

#DigitalHealth

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SIP
Societal Impact of Pain

WELCOME!

How can digitalising health services reduce the societal impact of pain?



The 'Societal Impact of Pain' (SIP) platform is a multi-stakeholder partnership led by the European Pain Federation EFIC and Pain Alliance Europe (PAE), which aims to raise awareness of pain and change pain policies. The scientific framework of the SIP platform is under the responsibility of EFIC and the strategic direction of the project is defined by both partners. The pharmaceutical company Grünenthal GmbH is the main sponsor of the Societal Impact of Pain (SIP) platform.



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IMI-PainCare and Patient Reported Outcomes (PRO) uptake by the European Medicines Agency (EMA)

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Conflicts of Interest declaration: Esther Pogatzki-Zahn

Part of the present presentation relates to results obtained in the Project IMI-PainCare. This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No [777500]. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.

The statements and opinions presented here reflect the author's view and neither IMI nor the European Union, EFPIA, or any Associated Partners are responsible for any use that may be made of the information contained therein.



www.imi-paincare.eu



www.imi.europa.eu

During the last 5 years, EPZ received received advisory board and lecture fees from Grünenthal GmbH, MSD Sharp & DOHME GmbH, Mundipharma GmbH; Mundipharma International; Janssen-Cilag GmbH; Fresenius Kabi, TAD and AcelRx and from Mundipharma GmbH and Grunenthal for research activities.

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EPZ is board/council member and/or vice chair/chair of several national and international pain and anaesthesia societies and committees including the International Association for the Study of Pain (IASP), Acute Pain SIG of the IASP; European Society Anesthesiology (ESA, past chair of the subcommittee Acute and Chronic Pain and Palliative Medicine Pain Management; member of the research committee), German Society of Pain (German Chapter of IASP), German Society of Anaesthesiology (DGAI, Pain subcommittee) and the Sertürner Society;

EPZ is Deputy Editor – in – Chief of the EJA

Patient – Reported – Outcomes (PRO) – it is the patients view that matters



<https://silverlinecrm.com/blog/healthcare/provider/5-reasons-patient-360-matters/>

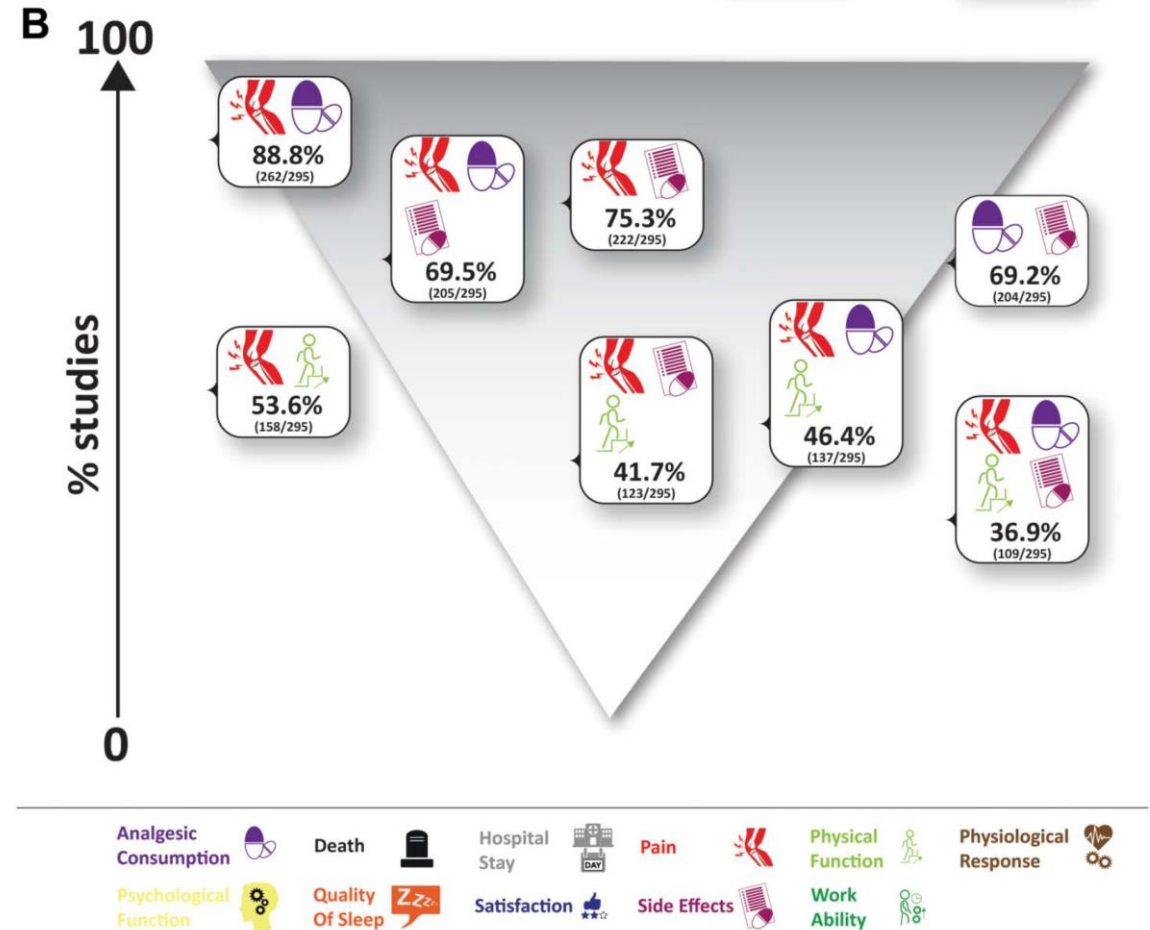
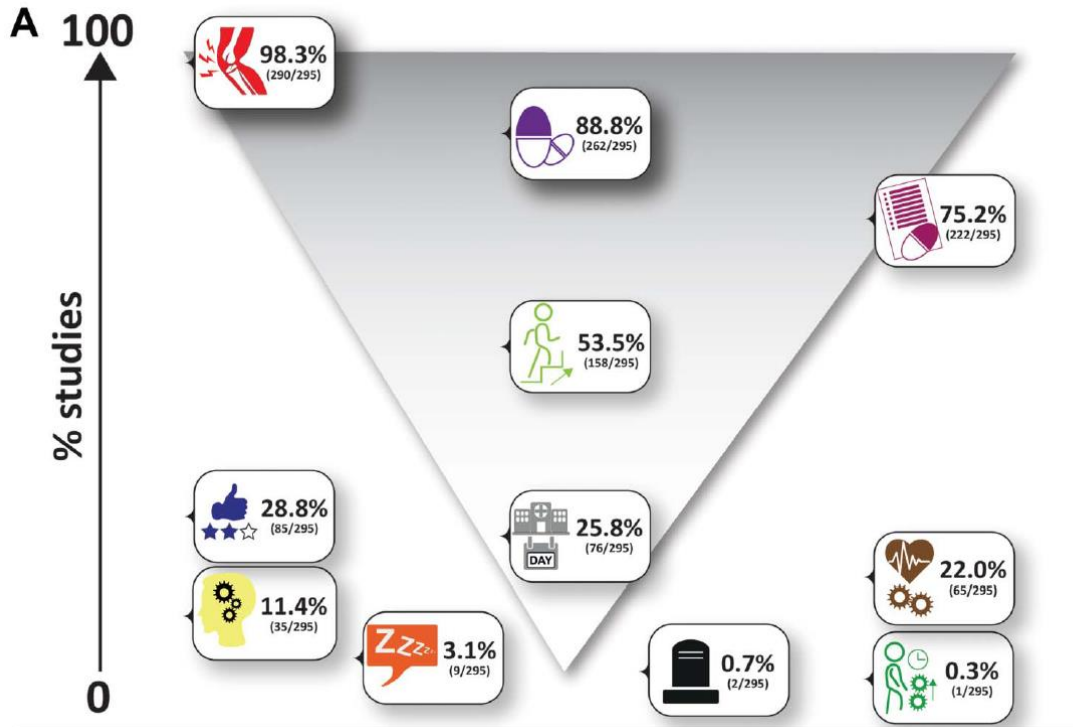
Outcome Assessment in Pain Studies (Postsurgical Pain)

Systematic Review and Meta-Analysis

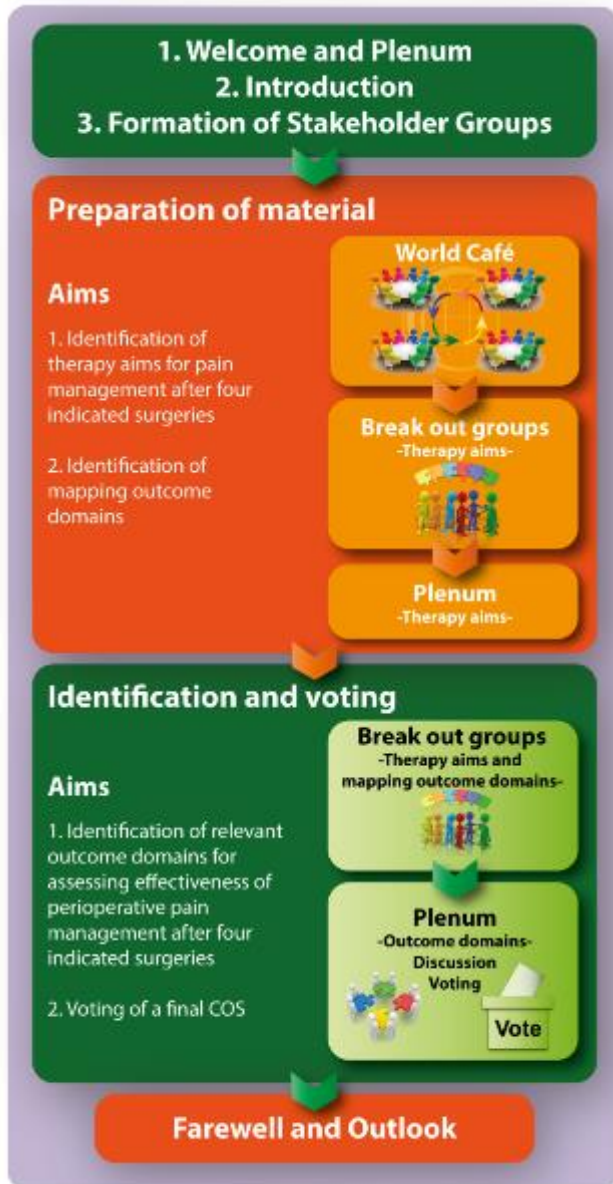
PAIN

Assessing outcome in postoperative pain trials: are we missing the point? A systematic review of pain-related outcome domains reported in studies early after total knee arthroplasty

Stephan Bigalke^{a,b}, Timo V. Maeßen^a, Kathrin Schnabel^a, Ulrike Kaiser^c, Daniel Segelcke^a, Christine H. Meyer-Frießem^b, Hiltrud Liedgens^d, Philipp A. Macháček^e, Peter K. Zahn^b, Esther M. Pogatzki-Zahn^{a,*}



