PATIENTS SCIENCE INDUSTRY

By the end of my 10 minutes, you will learn..

- What **IPPOSI** stands for?
- How Patient Experience Mapping **is relevant in/across Europe**?
- Importance of integrating **Patient Experience Data** with **Patient Engagement**

IPPOSI

PATIENTS SCIENCE INDUSTRY

Irish Platform for Patient Organisations, Science and Industry

IPPOSI is a patient-led organisation
that works with patients, science & industry
to put patients at the heart of health innovation

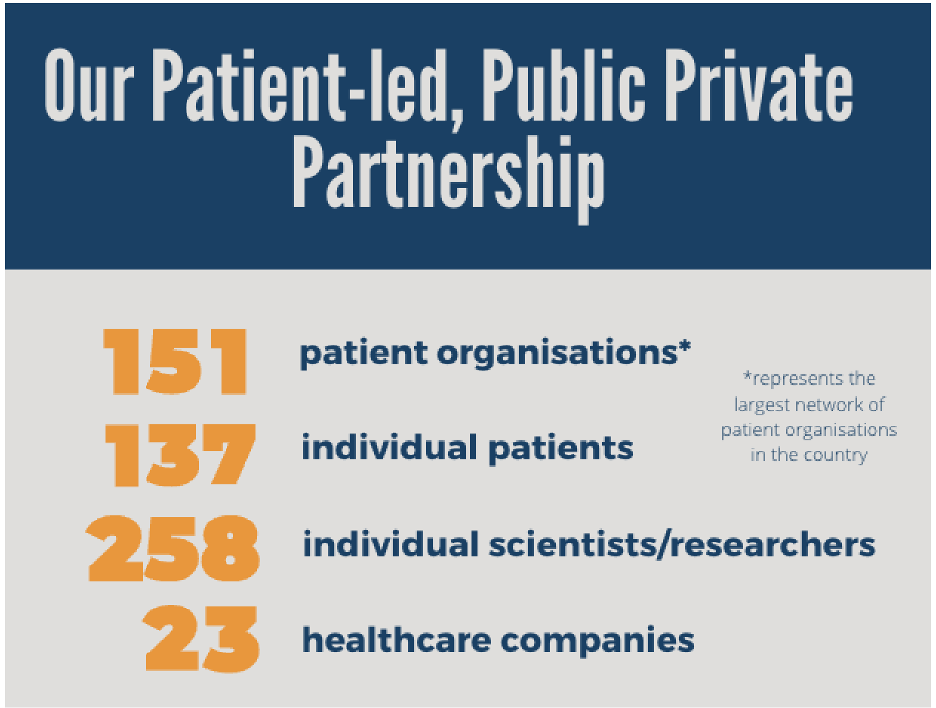
IPPOSI

What IPPOSI does, and how?

EDUCATION

ADVOCACY

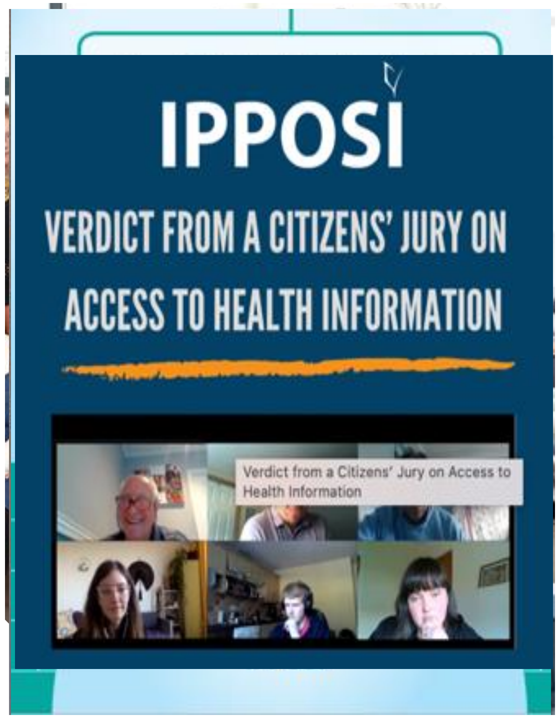
INSIGHT



Our Patient-led, Public Private Partnership

151	patient organisations*
137	individual patients
258	individual scientists/researchers
23	healthcare companies

