Patient Partnerships in Research

How we can co-create the future of research from bench to bedside

Deirdre Ryan, President of Pain Alliance Europe

QsPainRelief

Pain Alliance Europe

(Alan Dyer /VW PICS/UIG via Getty Images)

Pain Alliance Europe (PAE)
is a non-profit organisation based in Belgium,
functioning as an umbrella organisation
representing over 400,000 pain patients through
40 national and regional associations in 17 European countries,
concerned with chronic pain, regardless the underlying condition.

For PAE, quality of life for a chronic pain patient means giving the patient the right to choose the best possible solutions and support to live their life according to their possibilities and wishes.

We aim to promote awareness of chronic pain, to develop European policy on chronic pain, and to reduce the impact of chronic pain on European society in all areas.

In addition to the core activities that keep an organisation functioning there are 3 main pillars to PAE’s work

SIP

The **Societal Impact of Pain**
is a multi-stakeholder partnership led by PAE and the European Pain Federation (EFIC)

We are supported by 9 National Platforms that further the European agenda at national levels in France, Malta, Netherlands, Belgium, Spain, Finland, Portugal, Switzerland and Slovenia

Together we aim to raise awareness of pain, and to develop pain policies. We have created several position papers and give feedback on the EU Commission’s Health initiatives and roadmaps such as the Beating Cancer Plan, and the EU Health Data Space Roadmap

BMP GRANT Patient Centred Innovation

Soon to be the PAE
PAIN PATIENT-CENTRED INNOVATION GRANT

The PPCIG Grant encourages patient-centric, patient driven, scientifically robust innovation and research projects, while creating better access to innovative treatments, promoting prevention and self-management approaches, decreasing stigma and, finally, working together to improve the quality of life for people living with these disabling conditions.

The PPCIG Grant aims to create an environment where patient involvement is the basis for new initiatives. The projects must create new ideas which will directly impact on patients’ needs, and at the same time increase awareness of chronic pain conditions and diseases where pain is a significant symptom.

Research Initiatives

PAE wants to amplify pain patients’ voices from across Europe and we do this by surveying our network each year on topics that are most relevant and pressing to patients, in their own language.

We also collaborate with many EU research projects from co- designing protocols to developing patient materials, sourcing participants and disseminating findings directly to patients and other pain stakeholders.

The Societal Impact of Pain Platform

Milestones of the SIP platform:

- 2011: The Societal Impact of Pain A Road Map for Action
- 2014: Informal Health Conclusions Italian Presidency, Informal Health Council
- 2016: Eight Policy Recommendations: Time for Action
- 2017: Policy Recommendations 2017
- 2018: SIP Position Paper
- 2019: SIP Thematic Network Joint Statement
- 2020: New governance model for SIP
- 2020: **SIP Cancer Position Paper**
- 2021: **SIP Workplace Integration and Adaptation Position Paper**
- 2022: SIP Road Map Monitor
- 2022: **SIP Digital Health: Pain Assessment and Quality Indicators Position Paper**
- 2023: SIP Joint Statement on Pain and Mental Health
- 2023: **SIP ICD-11 Position Paper**

3 Editions of the BMP Grant Themes and Winners

2017 Overcoming problems in access to treatment

Master Your Pain: Improving Access to Personalized Treatment of Pain Due to Rheumatic Diseases. (Denise Hanssen, Groningen University)

MyBrainNet (Dystonia Europe)

Reduce Sensorial Pain in Autism Spectrum Disorders (ASPERGA – Asociación Galega de Asperger)

2019 Stop Stigma!

ASpida: Against Stigma pain intervention development Approach (*Vasilis Vasiliou, from the School of Applied Psychology, University College Cork*)

StigmApp (*Yiannis Koumpouros, from the University of West Attica*)

#RompeConElDolor – Breaking stigma on chronic pain in diabetes and other diseases through shared experiences on social media (*Federación Española de Diabetes (FEDE)*)

2022 Healthy Sleep

CBT-I World Café: Identifying what options are available to people with pain who also report poor sleep, and how acceptable and effective these options are. (*Kieran O'Sullivan from the University of Limerick)*

Expert Finder: Developing an interactive map will show doctors, sleep labs, and RLS support groups. *(Katharina Glanz of the European Alliance for Restless Legs Syndrome (EARLS)*

BMP GRANT Patient Centred Innovation

PAE Patient Surveys

2017 Diagnosis, treatment and impact of chronic pain. 3490, 17 EU Cs

2018 Pain and work life. 4403, 14 EU C’s <50 resp.

2019 Pain and stigma. 6069, 28 EU C’s,14 languages

2020 Pain and e-health and m-health. 1789, 28 EU C’s

2020,21 Covid 19 impact on chronic pain 1156, 19 EU C’s, 12 Lang,

970, 7 EU Cs

2021 Diagnosis and treatment. 2203, 12 EU C’s, 15 <30 resp.

2024 Your pain, self management, and mental health

Pain Alliance Europe

Research Initiatives

Recent PAE Publications

Bova, G., Domenichiello, A., Letzen, J. E., Rosenberger, D. C., Siddons, A., Kaiser, U., ... & Pogatzki-Zahn, E. M. (2023). Developing consensus on core outcome sets of domains for acute, the transition fro

Dupoiron, D., Brill, S., Eeltink, C., Barragán, B., Bell, D., Petersen, G., Eerdekens, M., Ryan, D. and Rakuša, M., 2022. Diagnosis, management and impact on patients' lives of cancer-related neuropathic pa

Tesfaye,S., Brill,S., Eerdekens, M., Maderuelo Labrador, M., Petersen, G., de Rooij Peek,A., Reta,A., Ryan, D., Schaper,N., Tölle,T., Truini,A., Ziegler, D., 2023, Diagnosis, management and impact of painf

Barke, A., Palomares, A.C., Cameron, P., Forget, P., Ryan, D., Vanhaute, O., and Wilkinson, J., 2022. Why do we need to implement the ICD-11? When pain science and practice meet policies. European jo