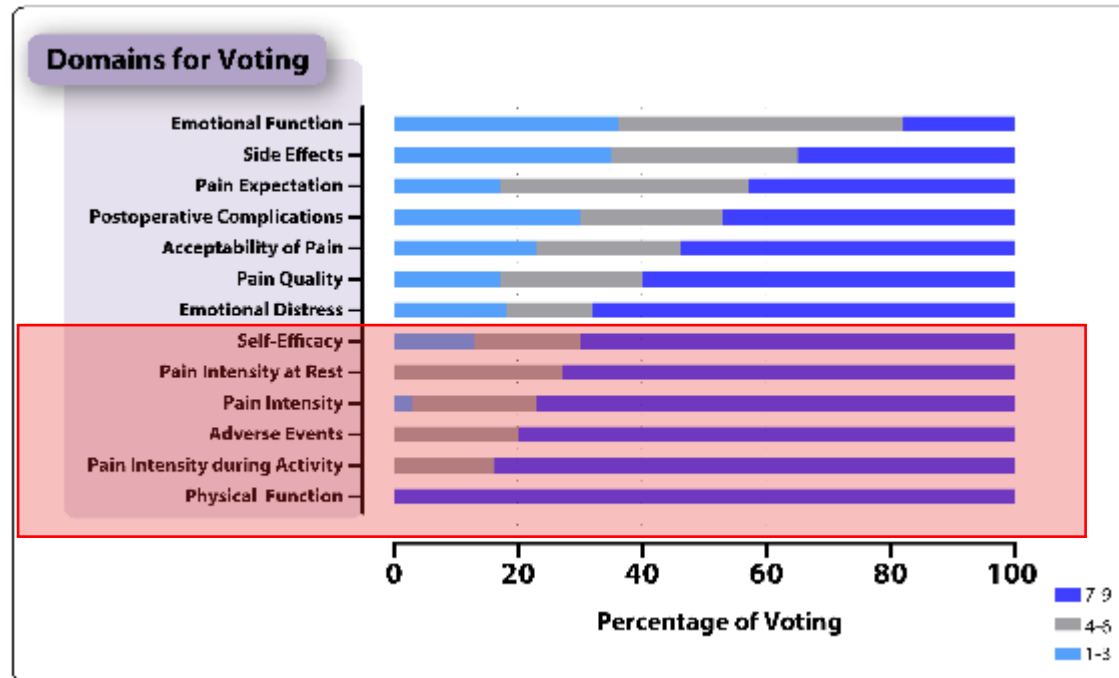
Consensus of PROs to be assessed in clinical trials after surgery



Panel member:
9 stakeholder groups:

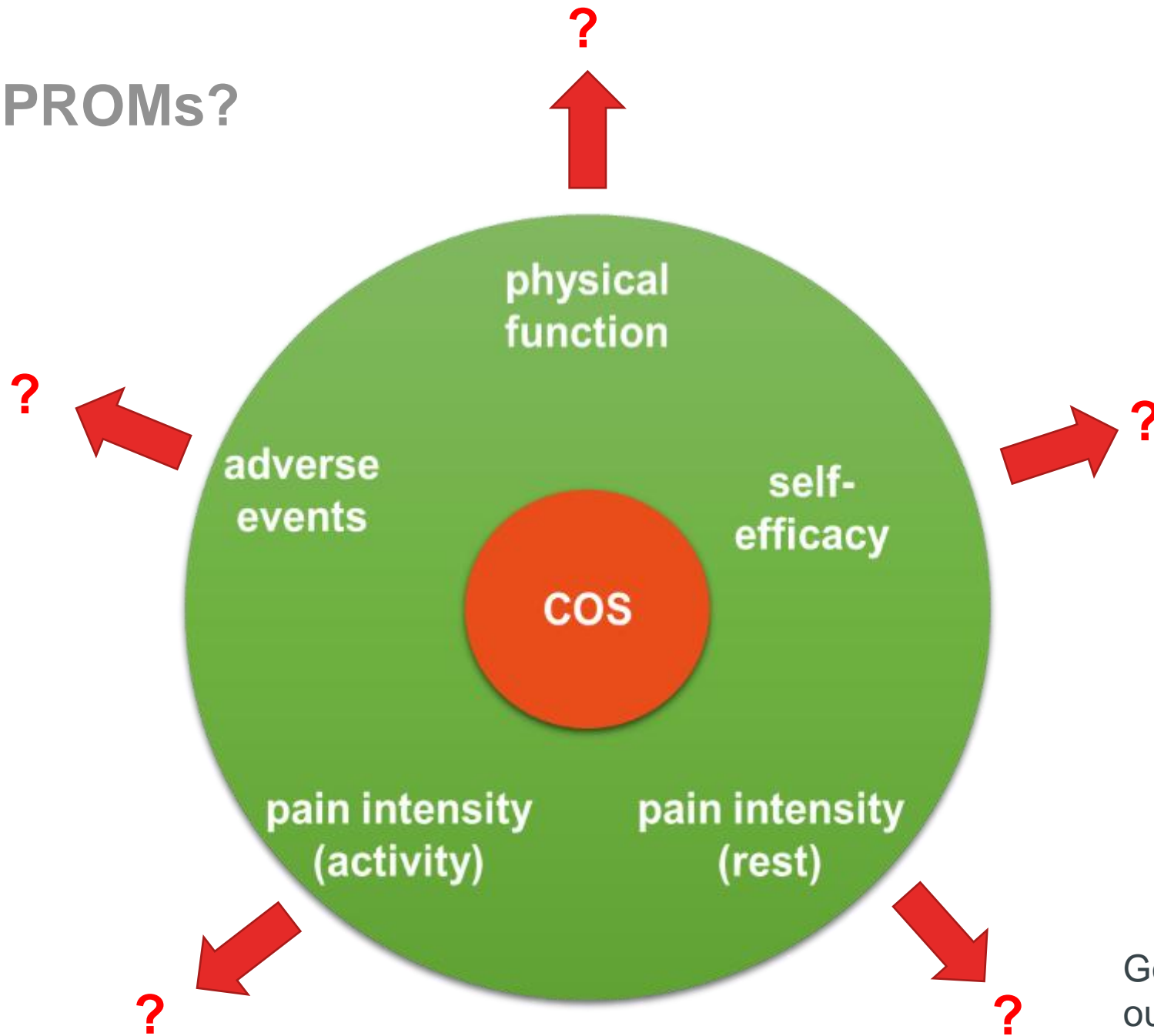
Anesthesiologists
Pain Specialists
IMI Group (clinical)
surgeons
clinical psychologists
physiotherapists
HTA/PRO experts and Regulatory experts
Pain Nurses
IMI-EFFPIA (pharmacists)

Patient representatives
4 participants / group



EU/IMI Horizon 2020 Grant #777500

PROMs?



Panel member:
9 stakeholder groups:

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Pain Nurses
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EU/IMI Horizon 2020 Grant #777500

Goal: Consensus on measurements for each outcome domain best suited for assessment of pain-related outcome early after surgery

Table 2. Examples of existing core outcome set recommendations for patient-reported outcome in chronic pain conditions

Name of initiative References	Condition Intervention Scope of application Location	Core outcome set – domains	Core outcome set – measurement instruments	Involvement of patients
IMMPACT [24,25]	Chronic pain No specific Clinical trials International	Pain Physical functioning Emotional functioning Participant's ratings of global improvement Symptoms and adverse events, and Participant's disposition	11 Pain (0–10) numerical rating scale of pain intensity Usage of rescue analgesics Categorical rating of pain intensity (none, mild, moderate, severe) in circumstances in which numerical ratings may be problematic Multidimensional Pain Inventory Interference Scale or Brief pain inventory interference items Beck depression inventory or Profile of mood states Patient global assessment of change Passive capture of spontaneously reported adverse events and symptoms and use of open-ended prompts Detailed information regarding participant recruitment and progress through the trial, including all information specified in the CONSORT guidelines	Not for domain and measurement instruments
Low back pain [26,27]	Nonspecific low back pain No specific Clinical trials International	Physical functioning Pain intensity Health-related quality of life Number of deaths	Oswestry Disability Index version 2.1; 24-item Roland Morris Disability Questionnaire NRS (0 no pain/10 worst pain) in a week recall period for average pain Short form health survey 12; 10.item PROMIS Global Health Number of deaths	Yes
VAPAIN [31]	Chronic pain Interdisciplinary multimodal pain therapy Effectiveness studies and daily record keeping International	Pain intensity Pain frequency Emotional wellbeing Physical activity Satisfaction with social roles and activities Productivity (including absenteeism and presentism) Patient perception of treatment goal achievement Health-related quality of life	In preparation	Yes
Fibromyalgia/ OMERACT [29]	Fibromyalgia No specific Clinical trials International	Pain Tenderness Fatigue Patient global Multidimensional function Sleep disturbance	Not recommended because of lack of evidence/psychometric properties of corresponding measurement instruments	Yes
COMPACT [30]	CRPS No specific All forms of research studies International	Pain Disease severity Participation and physical function Emotional and psychological function Self-efficacy Catastrophizing Patient's global impression of change	<i>Intensity</i> (worst, average, least): Numeric Rating Scale and PROMIS- 29 Profile (version 2), <i>Neuropathic components</i> : Short-Form McGill Pain Questionnaire-2 (SF-MPQ2); <i>Interference</i> : PROMIS-29 Profile (version 2); <i>Others</i> : EQ-5D-5L <i>Severity</i> : CRPS severity score; <i>Experience</i> : CRPS symptoms questions <i>Physical function/social participation</i> : PROMIS-29 Profile (version 2); <i>Others</i> : EQ-5D-5L <i>Anxiety, depression, fatigue, sleep</i> : PROMIS-29 Profile (version 2); <i>Suicidal ideation</i> : PROMIS suicidal ideation question; <i>Others</i> : Others: EQ-5D-5L Pain Catastrophizing Scale Pain Self-Efficacy Questionnaire Patient Global Impression of Change	

COS of PROs and PROMs for chronic pain trials:

Common PROs/ domains:

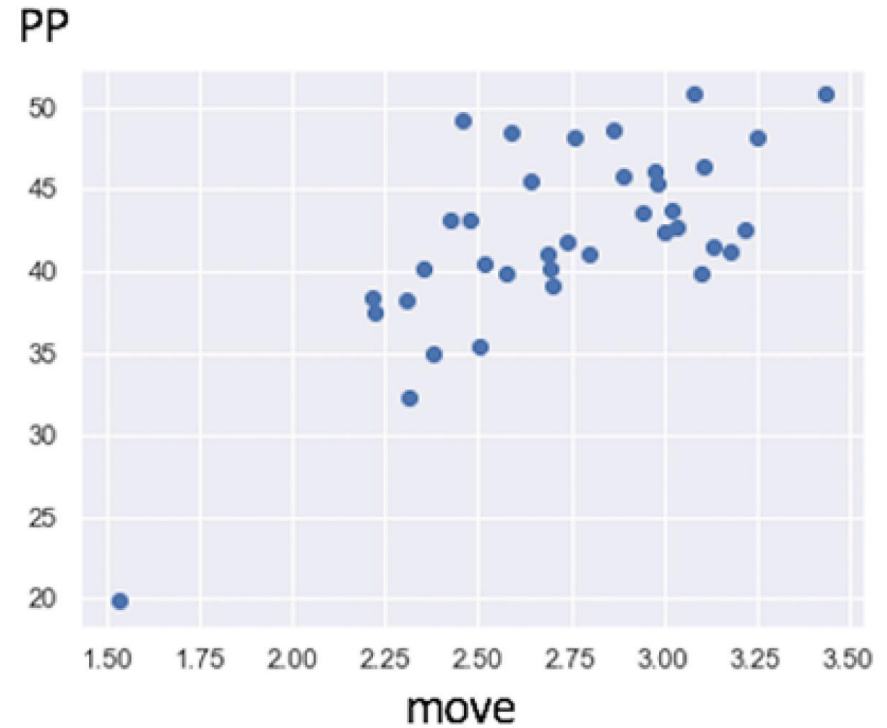
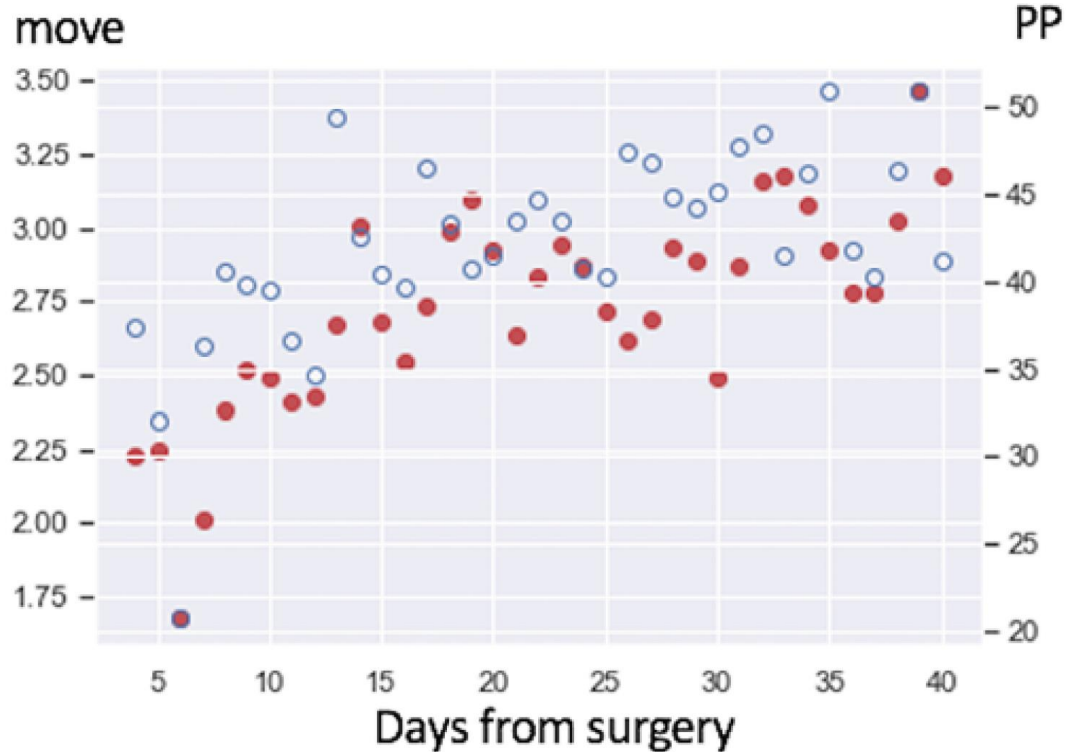
- Pain (intensity/severity)
- Physical functioning
- Some form of emotional functioning
- (Adverse Events)

Common PROMs:

- NRS (0-10), but....
- Physical functioning: no overlap
- Some form of emotional functioning
- (Adverse Events): no overlap

Next Steps: Operationalization of PROMs?

Smartphone GPS signatures of patients undergoing spine surgery correlate with mobility and current gold standard outcome measures



Next steps: Alignment and acceptance of PROs and PROMs for their use in clinical trials (EMA/FDA) and real world

The image shows a website banner for the INTEGRATE-Pain Consortium. The top section has a green-to-blue gradient background. On the left is the NIH logo with the text "National Institutes of Health". In the center, the text reads "INTEGRATE-Pain Consortium" in large white letters, followed by "Virtual Meeting" and "June 14, 2022" in smaller white text. On the right is the IMI-PainCare logo. Below this is a white navigation bar with links: HOME, ABOUT, SUMMER PAIN DOMAIN MEETING (highlighted in green), REGISTRATION, CORE OUTCOME SETS (COS), and TECHNICAL ASSISTANCE. The main content area below the navigation bar features the text "INTEGRATE-Pain Domain Meeting" in large blue letters, with "June 14, 2022" below it in smaller blue text.

Thanks to ...



Hitrud
Liedgens,
Grünenthal



Ulrike Kaiser,
Dresden



Winfried
Meissner,
Jena



Current Funding:



- POETpain (Prävention operations-bedingter anhaltender Schmerzen durch Einführung eines perioperativen „Transitional Pain Service“)



- EU/EFPIA/Innovative Medicines Initiative Joint Undertaking (IMI-PAIN-CARE); Grant #777500



- PO1319/3-1; (DFG Einzelantrag)
- PO1319/4-1 (DFG-FOR2690)
- PO1319/5-1 (DFG-FOR2690)



- BMBF/ERaNETLac (ELAC2015/T07-0713)
- BMBF IncMeta (P-KS2019-046)



- Pog2/027/20

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European Pain Federation (EFIC), Department of Anaesthesiology & Intensive Care, University Hospital FSU Jena



PROs as quality indicators and best practices from PAIN OUT

Winfried Meissner
Dept. of Anesthesiology and Intensive Care
Jena University Hospital

Disclosures

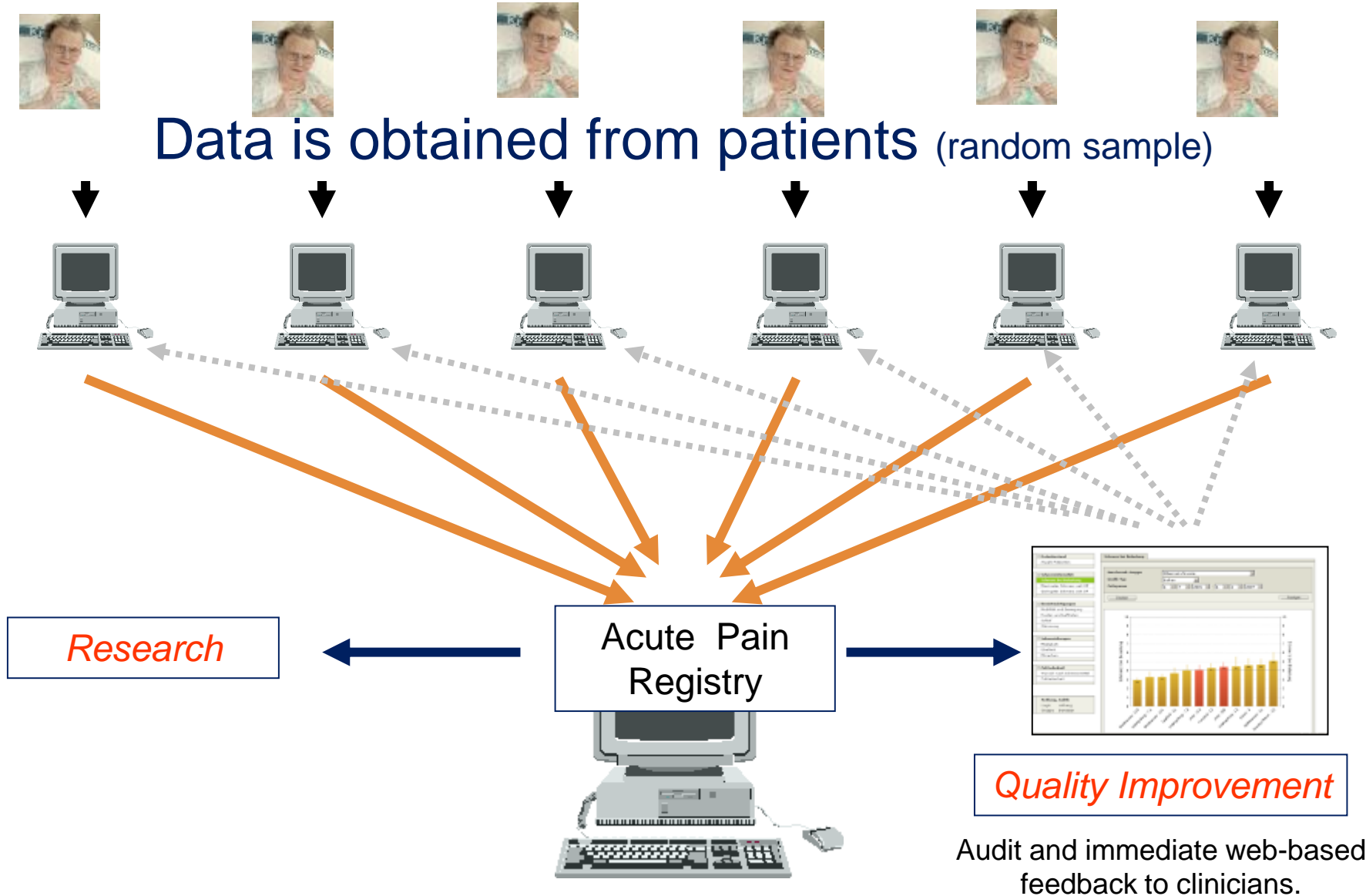
- Research: EU, DFG, BMBF, Pfizer, Mundipharma, Grünenthal
- Speaker / Advise: Grünenthal, Mundipharma, Ethypharm, Spectrum Therapeutics, Northern Swan, Kyowa, TAD



PAIN-OUT

Improvement in
Postoperative PAIN OUTcome

- A web-based quality improvement and research network addressing management of post-operative pain.
- Highly standardized assessment of PROs.
- Collaborators in Europe, Americas, Africa, South East Asia.
- Not-for-profit, academic project, coordinated from Jena University Hospital, Germany.