*represents the largest network of patient organisations in the country



IPPOSI

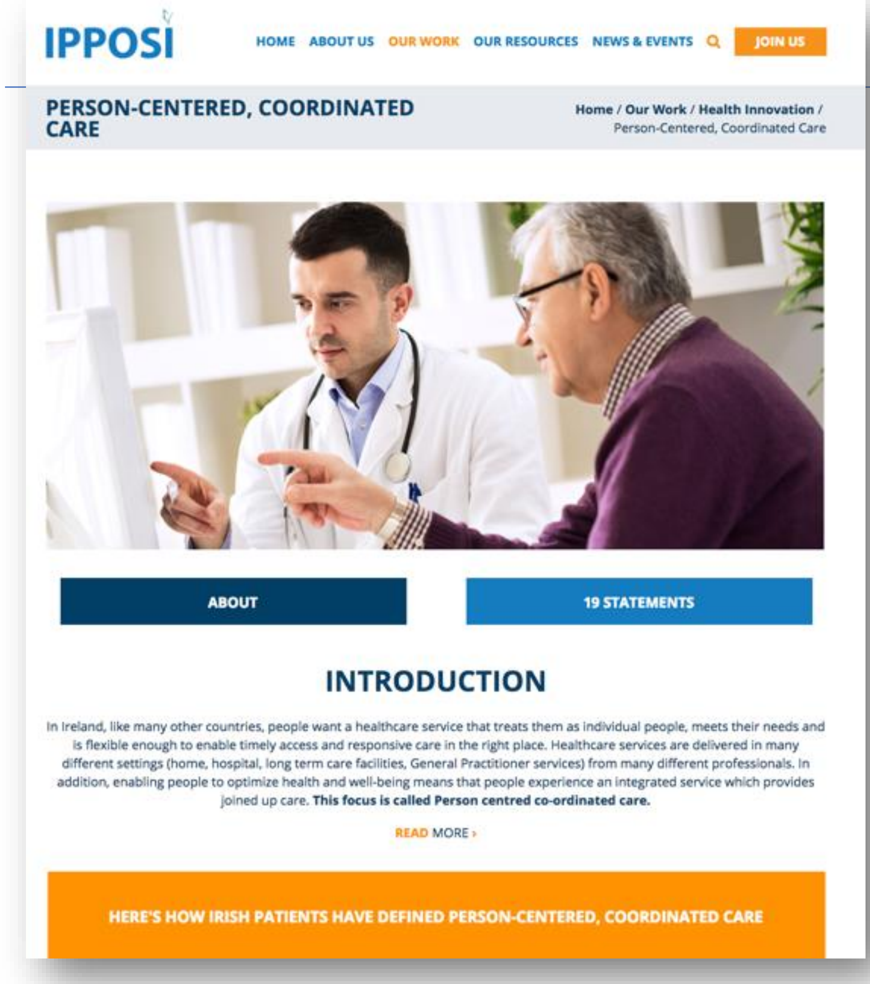
VERDICT FROM A CITIZENS' JURY ON ACCESS TO HEALTH INFORMATION

Verdict from a Citizens' Jury on Access to Health Information

- Patient Training programmes
- Patient Matchmaking
- Patient Dragon's Dens
- Citizens' Juries
- In-person/virtual conferences
- Policy consensus positions
- Member resources
- Coalitions and networks
- International leadership

https://ipposi.ie/news

Patient experience mapping in Ireland



IPPOSI

PERSON-CENTERED, COORDINATED CARE

Home / Our Work / Health Innovation / Person-Centered, Coordinated Care

INTRODUCTION

In Ireland, like many other countries, people want a healthcare service that treats them as individual people, meets their needs and is flexible enough to enable timely access and responsive care in the right place. Healthcare services are delivered in many different settings (home, hospital, long term care facilities, General Practitioner services) from many different professionals. In addition, enabling people to optimize health and well-being means that people experience an integrated service which provides joined up care. **This focus is called Person centred co-ordinated care.**

READ MORE ›

HERE'S HOW IRISH PATIENTS HAVE DEFINED PERSON-CENTERED, COORDINATED CARE

YOUR VOICE MATTERS

Stories to Build a Better Health Service

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Phelan A., Rohde D., Casey M., Fealy G., Felle P., Lloyd H. & O'Kelly G. (2017) Patient Narrative Project for Person-Centred Co-ordinated Care. UCD, IPPOSI & HSE, Dublin.