Forget, P., Patullo, C., Hill, D., Ambekar, A., Baldacchino, A., Cata, J., Chetty, S., Cox, F.J., de Boer, H.D., Dinwoodie, K. and Dom, G., 2022. System-level policies on appropriate opioid use, a multi-stakeho

ETUDE

PANDOS

Pain and Opioids after Surgery

neuron ERA-NET NEURON

Together for brain research

PAREA

PSYCHEDELIC ACCESS AND RESEARCH EUROPEAN ALLIANCE

SAFEPOLYMED

Citizen empowerment
&
Safety improvement

Funded by the European Union

VOT

by EBC

European Brain Council

QSPainRelief

OECD

BETTER POLICIES FOR BETTER LIVES

INTEGRATE-Pain Consortium

NIH National Institutes of Health

IMI-PainCare

neuron ERA-NET NEURON

Together for brain research

Networking Pain: PRiSE Research Strategy

Developing a Pain Research Strategy for Europe: an international network of world-leading experts and patient representatives

2023-2024

ELSE: STIMCODE

BRAIN STIMULATION RECONSIDERED ? PARTICIPATIVE DEVELOPMENT OF A CODE OF CONDUCT FOR THE EUROPEAN UNION

2021-2024

Networking Chronic Pain: AGORA

Advancing Guidelines with Original Research Achievements in pain

2023-2024

Networking Chronic Pain: IT-PAIN

Improving Translational Research for Chronic Pain ? data alignment in preclinical and clinical studies

2023-2024

What is Public and Patient Involvement?

Is there a difference between involvement and participation?

What is Patient and Public Involvement (PPI)?

In an effort to clarify what is meant by involvement, there are three different ways in which people can become a part of the research process:

Participation: Being recruited as study participants is defined as participation in research

Engagement: Efforts aimed at raising awareness among the public around research, such as newspaper articles, or outreach activities such as open days at research facilities. Engagement activities are required for both participation and involvement.

Involvement: Refers to co-created and co-produced research with a focus on collaboration.

The Irish Health Research Forum a partnership of organisations and stakeholders that aims to influence health research in Ireland, has described PPI as:

“occurring when individuals meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarising, distributing, sharing and applying its resulting knowledge”.

It is also useful to include the often-quoted definition of PPI developed by INVOLVE, a UK organisation that supports PPI in research:

“PPI is research carried out ‘with’ or ‘by’ patients/members of the public rather than ‘to’, ‘about’ or ‘for’ them”.

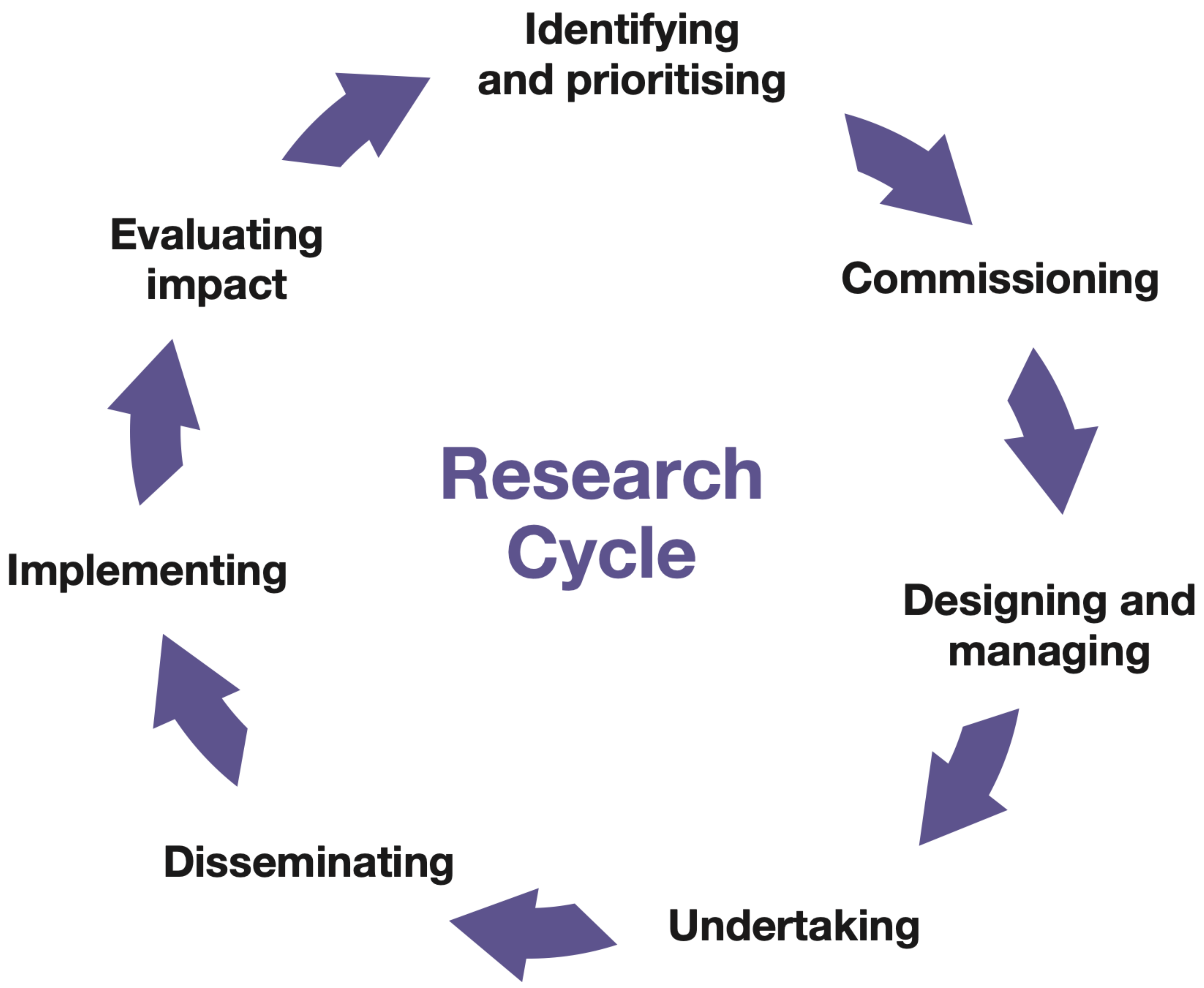
Why do patients and the public get involved in research?