Data is obtained from patients (random sample)

Research

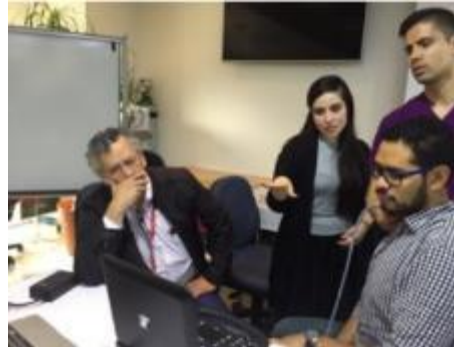
Acute Pain Registry

Quality Improvement

Audit and immediate web-based feedback to clinicians.

PAIN OUT: PDCA networks

- Mexico I & II
- France
- Ireland
- Spain
- Italy
- Belgium
- Switzerland
- Serbia I & II
- Netherlands
- China a
- China b + Pacific countries
- South Africa I & II
- Brazil

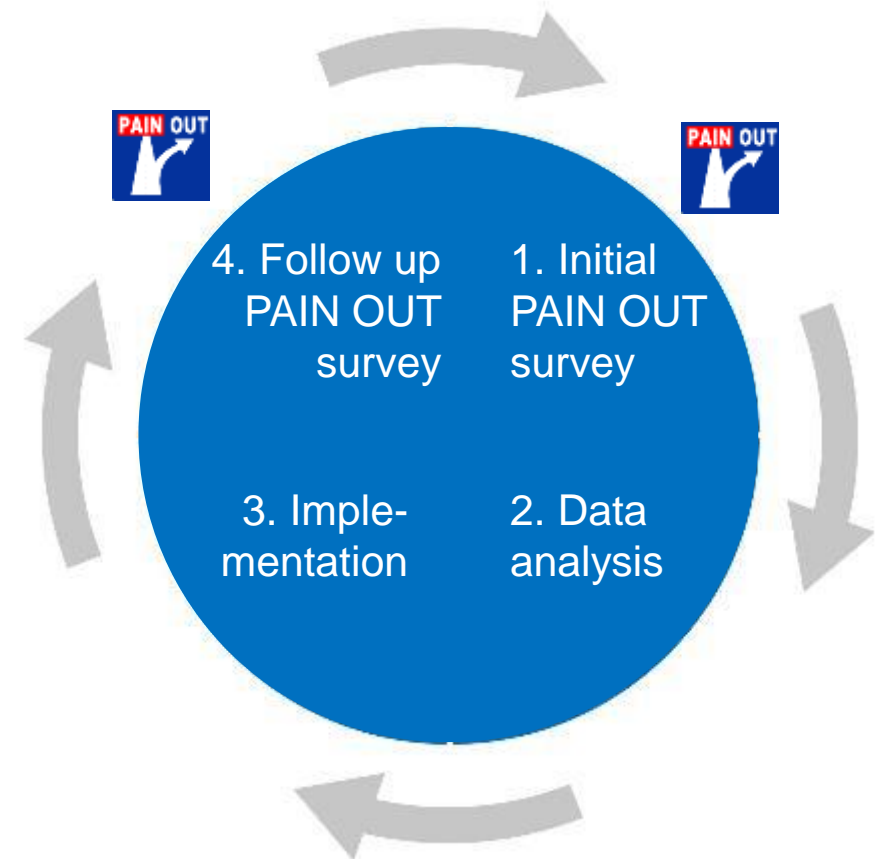


PAIN OUT: The Mexican Network

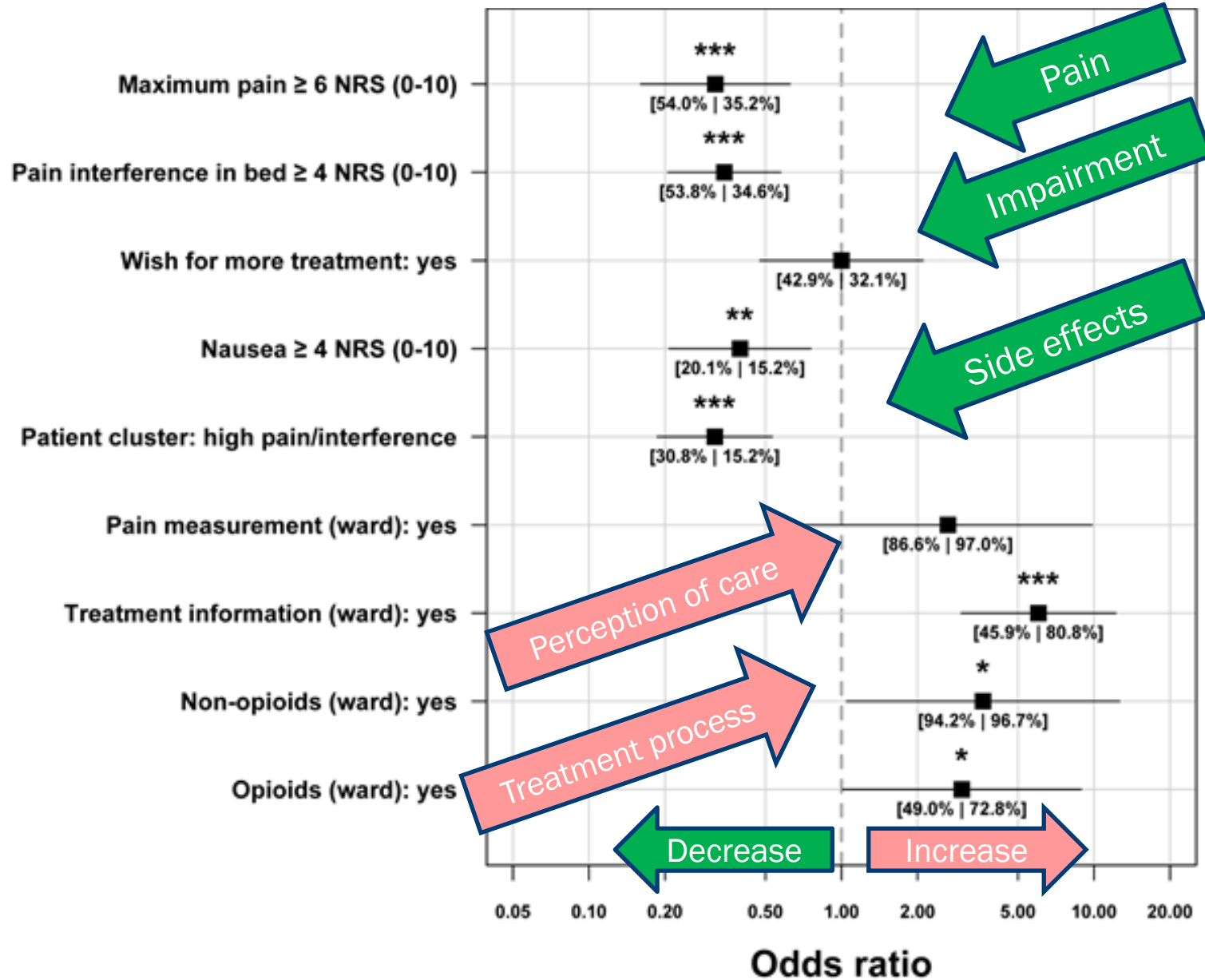
10 Hospitals in Mexico City, 15 surgical wards.

Network leaders:

**Drs Ana Garduño
& Victor Acosta,**
Salvador Zubiran Hospital



Odd ratios of parameter differences between initial and follow-up survey



Comments from Mexican colleagues:

The staff were **surprised** by the results we obtained during baseline showing high levels of pain in our patients ...

... some anesthetists **believed that they were doing things very** ... for example, some thought that it is unnecessary to use epidural catheters in open abdominal surgery ...

Interventions became part of the ... Now we are in constant communication with ... in charge ... We **introduced new protocols** in the ... orthopedic surgery, we need to work more in general ...

Gut feeling ≠ reality!

Change happens!

Summary: Lessons learnt...

- PRO-based feedback on quality is convincing („it's the patient's voice“) and effective
- Digital tools are helpful in quality improvement efforts but personal contact remains important
- You can learn not only from the best!
- QI: not only pain intensity!
 - Functional interference
 - Intensity of pain / intensity of treatment
 - Composite Scores
 - Generic QI preferred over procedure-specific QI

The team:

Ruth Zaslansky



Claudia Weinmann



Marcus Komann



Philipp Baumbach



And many more:

J Rothaug, A Goettermann, S Mescha, Germany
R Chapman, USA
N Rawal, R Backstrom, Sweden
D Fletcher, France
M Puig, Spain
R Langford, Dr K Ullrich, UK
C Konrad, U Stamer, Switzerland
M Schwenkglenks, Switzerland
T Volk, Dr A Kopf, Germany
E Pogatzki-Zahn, Germany
L Fodor, Romania
S Brill, Israel
Y Leykin, Italy
C Engel, Germany
R Taylor, UK
H Gerbershagen, Utrecht
I Buchholtz (TAKWA), Germany
...

German Society of Anesthesiology (DGAI, BDA)
German Society of Surgery (DGCH, BDC)
AK Akutschmerz der DGSS
International Pain Registry – IASP
ESA, EFIC, APS
Grünenthal, Pfizer, Mundipharma

German Ministry of Health
European Commission (EC)

PAIN OUT: Lessons learnt

People like it simple:

- Web access
- Graphic elements, “dash board”
- Comparison with ownself vs. with other sites
- Only few generic quality indicators – but which ones?

PAIN OUT: Lessons learnt

Learning from each other:

- Digital exchange works but personal interaction and local leader is important!
- “Real life” data more convincing than RCTs – specifically PROMs: “It’s the patient’s voice...”
- You can learn not only from the best!

