



Patient and family empowerment to protect and promote patient safety:

THE PATIENT PERSPECTIVE

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The banner features the EAASMedS logo (European Alliance for Access to Safe Medicines) on the left and the ECAMET logo (European Collaborative Action on Medication Errors and Traceability) on the right. The central text provides the event details.

European Alliance for Access to Safe Medicines
EAASMedS

ECAMET
European Collaborative Action on Medication Errors and Traceability

Tuesday, 22 March 2022, 11:30 - 13:30 CET
Hosted by MEP Tomislav Sokol (EPP, Croatia) and the European Alliance for Access to Safe Medicines

Virtual event

International Alliance of Patients' Organizations (IAPO) at a glance

In 2020, IAPO established **IAPO Patients for Patient Safety (P4PS) Observatory** as a single-point global platform for gathering and analyzing **patients' expertise and experience** that would feed into the **national, regional and global policies** aimed at **improving safety and quality of care for patients by the patients**



VISION

To see patients at the center
of healthcare



MISSION

To build patient-centered
healthcare worldwide

286

members

>1M

patients

71

countries

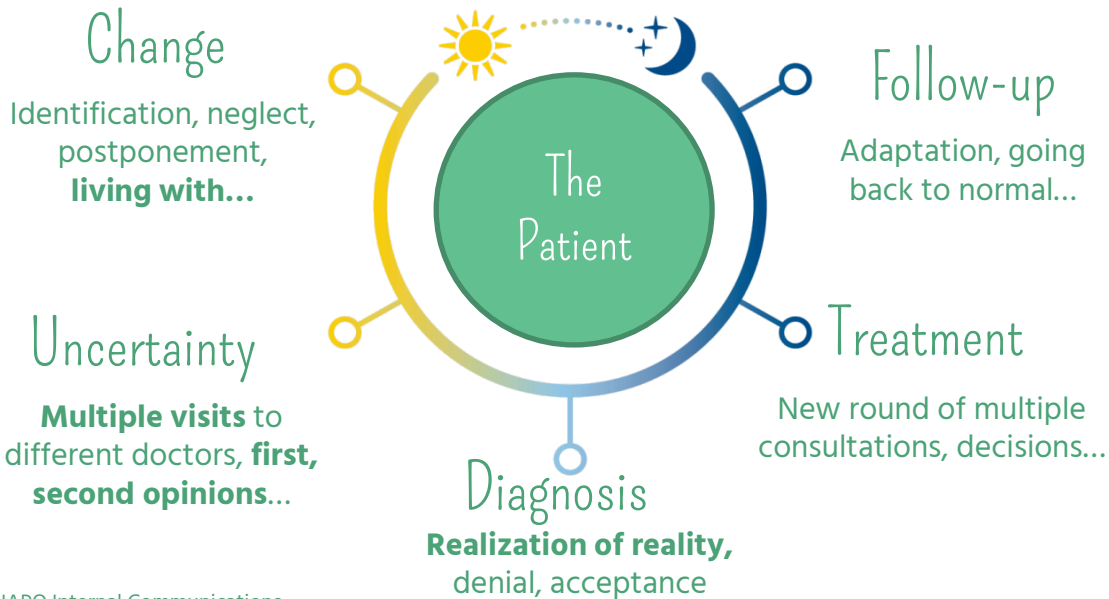
52

diseases
areas

The patient

*The good doctor treats the disease;
the great doctor treats the person who has the disease*

(Sir William Osler, 1849-1919)