Patients and the public get involved in research for a number of reasons:

- influenced by their diverse life experiences, interests, and prior involvement with healthcare and research
- wanting to help others and contribute to a better healthcare system
- wanting patient perspectives to be reflected and have influence in research and ultimately on healthcare
- interest in research and in contributing to scientific knowledge
- interest in the healthcare topic, often because of personal experience
- Altruistic reasons like helping others and giving back to the community are common motivators as is the belief that PPI can make research more meaningful for patients and facilitate tangible impacts to healthcare services.

The Healthcare Improvement Studies Institute, 2019

How and when can patients be involved?



Research Cycle

Identifying and prioritising

Commissioning

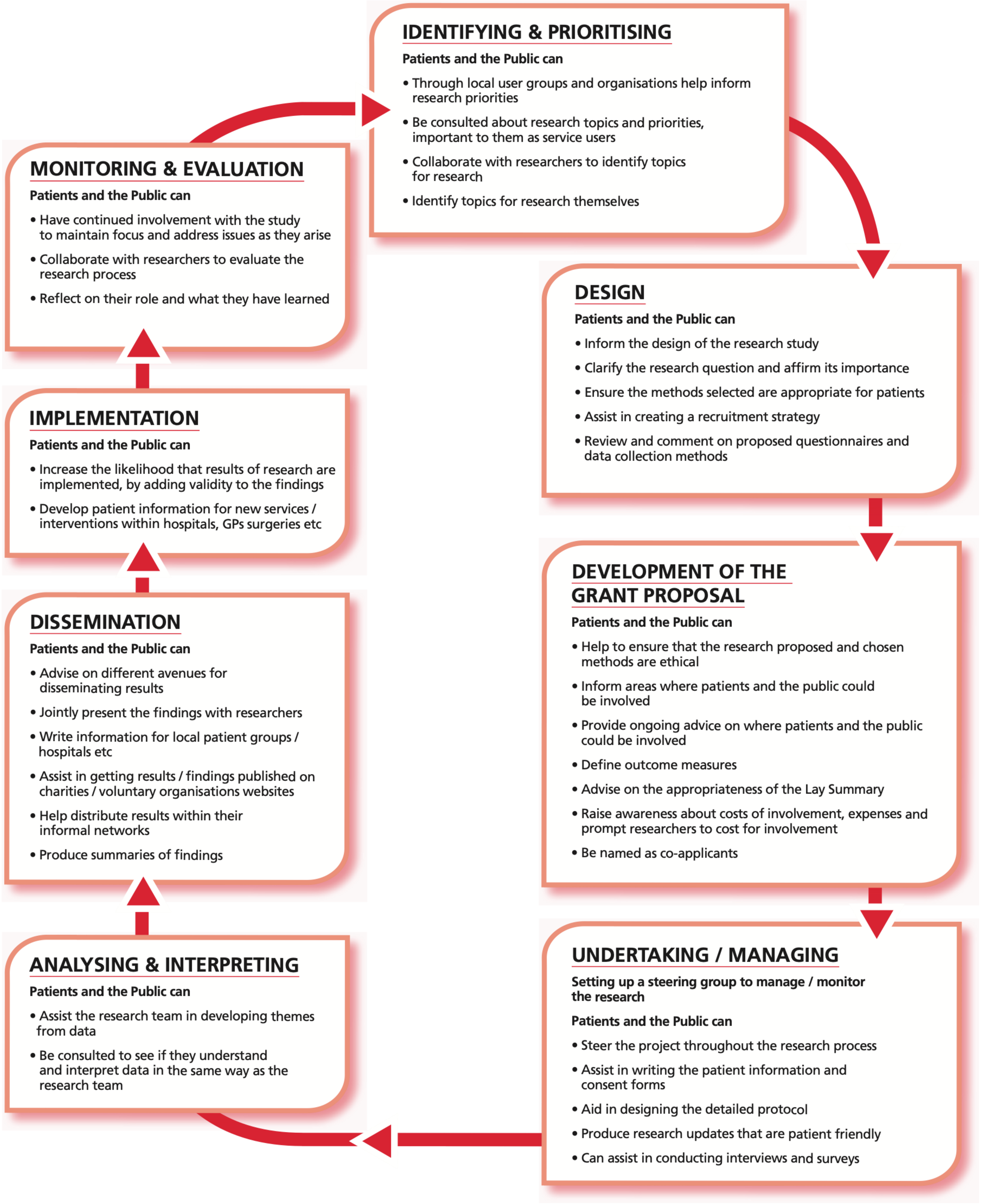
Designing and managing

Undertaking

Disseminating

Implementing

Evaluating impact



IDENTIFYING & PRIORITISING

Patients and the Public can

- Through local user groups and organisations help inform research priorities
- Be consulted about research topics and priorities, important to them as service users
- Collaborate with researchers to identify topics for research
- Identify topics for research themselves

DESIGN

Patients and the Public can

- Inform the design of the research study
- Clarify the research question and affirm its importance
- Ensure the methods selected are appropriate for patients
- Assist in creating a recruitment strategy
- Review and comment on proposed questionnaires and data collection methods

DEVELOPMENT OF THE GRANT PROPOSAL

Patients and the Public can

- Help to ensure that the research proposed and chosen methods are ethical
- Inform areas where patients and the public could be involved
- Provide ongoing advice on where patients and the public could be involved
- Define outcome measures
- Advise on the appropriateness of the Lay Summary
- Raise awareness about costs of involvement, expenses and prompt researchers to cost for involvement
- Be named as co-applicants

UNDERTAKING / MANAGING

Setting up a steering group to manage / monitor the research

Patients and the Public can

- Steer the project throughout the research process
- Assist in writing the patient information and consent forms
- Aid in designing the detailed protocol
- Produce research updates that are patient friendly
- Can assist in conducting interviews and surveys

ANALYSING & INTERPRETING

Patients and the Public can

- Assist the research team in developing themes from data
- Be consulted to see if they understand and interpret data in the same way as the research team

DISSEMINATION

Patients and the Public can

- Advise on different avenues for disseminating results
- Jointly present the findings with researchers
- Write information for local patient groups / hospitals etc
- Assist in getting results / findings published on charities / voluntary organisations websites
- Help distribute results within their informal networks
- Produce summaries of findings

IMPLEMENTATION

Patients and the Public can

- Increase the likelihood that results of research are implemented, by adding validity to the findings
- Develop patient information for new services / interventions within hospitals, GPs surgeries etc

MONITORING & EVALUATION

Patients and the Public can

- Have continued involvement with the study to maintain focus and address issues as they arise
- Collaborate with researchers to evaluate the research process
- Reflect on their role and what they have learned

Reality

How and when can patients and patient organisations be involved?