Deirdre RYAN

President of Pain Alliance Europe (PAE)

PERSPECTIVES FROM MEPS

MEP Sirpa PIETIKÄINEN (EPP, Finland)

Co-chair of the MEP Interest Group on Brain, Mind and Pain (BMP) – *Video message*

MEP Susana SOLIS PEREZ (RE, Spain)

Member of the European Parliament Special Committee on Artificial Intelligence in a Digital Age (AIDA), and Panel for the Future of Science and Technology (STOA) – *Video message*

Jerome DE BARROS

Policy Officer, Unit B3 – European Reference
Networks and Digital Health, DG SANTE,
European Commission



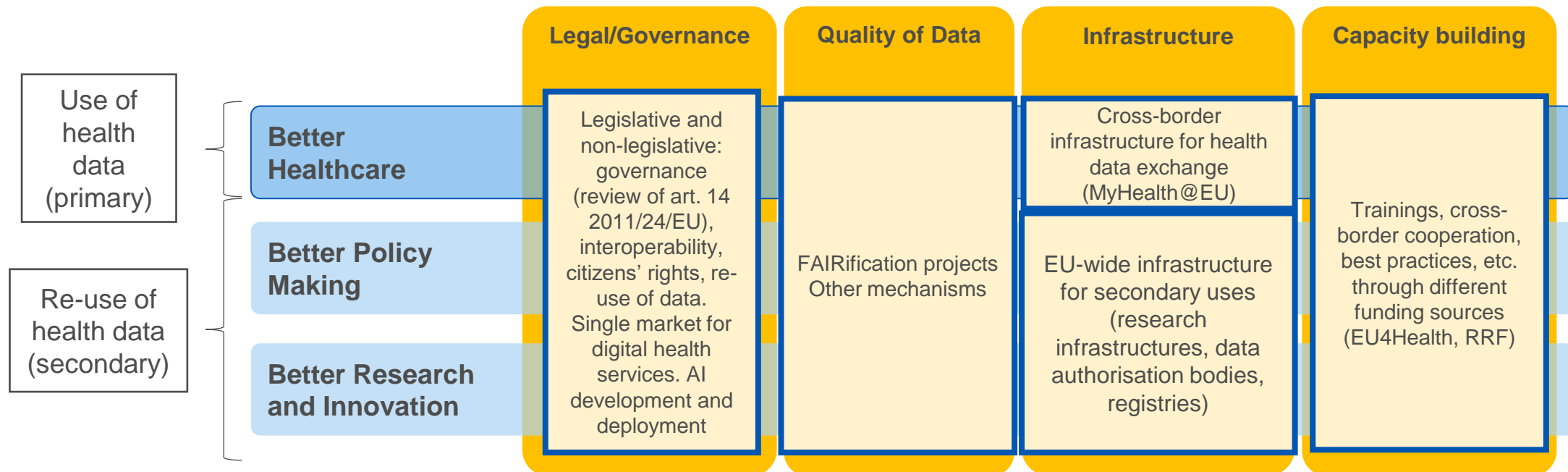
European Health Data Space

Jerome de Barros, Policy Officer

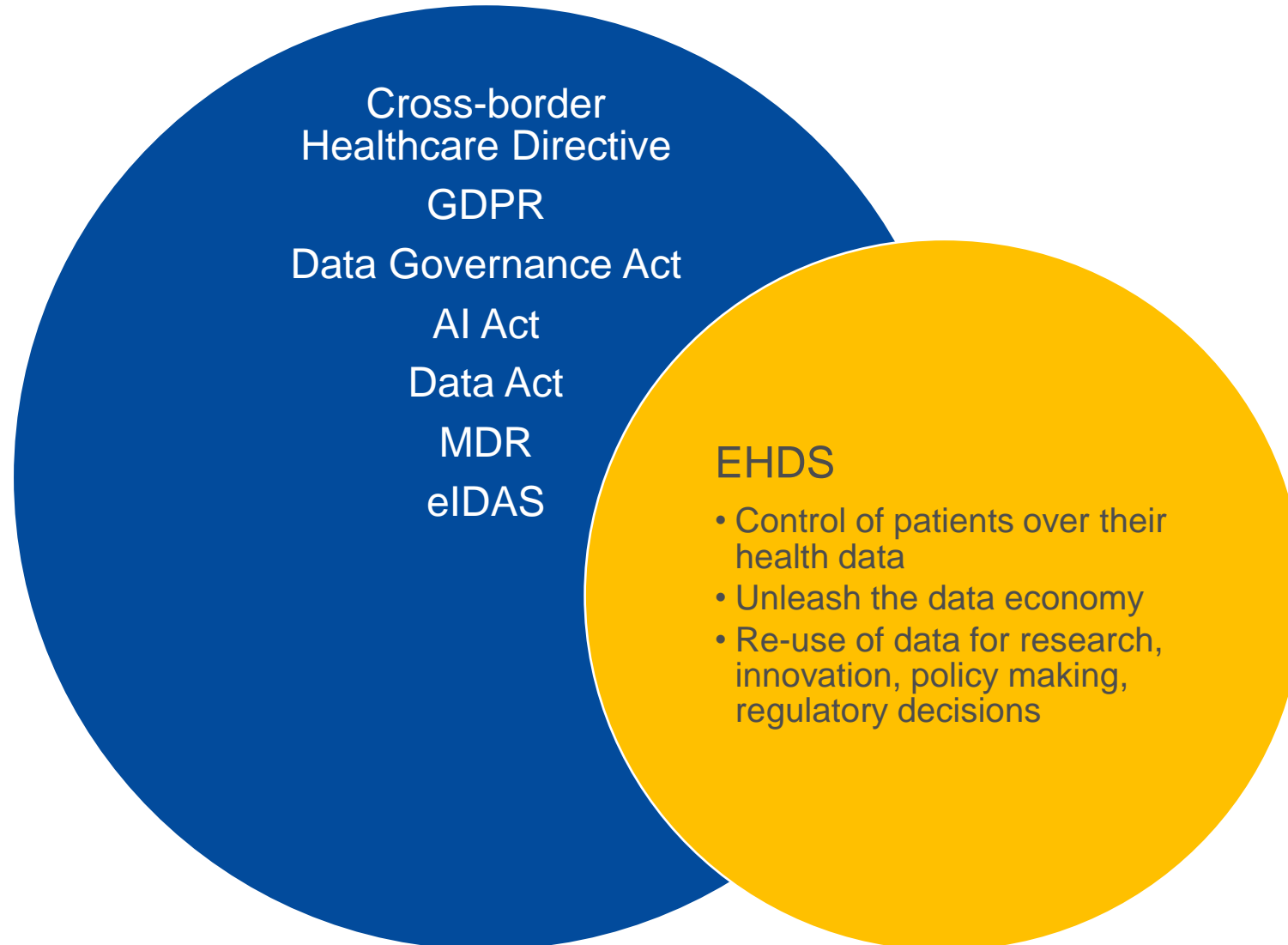


Primary and secondary uses of health data

- Timely and simplified *exchange of and access to* health data for different use cases:
 - Healthcare provision, access and control of patient over their data, (cross-border) exchange of health data;
 - Digital health services (including telehealth and m-health);
 - Research (eg on cancer, rare diseases, COVID-19 etc), pharmacovigilance, public health, policy making



EHDS: articulation within EU regulatory framework

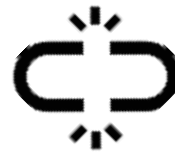


Main problems

Individuals have difficulty accessing and controlling their health data



Healthcare professionals have difficulty accessing health data



Providers of digital health services and products face barriers



Policy makers and regulators cannot easily access health data



Limited innovation takes place on the basis of health data

What are the objectives?

Empower individuals to control their health data



Foster a single market for digital health services and products



Ensure interoperability and security of health data and a level playing field for manufacturers



Unleash the power of the health data economy

Ensure a consistent and efficient framework for the reuse of health data for research, innovation, policy-making and regulatory activities



Access to health data in digital format

Today, a large number of EU citizens and healthcare professionals cannot access health data in a **digital format**. Data are often available in paper, or only a limited set of data categories are available in digital format.

Interoperable health data

Health data is collected in such a way, that **the format is different** everywhere. This makes it impossible to understand the meaning of health data in different contexts. Therefore, interoperability standards are required to **promote wider use and portability**.

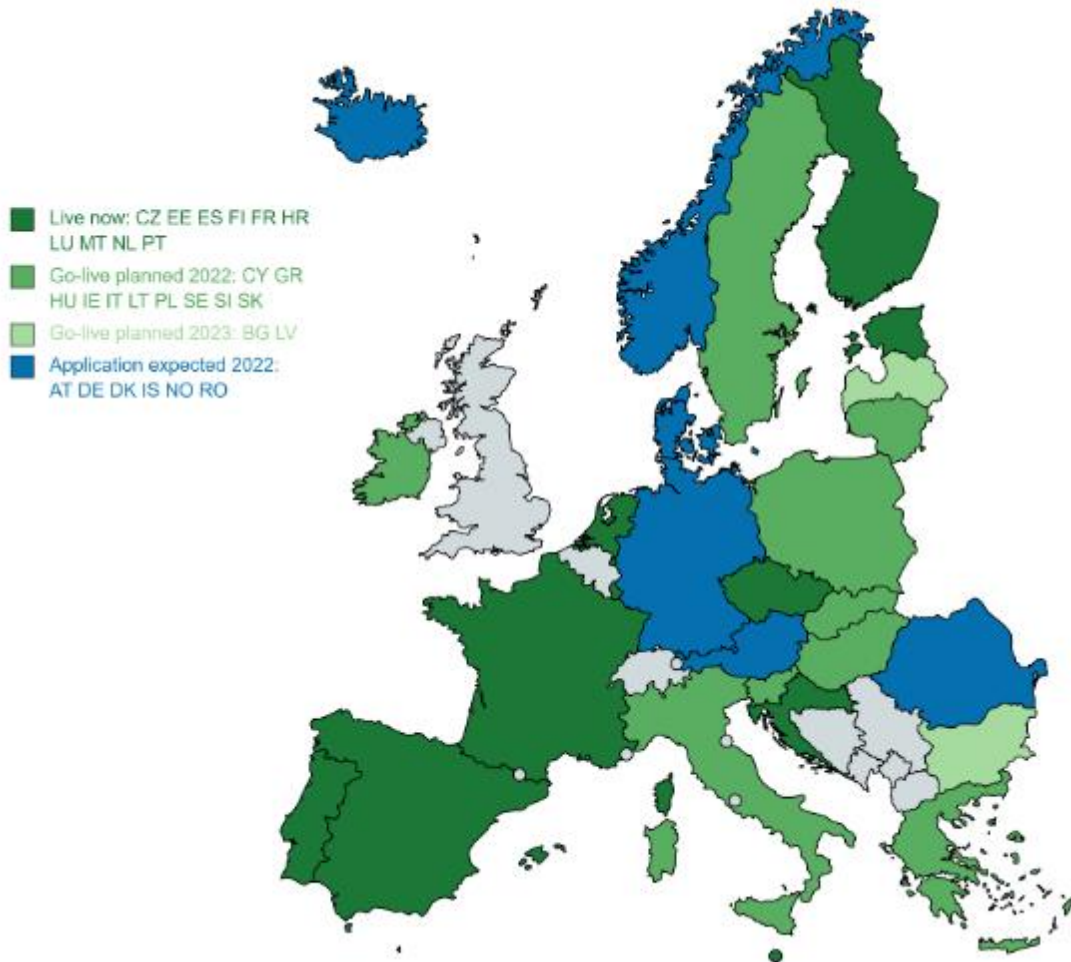


Tools and infrastructure

Member States organise health data access through different means. Some member states have patient or professional **portals** at the level of healthcare provider, region or nation, while others have apps or **personal data space** solutions. Also, registries of who should have **access** are also local, regional or national solutions. The Commission set up **MyHealth@EU infrastructure** to facilitate cross-border exchange of health data.