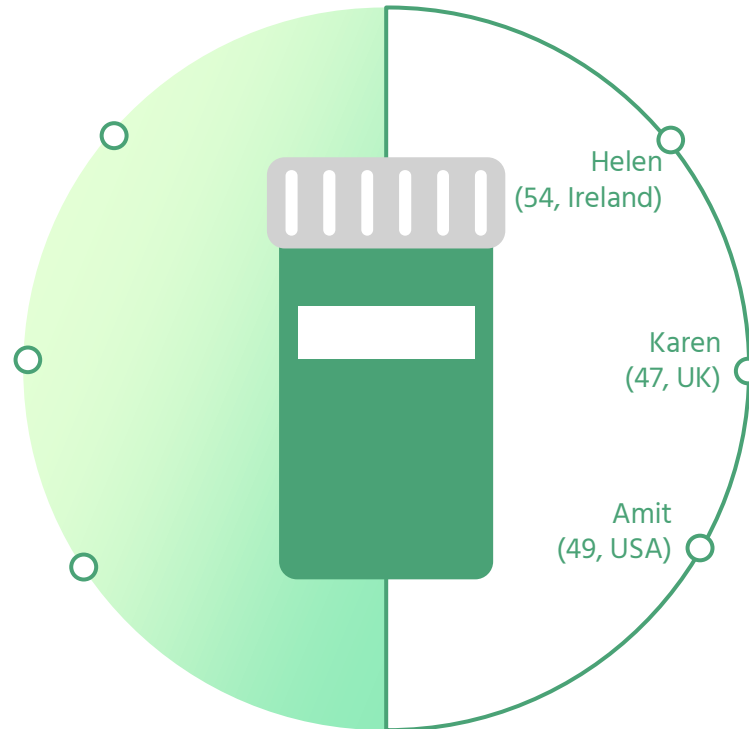
The patient – the two sides

The clinical

Rapid analysis of 154 studies.
Antibiotic data were available
from 30, 623 patients¹

The prevalence of
antibiotic prescribing
74.6% (95% CI 68.3 - 80.0%)¹

Estimated bacterial co-infection
8.6% (95% CI 4.7 - 15.2%)
from 31 studies¹



Helen
(54, Ireland)

Karen
(47, UK)

Amit
(49, USA)

The not so clinical

[Prescribed azithromycin] “as a
prophylactic by a doctor specializing
in respiratory medicine (due to
my asthma)”²

“I think the antibiotics made it worse – it
cleared out my guts; it got rid of most of
the bacteria, so I think the virus started
invading even there too”²

“I didn’t ask for it. You couldn’t get a
doctor appointment; telehealth was
the only option”²

1. Langford, BJ et al., *Clin Microbiol Infect.* 2021; 27(4):520–531;

2. Dahal D, et al., *JAC-Antimicrobial Resistance.* 2021; 3(1):1–3.

Paul's experience

I had severe stomach problems, ended up going to hospital and had surgery for an intestinal issue which lets me go on into **sepsis and septic shock**.