Agenda setting:
- Identifying or generating research topics or questions
- Prioritising topics for research
- Providing a patient perspective on outcomes that are important to patients and their families, e..g. through patent centred outcome s or PROMs

Funding:
- Providing input into funding decisions
- Contributing to the development of research proposals
- Reviewing research proposals

Design and Procedures:
- Advising on development of surveys and interview guides with respect to accessibility of language, question relevance and appropriateness to acceptability of format and timing
- Advise on scope to search strategy for reviews
- Advising on the feasibility of conducting research in ‘the real-world’ in relation to timing, type of intervention or identifying cultural issues that need to be considered
- Advising on outcomes that matter to patients/the public
- Advising on sampling
- Advising on ethical issues such as consent processes
- Developing patient information materials and reliable sources of information

Recruitment of study participants:
- Advising on recruitment/troubleshooting recruitment difficulties
- Identifying or assisting with access to potential research participants
- Developing recruitment materials
- Actively engaging in recruitment activities
- Advising on how to maintain adherence/continued participation

Data Collection:
- Contributing to literature reviews by locating relevant literature, screening and extracting or coding articles
- Collecting data from participants by conducting interviews, administering surveys, or co-facilitating focus groups
- Co-generating data with researchers on topics of interest through participatory methods
- Contributing to management of data collection e.g. tracking participant interaction/visits

Data Analysis:
- Actively conducting data analysis tasks e.g. coding interview transcripts
- Contributing to data analysis by guiding or identifying themes in reviews and/or qualitative studies
- Adding patient perspective to the synthesis and interpretation of findings
- Highlighting key findings
- Assist in the development of practice recommendations

Dissemination:
- Contribute to drafting journal articles/reports/posters/reviews
- Critically reviewing articles/reports etc
- Producing or co-creating accessible outputs on study findings such as ‘plain language’ summaries, participant feedback/ results communication, infographics or webinars
- Delivering or co-delivering presentations at conferences to project dissemination events
- Participating in the release of results or publications
- Determining avenues to share findings

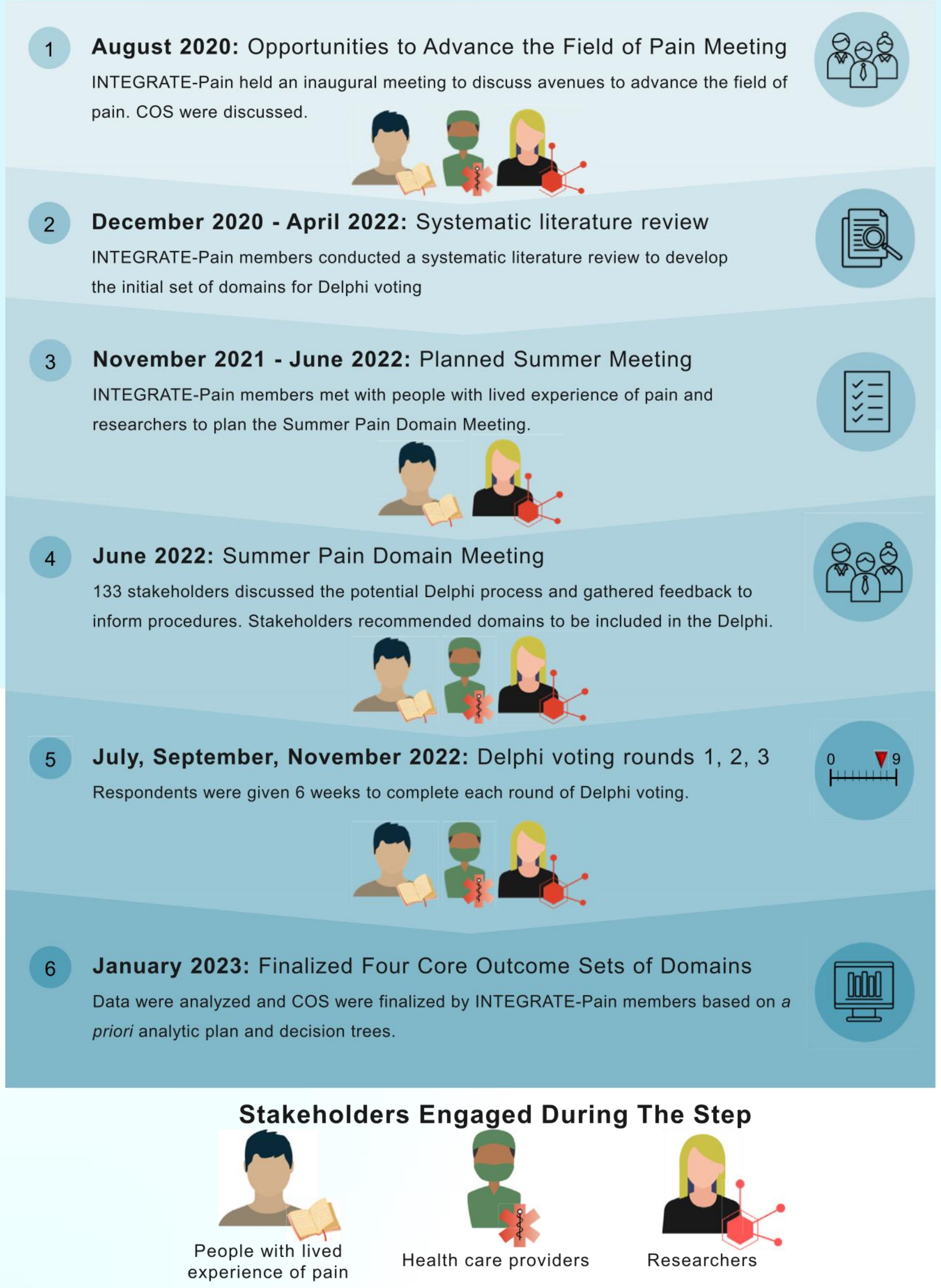
Facilitating Uptake:
- Contributing to clinical guideline development, and plain language question development
- Preparing decision aids for patients