MyHealth@EU



- Currently 10 Member States are live
- The number of connected Member States will grow rapidly in the years ahead
- Currently there are 2 services: Patient Summary and ePrescription
- This is being expanded to include Medical images, Lab results, Discharge letters, Rare disease data and other health information categories
- A Pilot will explore Patient Access to their health data in MyHealth@EU

Primary use of health data

- The legislative proposal will focus on a number of areas:
- Expanding the rights of citizens to **access** and **portability** of health data
- Strengthening the eHealth **governance**
- Expanding the **MyHealth@EU** services
- Promoting **interoperability** of health software solutions (including EHR, apps, medical devices)

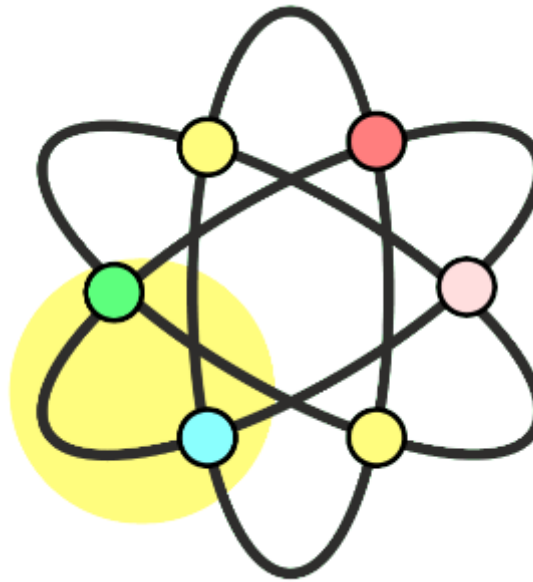
Secondary use in the EHDS



Reuse of health data by researchers, policy-makers and industry



Rules, protocols and governance

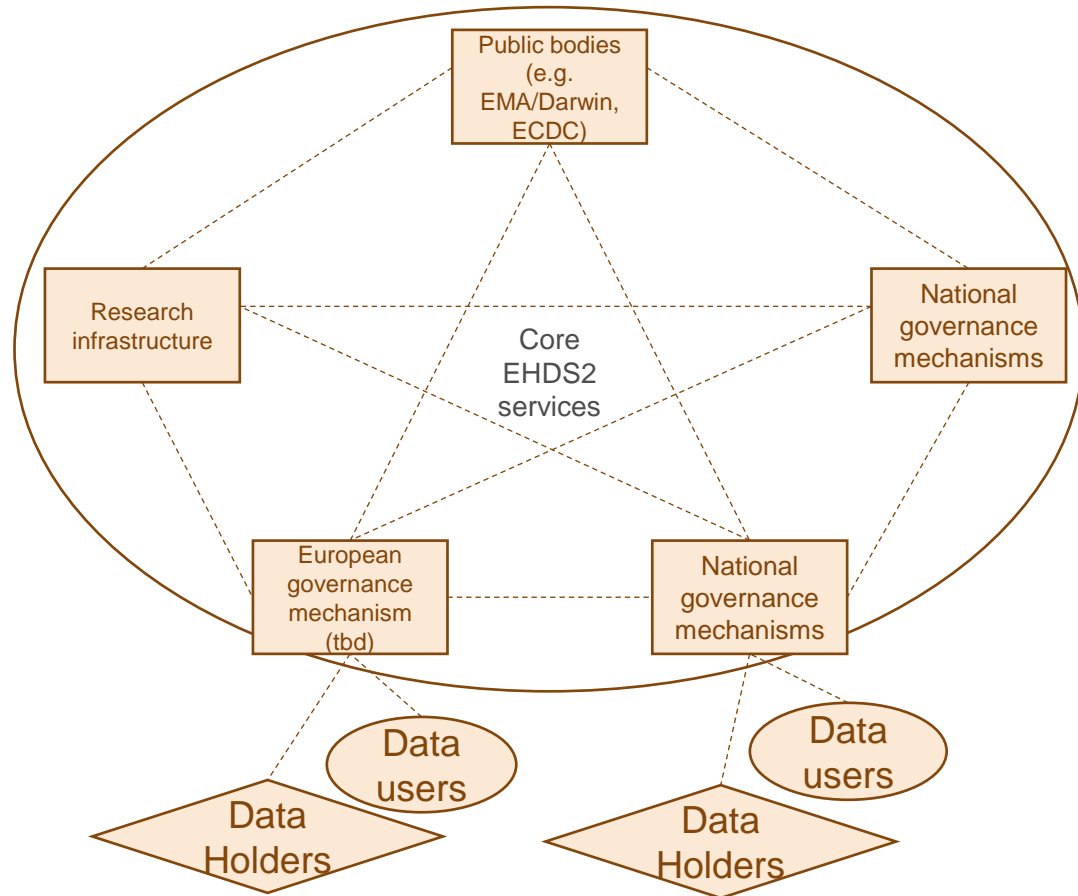


Health data from patients and healthcare professionals



Granting researchers, policy-makers and industry access to health data across borders in an interoperable, digital format

Access to data for research, innovation and policy making



- Creating a **network of nodes** as entry points into EHDS
- Nodes can be National **Data Authorisation Bodies** or European stakeholders (EMA, ECDC, Research Infrastructures)
- Rules are in place **governing the access** to health data (interoperability, data quality, privacy, security)
- Examples at national level are established in **Finland, Denmark, France and Norway**

TEHDAS

- On the secondary use of health data, the Joint Action TEHDAS has also published different recommendations:
- WP5: Report on barriers to cross border data sharing and potential governance mechanisms
- WP6: Report on regulating data quality
- WP7: Report on the user journey
- WP8: Literature review on data altruism, consent and access
- Please find the reports here: [Results - Tehdas](#)

Secondary use of health data

- The legislative proposal will focus on a number of areas:
 - Expanding on the existing **infrastructure** in Member States (Health Data Authorisation Bodies) Introduce a European infrastructure
 - Promoting **interoperability** and **data quality**
 - Strengthening the **legal base** for the re-use of health data

Studies

The EHDS legislative proposal is being drafted on the basis of input from:

- Public Consultation (May-July 2021)
- Study on the Assessment of rules in Member States on health data
- Study on the Interoperability of digital health systems in Member States
- Study on the use of Real World Data
- Study on regulatory gaps (to be published)
- Study on the Infrastructure options (to be published)
- Study on the Impact Assessment (to be published)

Projects

EU4Health funds a number of relevant projects to further expand the European digital health infrastructure

- A pilot project to allow **patients access** their health data in MyHealth@EU
- **Expansion of MyHealth@EU**, both by allowing more Member States to establish National Contact Points and by expanding the amount of services
- A pilot project to understand the potential of a European **network of National Health Data Access Bodies** collaborating on secondary use of health data

Next steps

- The next steps for the EHDS legislative proposal is to have approval from the Commission internally
- We expect the proposal to be published in the coming weeks
- If you have questions, don't hesitate to reach out: Jerome.de-barros@ec.europa.eu

Thank you



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Gertrude BUTTIGIEG

SIP Malta, and Chair of the Malta Health Network



DIGITAL HEALTH — A PATIENT PERSPECTIVE

Gertrude A. Buttigieg
(Chairperson MHN/ SIP Malta)

Digital health technologies

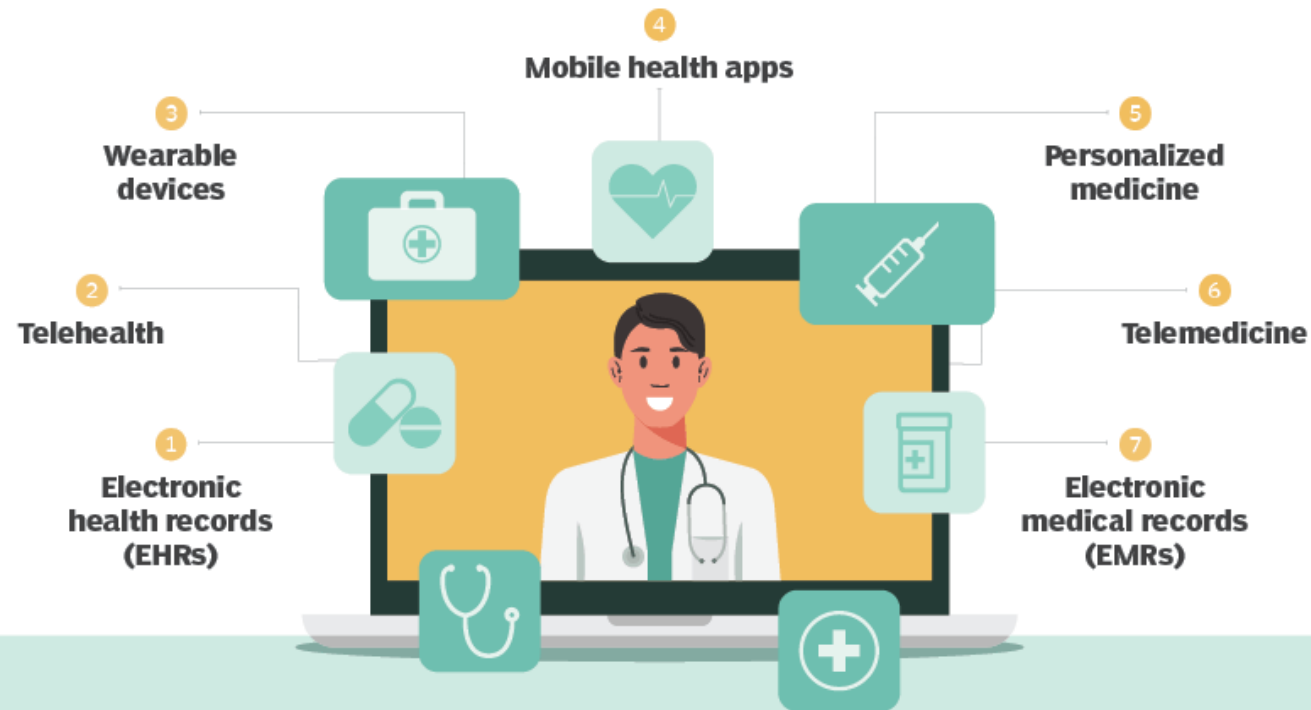
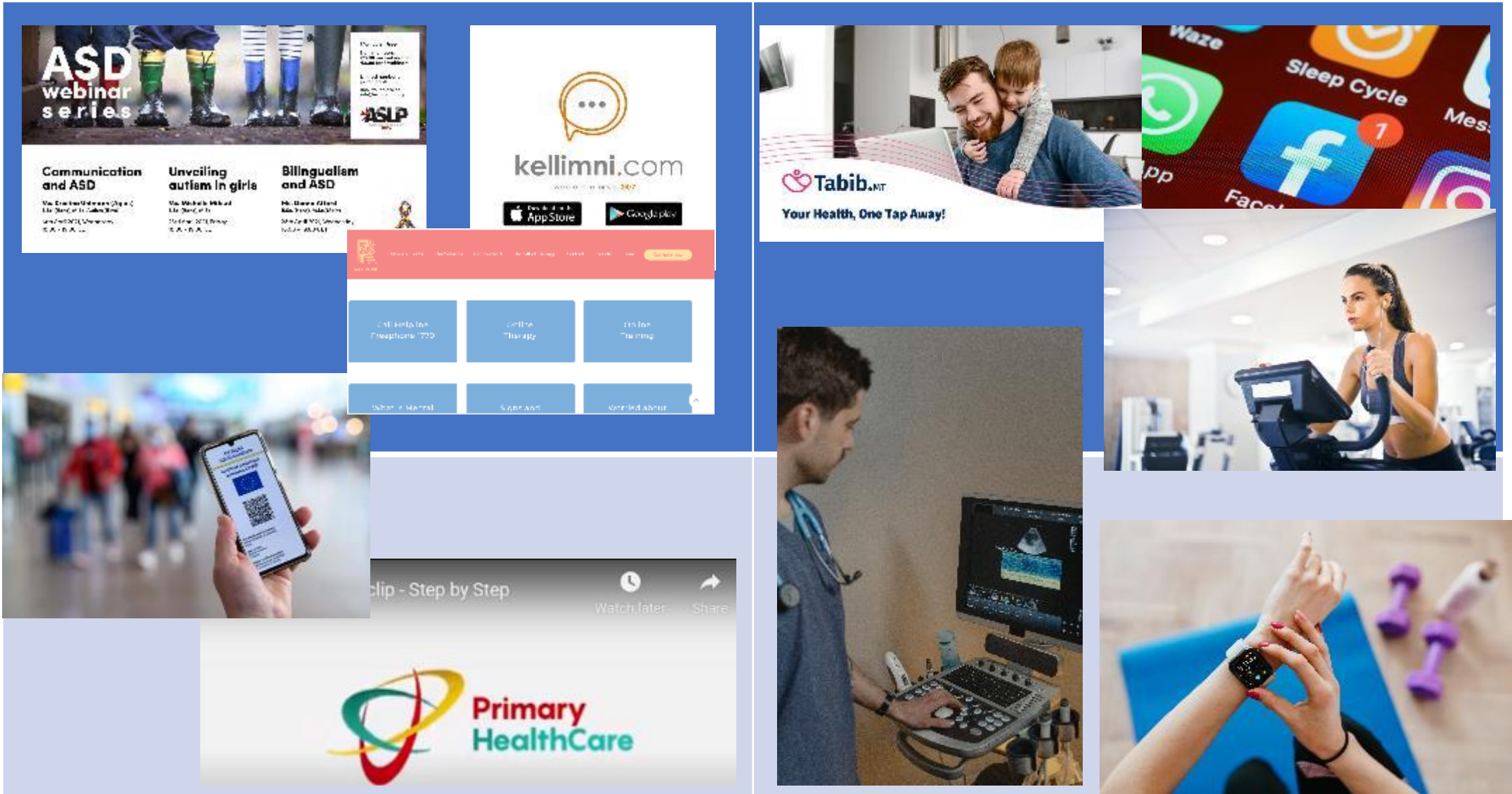


