Providers should identify what they want to achieve, how it can best benefit patients, and the best way to gather the data (e.g. survey, focus group, forming committees and consultations).

Anne also highlighted the need for genuine engagement from providers when it comes to gathering patient information. The sharing of knowledge is one of the main drivers for patient participation, and this should be embraced. There must be a willingness to listen to patients, to implement suggestions and demonstrate impact. Providers must treat patients as equals, explaining the reasons behind every step taken, and this will typically lead to greater participation.

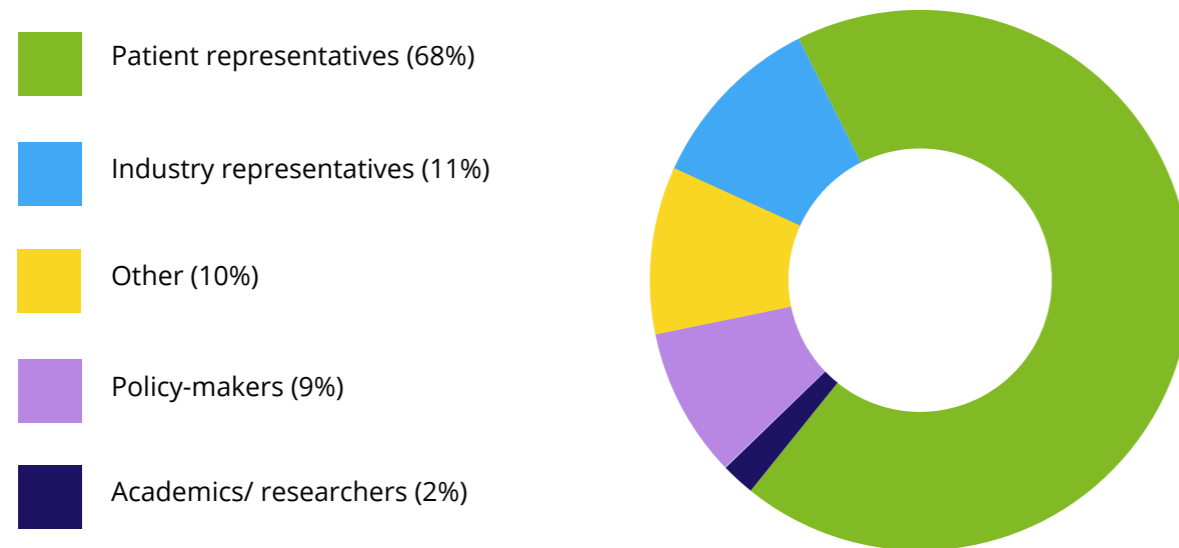


“The advantage of working with different groups is that you can see more clearly what the problem is, you don't go into a furrow, you can just have a bigger overview of what the problem is and how to resolve the situation.” - Peter Boyle

Speakers

Speakers by field

Congress brought together speakers from a range of fields. The majority of these were patients' representatives.



Speaker details

Many Congress speakers shared their presentation slides with IAPO for publication. They are available at: <https://www.iapo.org.uk/gpc-presentations>

Biographies of speakers are available at: <https://www.iapo.org.uk/gpc2016-speakers>

Digital impact

During Congress, many delegates used the **#GPC2016** hashtag to share quotes, photos, highlights, and take part throughout the weekend. The hashtag reached an estimated 261,521 people on Twitter alone, not including reach on Facebook and other social media sites.

IAPO hired a photographer to cover the event and the photos are available at: <http://bit.ly/1Qsey10>

A Congress video was also created and is available at: <https://www.iapo.org.uk/global-patients-congress>

Sponsors

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Novartis and GSK also sponsored a number of delegates to attend the Congress.



<https://www.iapo.org.uk/global-patients-congress>



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49-51 East Road, London N1 6AH, United Kingdom
Telephone: +4420 7250 8280 | Email: info@iapo.org.uk