Latest Phase

http://www.hse.ie/yourvoicematters

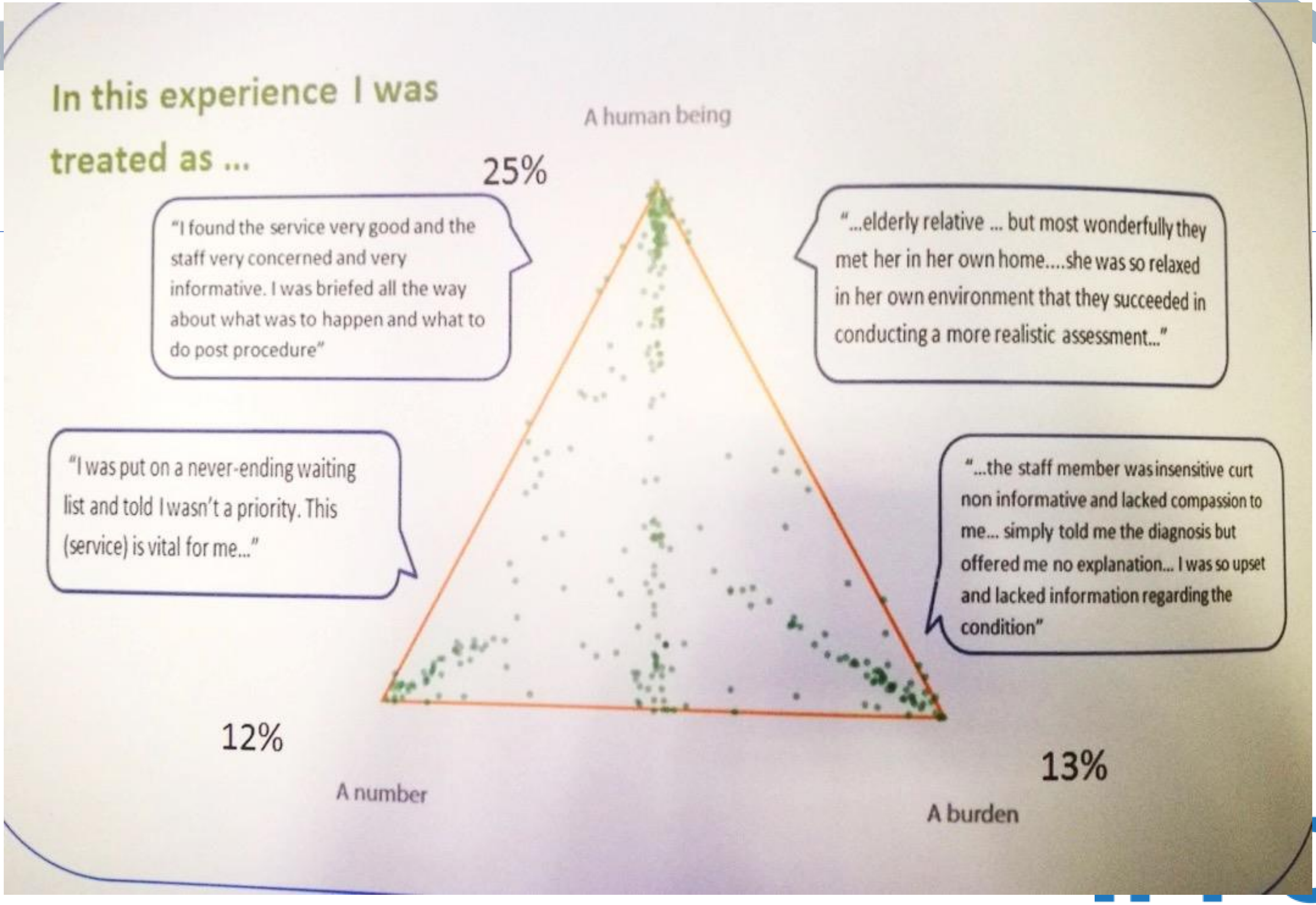
YOUR VOICE MATTERS

The patient engagement framework, based on the principles of co-design and co-production, consists of:

- an online survey that utilizes a software programme SenseMaker®
- processes for staff and patients to work together to analyse the data from the survey
- processes for staff and patients to identify key areas for service development or improvement

> *"Patients and service users cannot just be storytellers in the co-production process; they need to be involved in the solution"*
> *Patient Partnership Panel Member,*

PATIE



In this experience I was treated as ...