ILLUSTRATION: START/ADOBE STOCK

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Source: <https://searchhealthit.techtarget.com/definition/digital-health-digital-healthcare>

Various Digital Health Technologies



DIGITAL HEALTH

—
A PATIENT
PERSPECTIVE

PLUS 1

Improved patient records through eHealth Records which bring together reports, results and other information useful for patient

ePrescriptions where used save on time & money & facilitate Cross Border Healthcare

Telemedicine facilitates access for situations where face-to-face encounters are difficult to arrange.

Telehealth infrastructure facilitates access eg in long-distance health care.

DIGITAL HEALTH

A PATIENT PERSPECTIVE

PLUS 2

Reliable websites & Social Media as a means of gathering information, raising awareness & finding support

Mobile health APPs assist in self-monitoring and accessing information e.g. apps for fitness, nutrition, blood-pressure/heart rate monitoring, smoking cessation etc

Wearable devices help in self-management by keeping records of temperature, glucose levels, smartphone-based pacemaker devices, pain monitoring etc.

Various ways of communication e.g. reminders allow to decrease missed appointments and saves on DNA

DIGITAL HEALTH

A PATIENT PERSPECTIVE

MINUS

In eHealth records who 'owns' & has access to the data? What about informed consent?

ePrescriptions not working everywhere

Information over internet may be mistaken for a patient-healthcare provider encounter – may delay intervention or be damaging

Various levels of IT literacy & digital health literacy may be a disadvantage for the patients

What about data protection when using APPs?
Privacy and security standards may vary from country to country – need to have models focused on value and quality of care for patients.

Different systems which code data differently give rise to interoperability issues – difficulties with COVID green pass!

A COLLECTION OF COMMENTS

Research Carried out in 2020 by ASLP on the experience of practitioners and clients about their experience of tele-practice gave the following comments

- Positive comments re. online sessions – no effect on quality of service provision in most cases
- Technological difficulties e.g. poor internet connection
- Challenges met by elderly who might be unaccustomed to using technology
- Opportunity for indirect intervention especially for clients with poor attention maintenance and seating tolerance – zoning in on the quality of parental input
- Frequency of intervention was still limited in some cases

DIGITAL HEALTH

—
A PATIENT
PERSPECTIVE

INTERESTING

The quick growth of various aspects of digital health e.g. Telemedicine, personalised devices and Mobile Health apps over the past 2 years of COVID has pushed the fast-forward button which will certainly not have a rewind!

Digital Health may provide a more sustainable health care in an era of growing demands and shortages of funds, time and healthcare professionals. E.g. Mental Health Services as reported by Jacqueline Sperling (Clinical Psychologist, faculty of Harvard Medical School, McLean Hospital) where online intensive group therapy for children with Anxiety and OCD were found as effective as face-to-face sessions.

Digital Innovations can help in improved

- Diagnosis
- Therapeutic/Intervention options
- Time saving & increase access for homebound persons
- Research

DIGITAL HEALTH

A PATIENT PERSPECTIVE

FOOD FOR THOUGHT

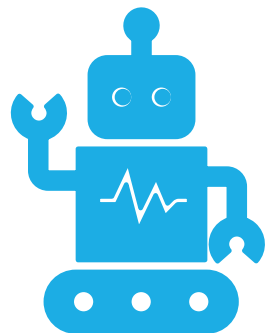
Digital era is here to stay so we have to find ways of making the best use of it – new developments such as Block Chain and Artificial Intelligence to be explored. Important that patients & carers are considered as active partners along the whole process

Recognition of the importance of Digital Health by WHO: Global Strategy on Digital Health 2020-2025.

The EU recognises the importance of Digital Health with budgets devoted to research and development of eHealth in its broadest dimensions including Digital technologies such as 5G mobile communication, artificial intelligence and supercomputing which offer new opportunities to transform the way we receive and provide health and care services. They enable innovative approaches to independent living and integrated health and social care.

Ethical issues to be considered e.g. – when medical robots are used who is responsible for mistakes, they make example in surgery, the hospital, the developer or manufacturer, the doctor who used the robot ... Who?

Digital Health implemented in a way that respects patients' choices, capacity and willingness to participate in shared decision making.



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Bernstein C (2021) Digital Health (digital Healthcare)

<https://searchhealthit.techtarget.com/definition/digital-health-digital-healthcare>

EPF position paper on eHealth: http://www.eu-patient.eu/globalassets/policy/ehealth/epf-final-position-paper-on-ehealth_19december2016.pdf

WHO (2021) Global Strategy on Digital Health

<https://apps.who.int/iris/bitstream/handle/10665/344249/9789240020924-eng.pdf>

THANK YOU

Andy BLEADEN

Community Director, ECHAlliance



The Global Connector for Digital Health

European Connected Health Alliance



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About ECHAlliance

WHO



**Member Organisation
(900+ organisations)**

Companies, policy-makers, research orgs, health & social care providers, patient groups, insurance, procurers, government ministries



**20,000+ experts
/ professionals**



**Not for Profit
Organisation**

Registered in Ireland and in the UK

WHERE

**Global reach across
78 Countries and
4.6 billion people**



**International Network of 70+
Digital Health Ecosystems**
(200+ ecosystem gatherings a year)

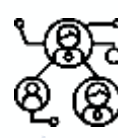
WHAT



**Connecting
the dots**



**Network of Geographical
& Thematic Health
Ecosystems**



**Comms &
networking**



**Supporting
our members**



**Global
Events**



**Funding/
Tenders**



Become a member of ECHAlliance



Boost your network



Join Working Groups



Make Direct Connections



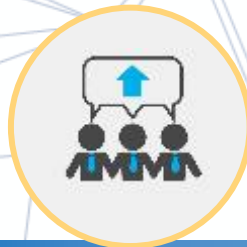
Funding and Tender



Collaboration in Funded Projects



Access our Ecosystems



Promote your organisation



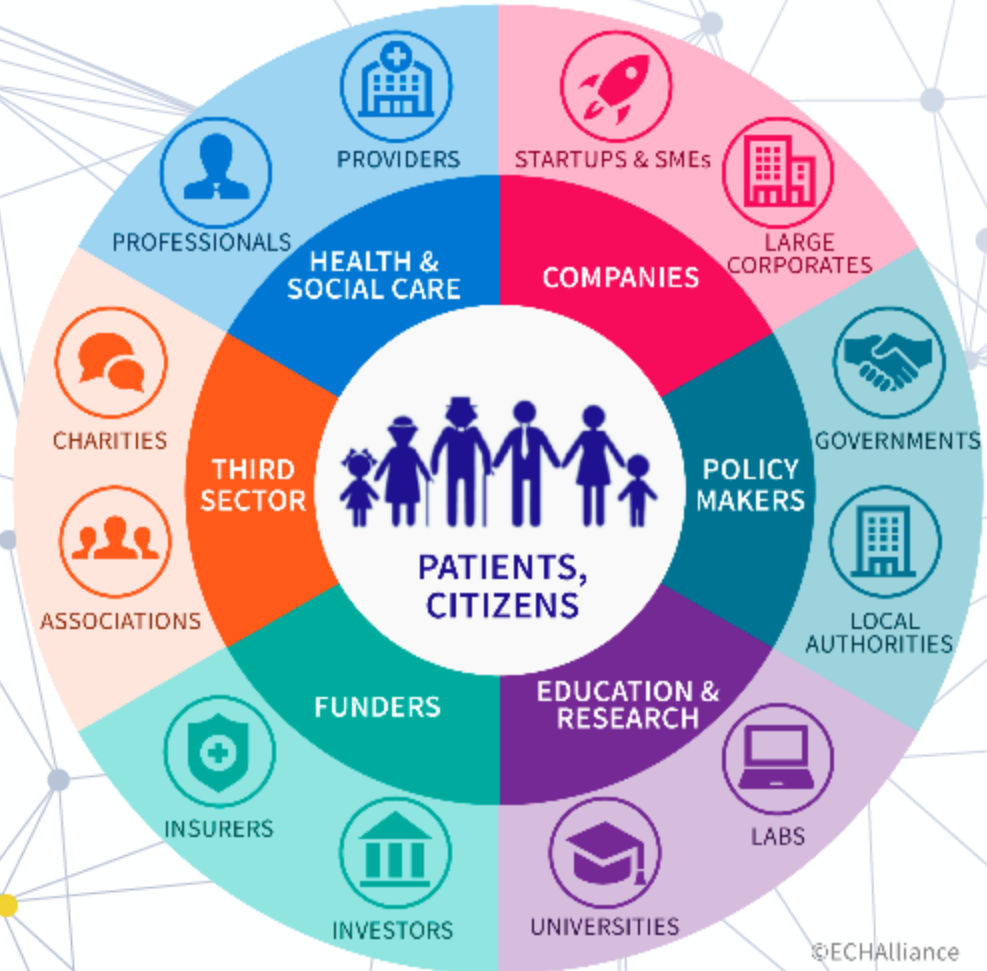
Discount on Events



Speaking Slots Opportunities



Ecosystems



...bring together a permanent community of stakeholders to develop a joint health agenda, aiming to address and find common solutions to regional health challenges

Match Need and Solution

The main benefit of working together in an Ecosystem is the multiplier effect of collaborating in our International Network of Ecosystems.