**My recovery was quite long...
I spent about**

10 Weeks

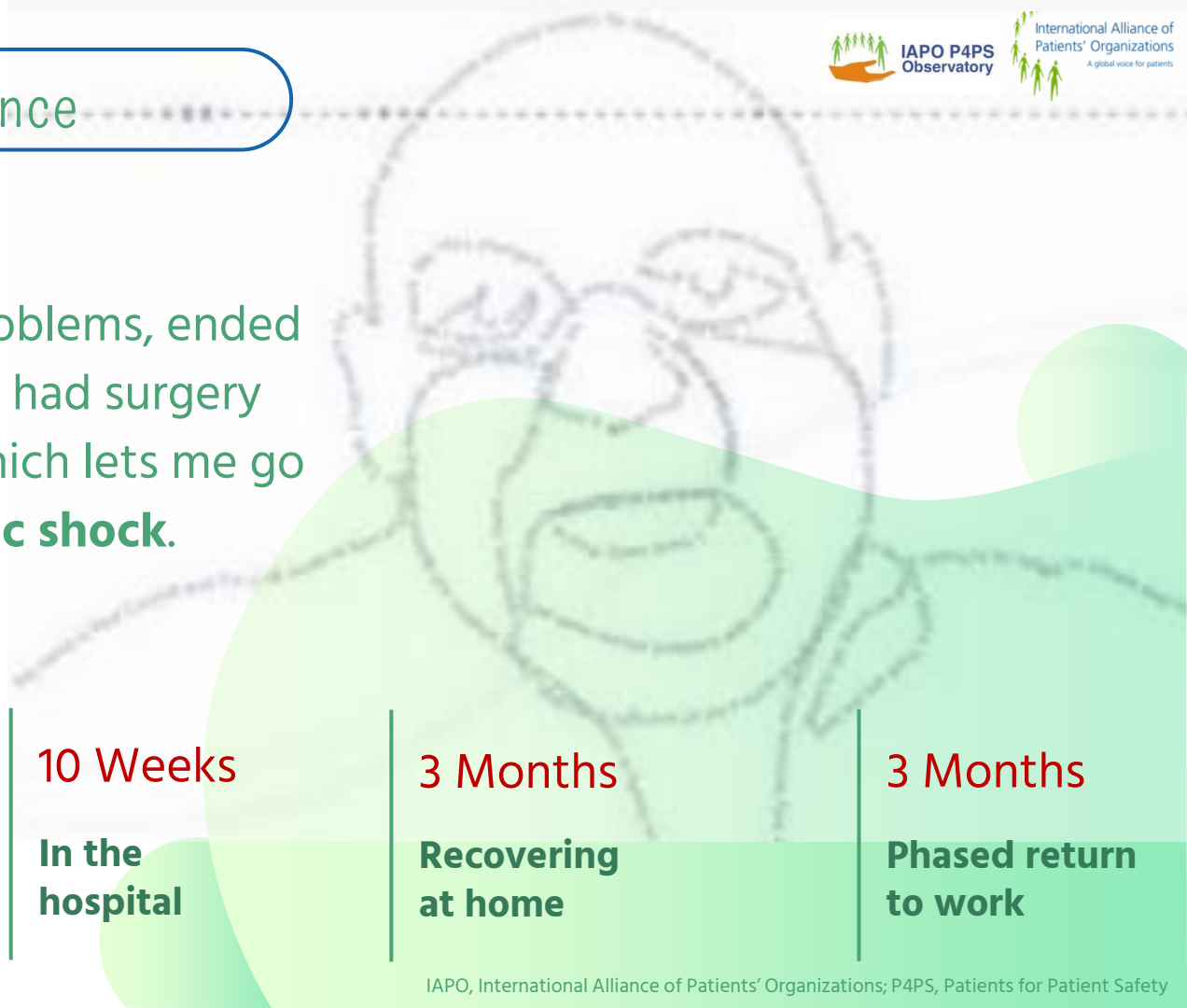
**In the
hospital**

3 Months

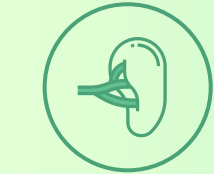
**Recovering
at home**

3 Months

**Phased return
to work**



Jessica's journey



Follow-up



When I was discharged, I never received any information about what my body has just gone through.

I never had a follow-up from my GP... had to find out what I'd been through by myself.

Capturing patient experiences

IAPO P4PS Observatory

Development agencies,
patient organizations, academia

Actual prevalence and incidence of
patient safety (rarely captured)

Disclosed patient safety
(survey-based data)

Reported patient safety
(administrative data)