Evaluation of Research:
- Providing feedback on the experience as a PPI contributor
- Participating in research directly relation to the topic and experience of PPI

Developing consensus on core outcome sets of domains for acute, the transition from acute to chronic, recur

Bova G, Domenichiello A, Letzen JE, Rosenberger DC, Siddons A, Kaiser U, Anicich A, Baron R, Birch J, Bouhassira D, Casey G. Developing consensus on core outcome sets of domains for acute, the transition from acute to chronic, recurrent/episodic, and chronic pain: results of the INTEGRATE-pain Delphi process. eClinicalMedicine. 2023 Dec 1;66.

INTEGRATE-Pain Core Outcomes Sets (COS) Project Timeline



1 **August 2020:** Opportunities to Advance the Field of Pain Meeting

INTEGRATE-Pain held an inaugural meeting to discuss avenues to advance the field of pain. COS were discussed.

2 **December 2020 - April 2022:** Systematic literature review

INTEGRATE-Pain members conducted a systematic literature review to develop the initial set of domains for Delphi voting

3 **November 2021 - June 2022:** Planned Summer Meeting

INTEGRATE-Pain members met with people with lived experience of pain and researchers to plan the Summer Pain Domain Meeting.

4 **June 2022:** Summer Pain Domain Meeting

133 stakeholders discussed the potential Delphi process and gathered feedback to inform procedures. Stakeholders recommended domains to be included in the Delphi.

5 **July, September, November 2022:** Delphi voting rounds 1, 2, 3

Respondents were given 6 weeks to complete each round of Delphi voting.

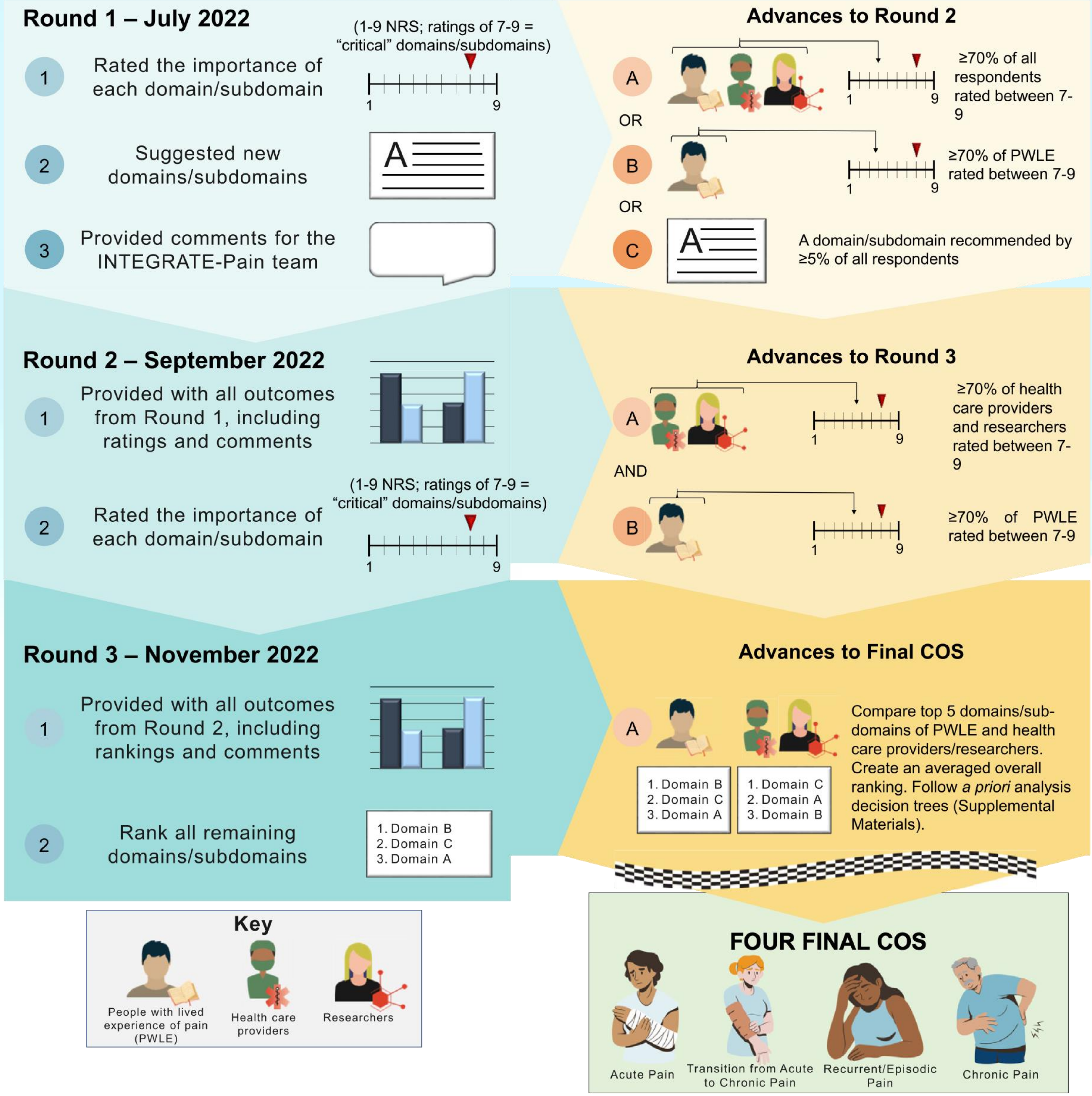
6 **January 2023:** Finalized Four Core Outcome Sets of Domains

Data were analyzed and COS were finalized by INTEGRATE-Pain members based on a *priori* analytic plan and decision trees.