A human being

25%

"I found the service very good and the staff very concerned and very informative. I was briefed all the way about what was to happen and what to do post procedure"

"...elderly relative ... but most wonderfully they met her in her own home....she was so relaxed in her own environment that they succeeded in conducting a more realistic assessment..."

"I was put on a never-ending waiting list and told I wasn't a priority. This (service) is vital for me..."

"...the staff member was insensitive curt non informative and lacked compassion to me... simply told me the diagnosis but offered me no explanation... I was so upset and lacked information regarding the condition"

12%

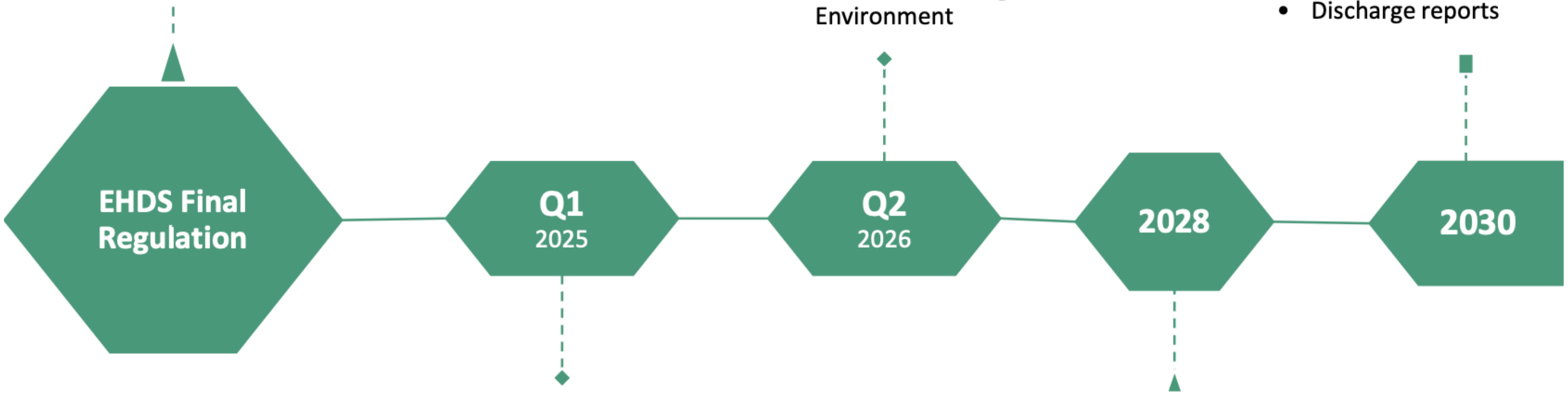
A number

13%

A burden

Setting up national health data access services

European Health Data Space



Trilogues conclude and final EHDS regulation published

EHDS Final Regulation

Q1 2025

WP5 Data application management solution

WP6 National Health Data Catalogue WP8 Health Data Quality Enhancement

WP6 National Health Data Catalogue WP8 Health Data Quality Enhancement

Q2 2026

WP7 Secure Processing Environment

2028

EHDS required compliance with:

- Patient summaries
- Electronic prescriptions
- Electronic dispensations
- secondary priority category datasets

2030

EHDS required compliance with:

- Medical images and related image reports
- Laboratory results and related laboratory reports
- Discharge reports

(Timelines under negotiation)