Ecosystems:

- **break down silos,**
- **transform healthcare delivery,**
- **create economic growth**



Our International Network of Ecosystems

 **ARGENTINA**

 **AUSTRALIA** - Melbourne

 **BELGIUM** - Brussels
BELGIUM - Flanders

 **BRASIL** 




 **BULGARIA** 

 **CANADA** - Quebec

 **CHILE**

 **CZECH REPUBLIC**









 **CROATIA** 




 **DENMARK** - Southern Denmark
 **DENMARK** - Scandinavia Nordic Health 2030 

 **ENGLAND** - Manchester
 **ENGLAND** - North West Coast
 **ENGLAND** - London
 **ENGLAND** - Yorks/Humber
 **ENGLAND** - South West Coast



 **ESTONIA**

 **FINLAND** - Oulu
 **FINLAND** - Ostrobothnia
 **FINLAND** - South Ostrobothnia
 **FINLAND** - Kuopio
 **FINLAND** - Central Finland
 **FINLAND** - Helsinki

 **FRANCE** - Bretagne 
 **FRANCE** - Hauts-de-France 
 **FRANCE** - Nice 
 **FRANCE** - Normandy 

 **GERMANY** - Hess
 **GERMANY** - Nuremberg
 **GERMANY** - Rheinland

 **GREECE** - Athens

 **HUNGARY** - West Hungary 

 **INDIA** 





 **ISRAEL** 

 **ITALY** - Treviso



 **LITHUANIA**

 **MALTA**

 **MEXICO**

 **NETHERLANDS** - Friesland 
 **NETHERLANDS** - Health Valley 

 **NORTHERN IRELAND**

 **NORWAY** - Smart Care Cluster
 **NORWAY** - Health Tech Cluster



 **POLAND** 


 **PORTUGAL** - SHAFE Portugal
 **PORTUGAL** - Digital Health Portugal
 **PORTUGAL** - Health Cluster Portugal

 **REPUBLIC OF IRELAND**


 **ROMANIA** - Transylvania 
 **ROMANIA** - South West Oltenia 

 **SERBIA**


 **SCOTLAND** - Highlands & Islands
 **SCOTLAND** - Scottish Digital Health and Care Ecosystem

 **SLOVENIA**

 **SPAIN** - Extremadura
 **SPAIN** - Valencia
 **SPAIN** - Galicia
 **SPAIN** - Catalonia
 **SPAIN** - Basque Country

 **SWEDEN** - North Sweden Life Science Ecosystem
 **SWEDEN** - Health & Welfare Technology Ecosystem

 **URUGUAY**

 **USA** - New York

 **WALES**

 **Moldova Ecosystem**

 **Iceland Ecosystem**

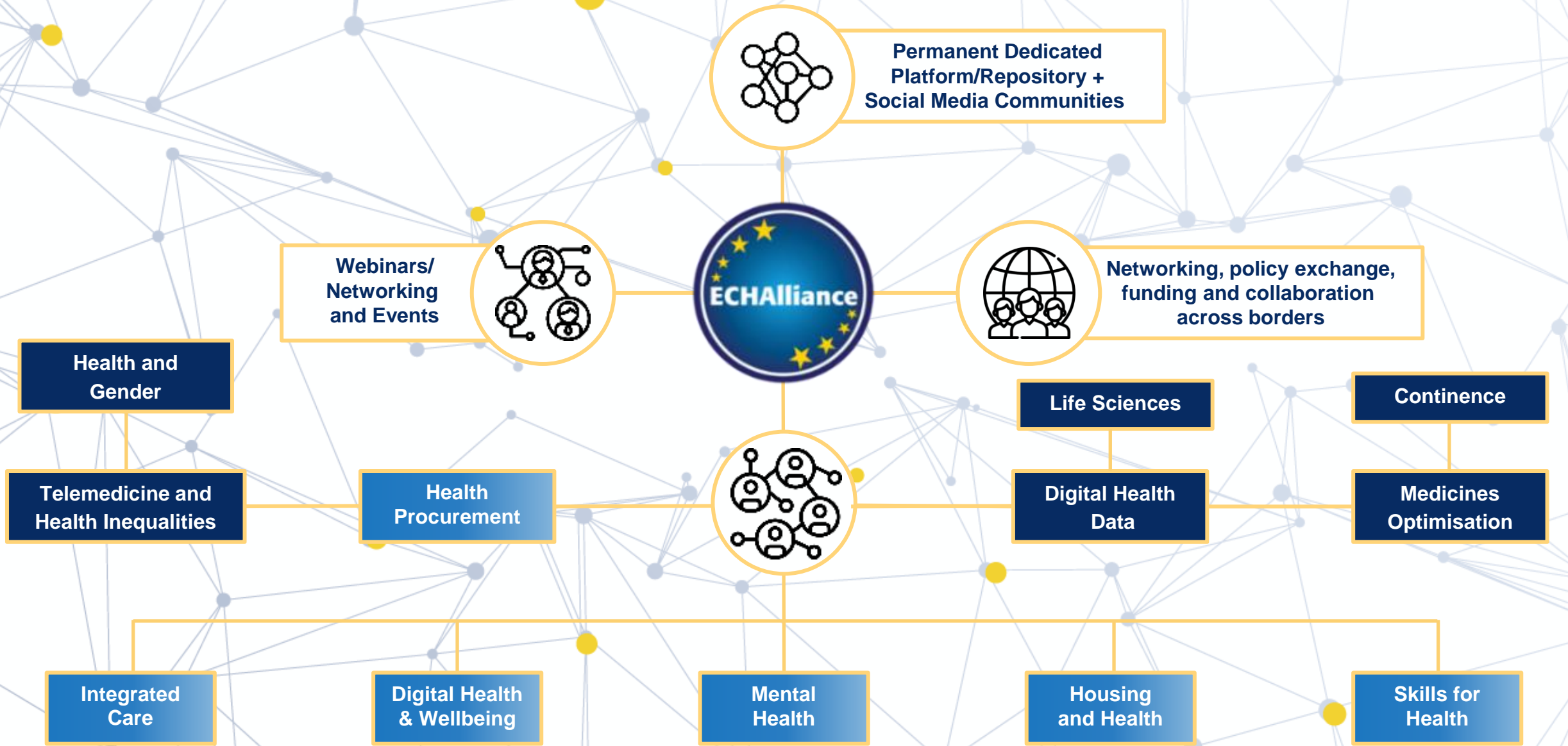
 **6th English Ecosystem - Leeds**

 **6th Spanish Ecosystem**

 **Japan IPARK Ecosystem**



Thematic Ecosystems





Our EU Projects



Digital health and data policies



Health management and safe medication



Smart cities



Skills for health and care workforce



AI for health and wellbeing



Demographic change and healthy living





The Digital Health Society

A multi-stakeholder initiative



**The Digital Health Society (DHS) is
the data arm of ECHAlliance**



Share

**Share Insights on Harnessing
the Potential of Data**



Reflect

**Reflect on Health data
Governance**



Mobilize

**Mobilize the European
Health Data Space**

contact: dhs@echalliance.com

www.thedigitalhealthsociety.com

RESPONSES FROM THE AUDIENCE / Q&A



15h30-15h45: Responses from the audience / Q&A

Patrice FORGET Chair of SIP

HIGH-LEVEL SUMMARY FROM BREAKOUT SESSION 1 – UPTAKE OF PATIENT REPORTED OUTCOMES BY REGULATORS

1. Implementation of ICD-11 & ICF by all EU MS for the digitalisation of healthcare services
2. PROMs need to be related to the ICD-11 diagnosis/condition - like disease specific PROMs (if available) and be validated
3. Pain as a quality indicator assessment by the use of PROMs, e.g. pain intensity and functioning as a COS (pain is subjective) to be used in clinical trials & real life
4. Patient- and clinician-friendly digital tools for health services and health & digital literacy – participation of patients at every step

HIGH-LEVEL SUMMARY FROM BREAKOUT SESSION 2 – LEARNING FROM EACH OTHER AND EXCHANGING BEST PRACTICES IN DIGITAL HEALTH

1. Promote the alignment of best practices for assessment and management from in-person care to digital health spaces (e.g. interdisciplinary and multimodal)
2. Establish standardised measurements throughout electronic medical recording and patient reported outcomes
3. Accommodate patients' expectations, assess patients' needs, plan proper and timely treatment plan to inform different stages of digital care

HIGH-LEVEL SUMMARY FROM BREAKOUT SESSION 3 – DIGITAL HEALTH LITERACY

1. Foster the infrastructure for digital health literacy for all, including patients and HCPs, by including them in the development process of the systems, to ensure it covers their needs
2. Support the training and education of HCPs and patients and organisations, in order to contribute to the continued development of digitalisation of healthcare services/systems
3. Allocate adequate resources and funding for digital health literacy, to close the digital skills gap, and to address the importance of early and late learning
4. Ensure plain language, appropriate media, and that all materials are reviewed by patient groups

Deirdre RYAN

President of Pain Alliance Europe (PAE)

THANK YOU!

An event report is available on our website:

<https://www.sip-platform.eu/events/save-the-date/sip-digital-health-event-31-03-2022>

Download our Position Paper on Digital Health:

<https://www.sip-platform.eu/resources/sip-positions/digital-health-and-pain-policy>

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The 'Societal Impact of Pain' (SIP) platform is a multi-stakeholder partnership led by the European Pain Federation EFIC and Pain Alliance Europe (PAE), which aims to raise awareness of pain and change pain policies. The scientific framework of the SIP platform is under the responsibility of EFIC and the strategic direction of the project is defined by both partners. The pharmaceutical company Grünenthal GmbH is the main sponsor of the Societal Impact of Pain (SIP) platform.

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