Stakeholders Engaged During The Step

Fig. 1: The timeline for the INTEGRATE-Pain core outcomes set initiative.

Delphi Voting Process for All Four COS



Round 1 – July 2022

1 Rated the importance of each domain/subdomain

(1-9 NRS; ratings of 7-9 = "critical" domains/subdomains)

2 Suggested new domains/subdomains

3 Provided comments for the INTEGRATE-Pain team

Advances to Round 2

A ≥70% of all respondents rated between 7-9

OR

B ≥70% of PWLE rated between 7-9

OR

C A domain/subdomain recommended by ≥5% of all respondents

Round 2 – September 2022

1 Provided with all outcomes from Round 1, including ratings and comments

2 Rated the importance of each domain/subdomain

(1-9 NRS; ratings of 7-9 = "critical" domains/subdomains)

Advances to Round 3

A ≥70% of health care providers and researchers rated between 7-9

AND

B ≥70% of PWLE rated between 7-9

Round 3 – November 2022

1 Provided with all outcomes from Round 2, including rankings and comments

2 Rank all remaining domains/subdomains

1. Domain B
2. Domain C
3. Domain A

Advances to Final COS

A Compare top 5 domains/subdomains of PWLE and health care providers/researchers. Create an averaged overall ranking. Follow *a priori* analysis decision trees (Supplemental Materials).

1. Domain B
2. Domain C
3. Domain A

1. Domain C
2. Domain A
3. Domain B

FOUR FINAL COS

Acute Pain
Transition from Acute to Chronic Pain
Recurrent/Episodic Pain
Chronic Pain

Key

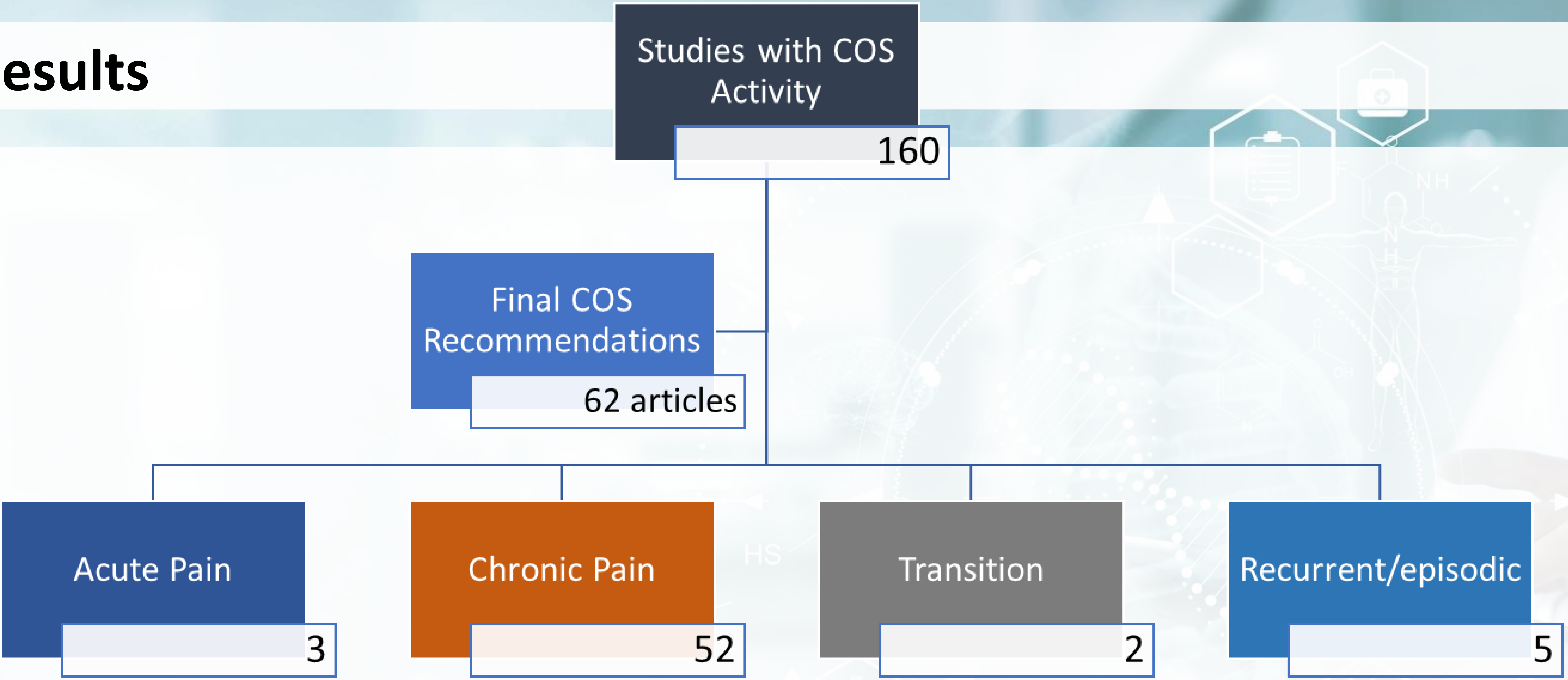
People with lived experience of pain (PWLE)
Health care providers
Researchers

Fig. 2: Methods and consensus definition decisions involved in the Delphi method across all three rounds. Based on advice from the advisory committees and feedback from Delphi respondents, changes in procedures were made (as advised) and clearly communicated to Delphi respondents prior to the dissemination of the subsequent round.