IPPOSI at EU + Global Levels

PATIENT FOCUSED
MEDICINES DEVELOPMENT

www. pfmd.org

EUPATI
European Patients' Academy
on Therapeutic Innovation

www.eupati.eu

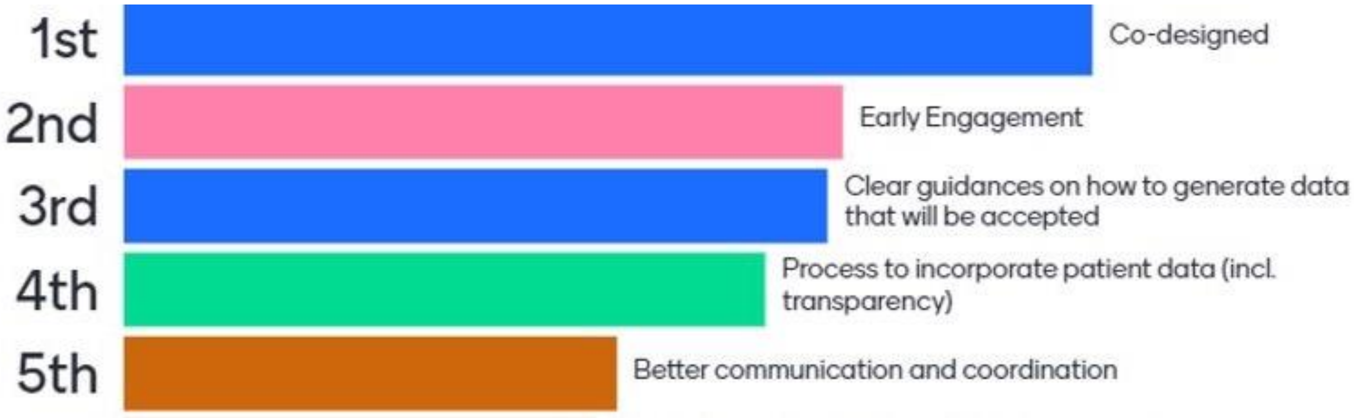
PaRIS
Patient Reported Indicator Surveys
OECD

www.oecd.org/health/paris

ISPOR
Improving healthcare decisions

Regulatory Level Considerations

*The **top 5 ‘Guiding principles’** to help stakeholders ensure that Patient-Generated Health Data (PGHD) is incorporated to meaningfully improve HTA*



ISPOR European Patient Round-Table, 2021

Leveraging patient experience data to guide medicines development, regulation, access decisions and clinical care in the EU

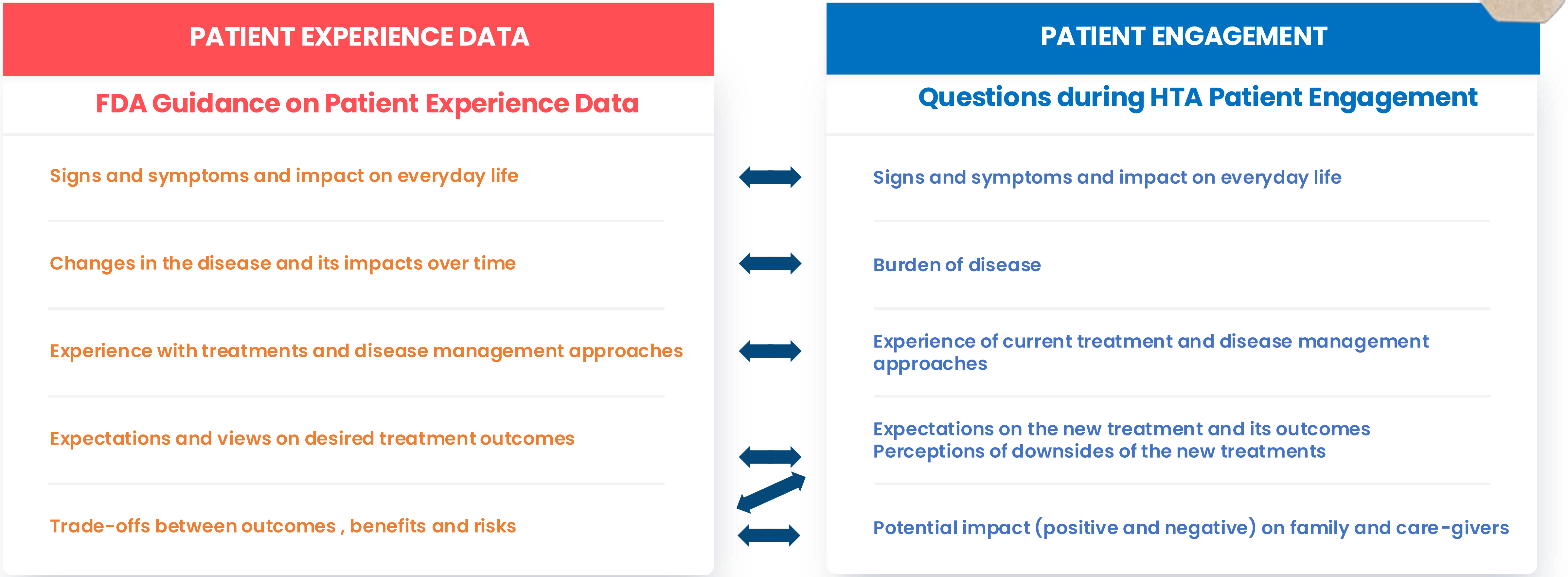
Diogo Almeida[1,2] Denise Umuhire[3] Rosa Gonzalez-Quevedo[4]
Ana António[5] Juan Garcia Burgos[4] Patrice Verpillat[3]
Nathalie Bere[6] Bruno Sepodes[1,2†] Carla Torre[1,2*†]