Official statistics

Global/Regional level

- Global Health Observatory
- Regional data hubs
- European HSP Observatory

National bodies

National governments

National level

Capturing patient experiences – the six roles

Research participant

- Contributes with biological material or participates in clinical trials

Insight provider

- Provides information for use in a clinical trials and behavioural studies

Advisor

- Gives advice or participates as member of clinical research committee

Reviewer

- **Reviews** patient-related content and lay summary of research data

Co-designer

- **Designs** projects, gathers data and translates research results

Driving force

- **Collaborates** in projects, **influences** policy making and implementation

Substantial lack of
patient-led research
creating a gap in
ground-level data

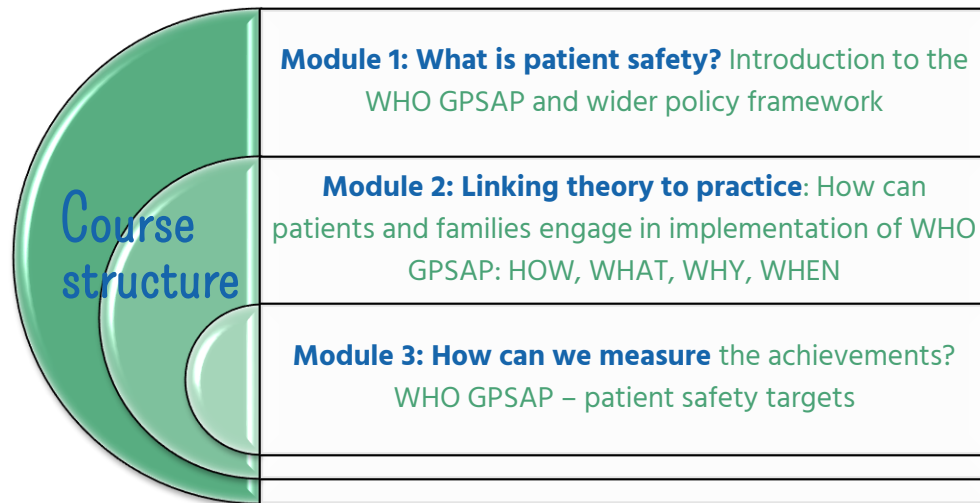
Patient and family empowerment: Patient Safety Advocacy Course

Course objectives

- **Develop capacity to understand the WHO GPSAP 2021-2030, and be able to engage at national and local levels**
- **Strengthen awareness on the WHO GPSAP 2021-2030 existence, and how to engage**
- **Empower for engagement in research and involvement in patient safety programs**

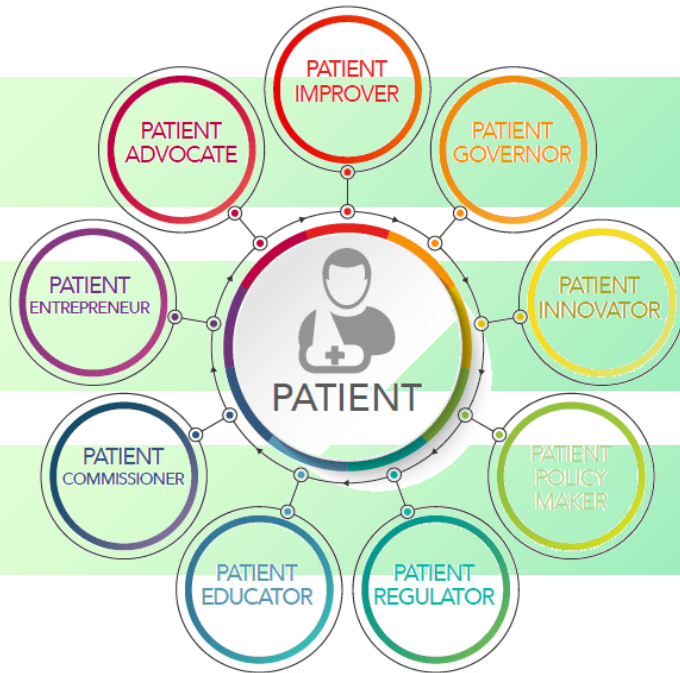
Topic 1: Patient Safety as key element of universal health coverage.

Mark as done



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In summary



01

Patients come to the healthcare system not just with a disease, but with cultural and traditional values, habits and beliefs

02

Patients observations and lived experience can be invaluable in preventing harm or complications

03

Societies should strive to create systems for and with people not systems structured around diseases and facilities



**IAPO P4PS
Observatory**



Thank you

Do you have any questions?

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IAPO, International Alliance of Patients' Organizations; P4PS, Patients for Patient Safety



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