Pain Categories for Delphi

Pain Category	Definition	Example Condition(s)
Acute pain	Pain experiences and conditions lasting for a relatively limited time, up to a few weeks, and generally remitting when the underlying pathology resolves; often occurs after trauma, surgical interventions, and some disease processes	Acute post-operative pain, pain in labor, fracture, and ulcer
Transition from acute to chronic pain	Pain experiences and conditions lasting from a few weeks to three months	Post-operative recovery
Recurrent/episodic pain	Pain experiences and conditions lasting for a relatively short time but recurring across an extended period.	Sickle cell-associated pain, migraine, polymyalgia rheumatica, and calcium phosphate deposition
Chronic pain	Pain experiences and conditions lasting longer than three months	Chronic low back pain, chronic postsurgical pain, chronic pelvic pain, and diabetic neuropathy

Results



Studies with COS Activity

160

Final COS Recommendations

62 articles

Acute Pain

3

Chronic Pain

52

Transition

2

Recurrent/episodic

5

N=30 distinct domains

Range of domains recommended per article: (4-9)

N=241 distinct domains

Range of domains recommended per article: (2-21)

N=19 distinct domains

Range of domains recommended per article: (13-15)

N=29 distinct domains

Range of domains recommended per article: (4-7)

?

What percentage of PROMS are content validated by patients?

Final Core Outcome Sets (COS) Based on Delphi Voting

ACUTE PAIN

COS Must Include*:

Domains
- **Pain**
  - *Sub-domains*: Pain Intensity; Pain Interference
- **Physical Function**
- **Quality of Life**

Domain(s) that might be considered^:

- **Analgesic Use**

TRANSITION FROM ACUTE TO CHRONIC PAIN

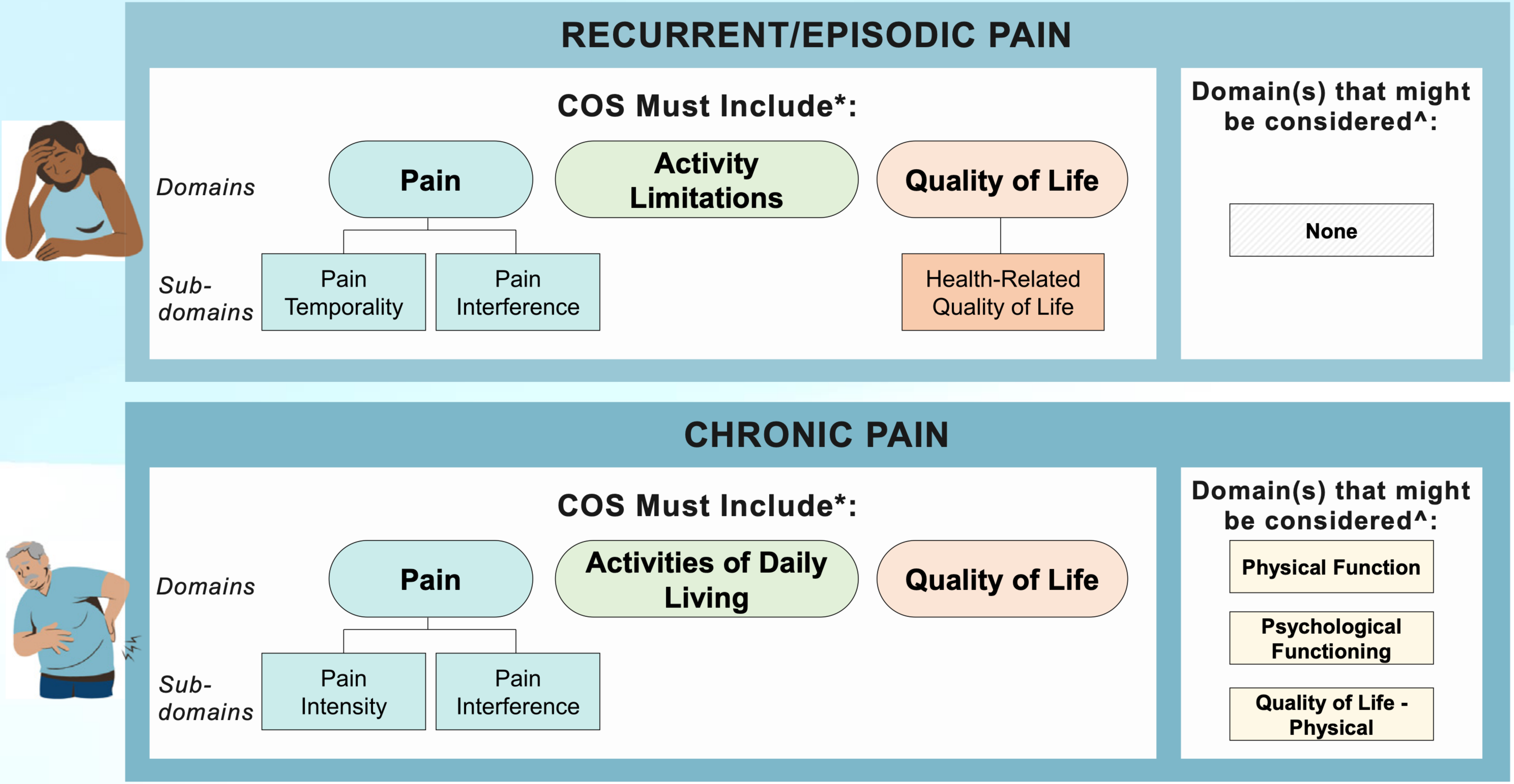
COS Must Include*:

Domains
- **Pain**
  - *Sub-domains*: Pain Intensity; Pain Interference
- **Physical Function**
- **Quality of Life**

Domain(s) that might be considered^:

- **Psychological Functioning**
- **Sleep**

Final Core Outcome Sets (COS) Based on Delphi Voting



RECURRENT/EPISODIC PAIN

COS Must Include*:

Domains: **Pain** | **Activity Limitations** | **Quality of Life**

Sub-domains: Pain Temporality, Pain Interference (Pain) | Health-Related Quality of Life (Quality of Life)

Domain(s) that might be considered^:

- **None**

CHRONIC PAIN

COS Must Include*:

Domains: **Pain** | **Activities of Daily Living** | **Quality of Life**

Sub-domains: Pain Intensity, Pain Interference (Pain)

Domain(s) that might be considered^:

- **Physical Function**
- **Psychological Functioning**
- **Quality of Life - Physical**

*Must Include = Domains/subdomains that were top ranked in the averaged overall rankings across both groups and met the ***a priori*** decision tree rules to be part of the final COS
^Might Be Considered = Domains/subdomains that did not meet the ***a priori*** decision tree rules for the final COS but were ranked in either group's top 5 domains/subdomains

Fig. 3: Final core outcome sets across all four pain stage categories.