[1] Laboratory of Systems Integration Pharmacology, Clinical and Regulatory Science, Research Institute for Medicines (iMed.ULisboa), Lisbon, Portugal
[2] Faculdade de Farmácia, Universidade de Lisboa, Lisbon, Portugal
[3] Data Analytics and Methods Task Force, European Medicines Agency, Amsterdam, Netherlands
[4] Public and Stakeholders Engagement Department, European Medicines Agency, Amsterdam, Netherlands
[5] Referrals Office, Quality and Safety of Medicines Department, European Medicines Agency, Amsterdam, Netherlands
[6] Regulatory Practice and Analysis, Medsafe—New Zealand Medicines and Medical Devices Safety Authority, Wellington, New Zealand

https://www.frontiersin.org/journals/medicine/articles/10.3389/fmed.2024.1408636/full

Both PE and PED are currently used to answer patient-relevant questions

made with patients
pfmd

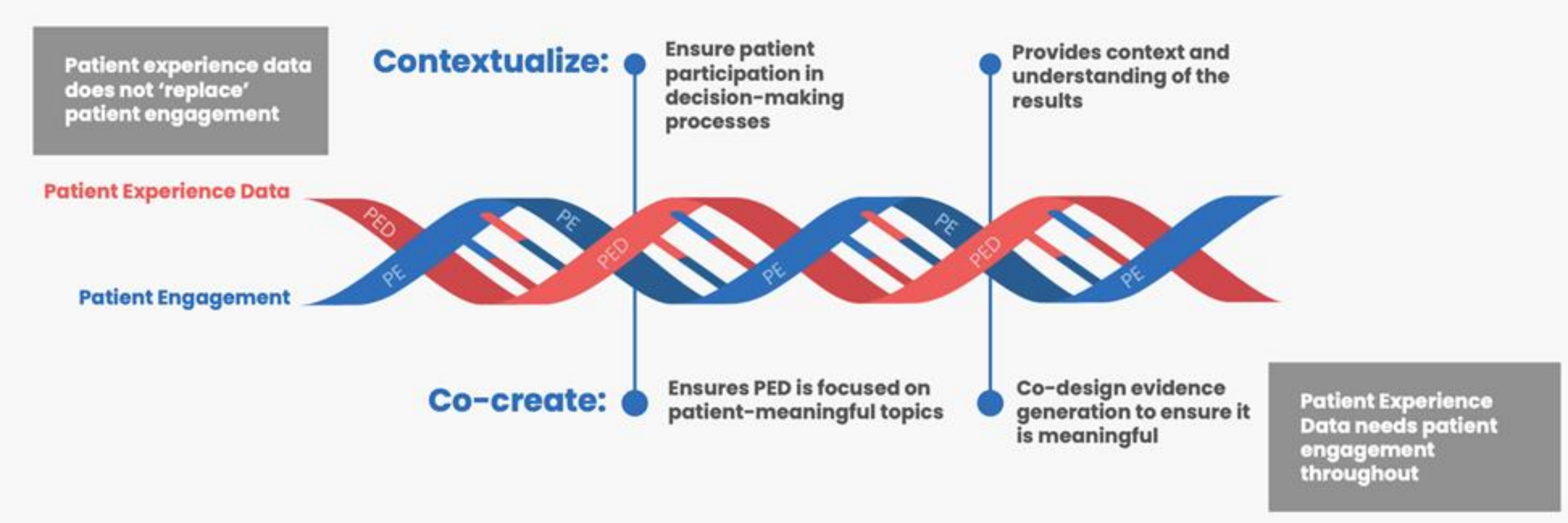


PATIENT EXPERIENCE DATA	**PATIENT ENGAGEMENT**
FDA Guidance on Patient Experience Data	**Questions during HTA Patient Engagement**
Signs and symptoms and impact on everyday life	Signs and symptoms and impact on everyday life
Changes in the disease and its impacts over time	Burden of disease
Experience with treatments and disease management approaches	Experience of current treatment and disease management approaches
Expectations and views on desired treatment outcomes	Expectations on the new treatment and its outcomes Perceptions of downsides of the new treatments
Trade-offs between outcomes , benefits and risks	Potential impact (positive and negative) on family and care-givers

PATIENT FOCUSED MEDICINES DEVELOPMENT

Slide courtesy of Hayley Chapman, PFMD & The Synergist

Working **WITH** patients is essential to ensure integration of patient engagement in PED generation and use



Patient experience data does not 'replace' patient engagement

Patient Experience Data

Patient Engagement

Contextualize:
- Ensure patient participation in decision-making processes
- Provides context and understanding of the results

Co-create:
- Ensures PED is focused on patient-meaningful topics
- Co-design evidence generation to ensure it is meaningful

Patient Experience Data needs patient engagement throughout

> *PE can support PED to ensure patient-centricity of measurement, contextualization of data, increased understanding of the evidence generated, and the co-creation of the design, generation, collection and analysis of PED.*

PFMD.org
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Slide courtesy of Hayley Chapman, PFMD & The Synergist

IPPOSI

Co-creating insights and tools to advance PE & PED across the healthcare continuum

1. Collective Value Publication

DIA

2. Landscape White Paper v.1

Highlighting Recent Trends in the Fast-Evolving Patient Engagement & Patient Experience Data Landscape

3. Global PED Navigator & Methods Publication

Co-creation of the Global Patient Experience Data Navigator: a multi-stakeholder initiative to ensure the patient voice is represented in health decision-making

4. PE & PED Global Landscape Publication

DIA

Patient Engagement and Patient Experience Data in Regulatory Review and Health Technology Assessment: A Global Landscape Review

5. PE & PED Integrated Navigator

Public Consultation

https://www.survey■o■key.com/r/P6D■D2V

Please find here the links for: the PE & PED Project, Landscape White Paper v1, Collective Value Publication, and Global PED Navigator

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Slide courtesy of Hayley Chapman, PFMD & The Synergist

IPPOSI

The Global PED Navigator responds to 5 key questions about Patient Experience Data resulting in 4 integrated templates

1. **WHAT:**

   Highlight the needs that are most important to patients

2. **HOW:**

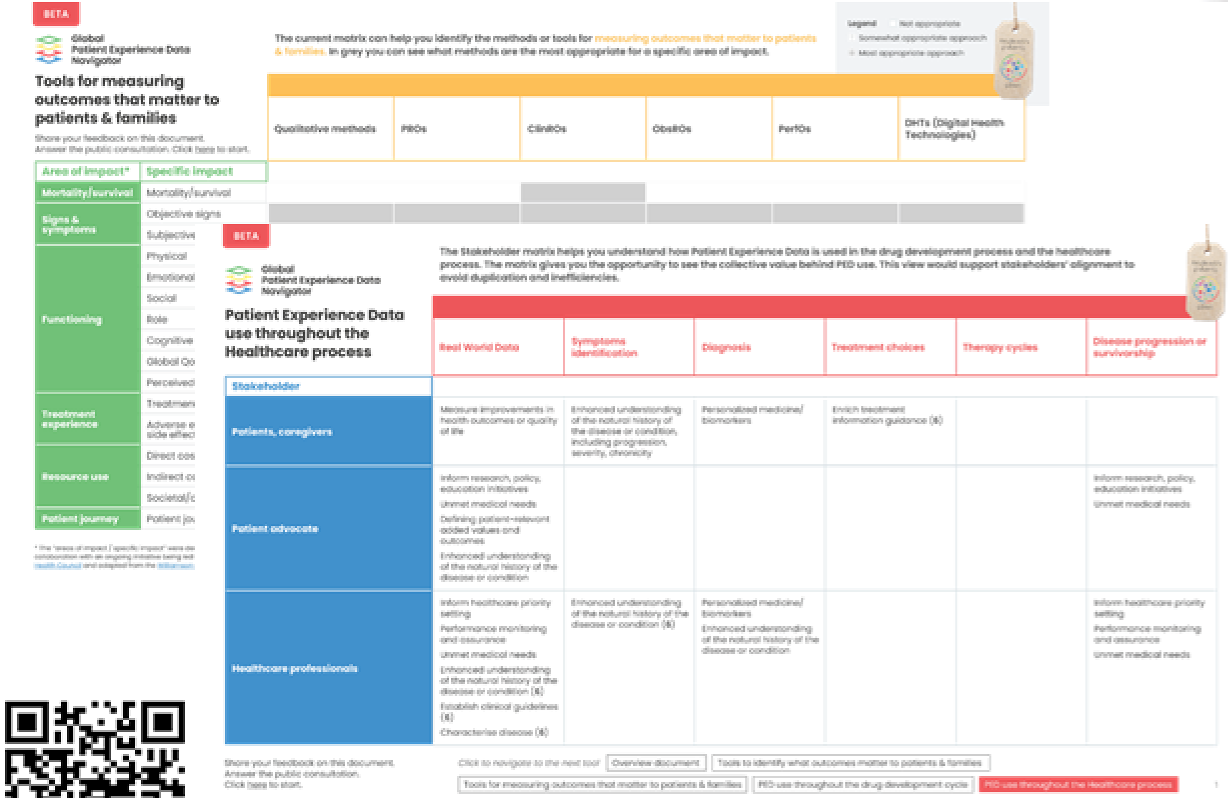
   Review the approaches and methodologies available (and identify gaps) to measure these patient experiences

3. **WHEN:**

   Consider when stakeholders are using this data and **4. WHY**

5. **WHO:**

   Identify the stakeholders that are using PED
   Review the approaches and methodologies available (and identify gaps) to measure these patient experiences



BETA

Global Patient Experience Data Navigator

Tools for measuring outcomes that matter to patients & families

Share your feedback on this document.
Answer the public consultation. Click here to start.

The current matrix can help you identify the methods or tools for measuring outcomes that matter to patients & families. In grey you can see what methods are the most appropriate for a specific area of impact.

Legend: Not appropriate
Somewhat appropriate approach
Most appropriate approach

Qualitative methods | PROs | ClinROs | ObsROs | PerfOs | DHTs (Digital Health Technologies)

Area of impact* | Specific impact
Mortality/survival | Mortality/survival
Signs & symptoms | Objective signs
Subjectiv
Functioning | Physical
Emotional
Social
Role
Cognitive
Global Qo
Perceived
Treatment experience | Treatmen
Adverse e side effec
Resource use | Direct cos
Indirect c
Societal/c
Patient journey | Patient jo

BETA

Global Patient Experience Data Navigator

Patient Experience Data use throughout the Healthcare process

The Stakeholder matrix helps you understand how Patient Experience Data is used in the drug development process and the healthcare process. The matrix gives you the opportunity to see the collective value behind PED use. This view would support stakeholders' alignment to avoid duplication and inefficiencies.

Stakeholder	Real World Data	Symptoms identification	Diagnosis	Treatment choices	Therapy cycles	Disease progression or survivorship
Patients, caregivers	Measure improvements in health outcomes or quality of life	Enhanced understanding of the natural history of the disease or condition, including progression, severity, chronicity	Personalized medicine/ biomarkers	Enrich treatment information guidance ($)		
Patient advocate	Inform research, policy, education initiatives Unmet medical needs Defining patient-relevant added values and outcomes Enhanced understanding of the natural history of the disease or condition					Inform research, policy, education initiatives Unmet medical needs
Healthcare professionals	Inform healthcare priority setting Performance monitoring and assurance Unmet medical needs Enhanced understanding of the natural history of the disease or condition ($) Establish clinical guidelines ($) Characterise disease ($)	Enhanced understanding of the natural history of the disease or condition ($)	Personalized medicine/ biomarkers Enhanced understanding of the natural history of the disease or condition			Inform healthcare priority setting Performance monitoring and assurance Unmet medical needs

Share your feedback on this document.
Answer the public consultation.
Click here to start.

Click to navigate to the next tool: Overview document | Tools to identify what outcomes matter to patients & families | Tools for measuring outcomes that matter to patients & families | PED use throughout the drug development cycle | PED use throughout the Healthcare process

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Made WITH Patients

Global
Patient Experience Data
Navigator

Slide courtesy of Hayley Chapman, PFMD & The Synergist

In Conclusion

Patient mapping tools becoming more sophisticated

Elevating co-produced PED to sit alongside clinical & economic evidence

Regulatory / RWE requirements for PED remain to be defined

Need common tools for PED collection (some in progress)

Need greater participation of patients in the selection, analysis, and interpretation of all data, no matter what the source

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