?

Do you believe the same COS Domains in clinical research can be applied in the pre-clinical and basic/fundamental science spheres?

Patient engagement in preclinical laboratory research: A scoping review

Fox, Grace, et al. "Patient engagement in preclinical laboratory research: a scoping review." *EBioMedicine* 70 (2021).
https://doi.org/10.1016/j.ebiom.2021.103484

Background: ‘Patient engagement’ involves meaningful collaboration between researchers and ‘patient partners’ to co-create research. It helps ensure that research being conducted is relevant to its ultimate end-users. Although patient engagement within clinical research has been well documented, the prevalence and effects of patient engagement in translational preclinical laboratory research remain unclear. The aim of this scoping review is to present current patient engagement activities reported in preclinical laboratory research.

Methods: MEDLINE, Embase, and grey literature were systematically searched from inception to April 2021. Studies that described or investigated patient engagement in preclinical laboratory research were included. Patient engagement activities where patients (i.e. patients, family members, caregivers or community mem- bers) provided input, or consultation on at least one element of the research process were eligible for inclu- sion. Study characteristics and outcomes were extracted and organized thematically.

Findings: 32 reports were included (30 primary studies, 1 narrative review, and 1 researcher guide). Most studies engaged patients at the education or priority setting stages (n=26). The most frequently reported ben- efit of patient engagement was ‘providing a mutual learning opportunity’. Reported barriers to patient engagement reflected concerns around ‘differences in knowledge and research experience’ and how this may challenge communication and limit meaningful collaboration.

Interpretation: Patient engagement is feasible and beneficial for preclinical laboratory research. Future work should focus on assessing the impacts of patient engagement in this area of research.

Funding: None.

Study details	Method of stakeholder recruitment						Stage of research where patient partners contributed							
	Partnering with other organization	Social marketing	Other	Community outreach	Health system	N/R	Education	Funding	Priority setting	Study design	Data collection	Data analysis	Dissemination of results	Awareness
Rheault et al. [18]	√								√					
van den Berg et al.[19]						√			√	√				
Boenink et al.[20]						√			√	√				
Russell et al.[21]	√	√					√		√					√
Tamagnini et al.[22]	√√						√		√	√				√
Frazier et al.[23]	√	√							√					
Talebizadeh et al.[24]			√			√			√	√				
McDonnell et al.[25]	√	√							√	√				
Parsons et al.[26]	√				√				√					
Zoeller [27]						√			√				√	
Filocamo et al.[28]						√	√		√√	√			√	√
Black and Brockway-Lunardi[29]	√						√	√	√					√
Godard et al. [30]	√												√	
*Haga et al.[31]		√					√						√	√
*O'Daniel et al.[32]		√					√							
Terry et al.[33]	√	√					√		√	√			√	
Pulver et al.[34]				√			√							
Arturi [35]			√				√	√	√				√	√
Baart and Abma [36]	√						√		√					√
Boon and Broekgaarden [37]						√	√	√	√					√
Van Olphen et al. [38]	√						√	√					√	
Haddow et al.[39]						√	√							
Riter and Weiss[40]	√	√					√							
Mollan et al. [42]		√								√				
Costello and Dorris[43]	√												√	
Davies et al. [45]						√	√		√					
Taruscio et al.[46]			√				√		√					
Moore et al.[47]	√						√			√			√	
Mahler and Besser[48]				√			√							
Birch et al. [49]	√		√										√	√
Total (%)**	15 (52)	7 (24)	4 (14)	2 (7)	1 (3)	8 (28)	17 (59)	4 (14)	18 (62)	9 (31)	0 (0)	0 (0)	10 (34)	9 (31)

Which challenges are presented by involving patients?

Table 4
Reported barriers and enablers to patient engagement (*n*=32).

Barriers	Studies
Addressing the priorities of all team members can be difficult to achieve [R]	8
It is challenging to capture diverse viewpoints and research priorities from members with different research backgrounds	
Structural barriers to patient engagement exist [R]	7
Insufficient researcher resources to support patient partners including time and budget restrictions	
Defining the patient partner population to recruit can be challenging [R]	5
Recruitment may inadvertently exclude members of particular groups	
Lack of researcher training opportunities to guide meaningful patient engagement in basic science research [R/P]	4
Lack of research experience, preparation, and clarity around patient engagement expectations	
Enablers	Studies
Creating a safe space where patient partners and researchers feel comfortable to collaborate [R/P]	6
Ensure team members feel comfortable in sharing individual views	
Distribute learning materials before and after meetings	
Consider arranging the team structure to support patient engagement [R/P]	5
Training and resources for researchers to overcome challenges	
Critically building study team composition including an engagement coordinator	
Develop patient engagement strategies ahead of time [R]	2
Plan for equitable division of responsibilities to reduce the burden on the project team and help partners feel more invested	
Consider the needs of the community	
External organizations that actively support patient engagement in basic science research projects [R/P]	1
Enforcing and facilitating the involvement of patient partners	

Abbreviations: R and P denote themes that pertain to researchers and patient partners, respectively.

Barriers to patient engagement in basic science

Benefits to patient engagement in basic science

Table 3

Reported benefits and challenges of patient engagement (*n*=32).

Benefits	Studies
A mutual learning opportunity [R/P]	16
Patient engagement facilitates patient partner understanding and interest in basic science research	
Patient partners can improve researcher understanding of the real-life priorities and impact of their work	
An opportunity to build new skills, knowledge, interests, and perspectives [R/P]	13
Engagement experiences can inform and broaden perspectives of researchers	
Engaging a diverse patient partner group provides a greater understanding of diverse experiences	
Patient partner input can improve study quality and efficiency [R/P]	9
Patient engagement informs the research question, study methodology, and future research by fostering important discussions	
Patient partners can play an important role in disseminating research findings	
Improves communication with the public and strengthens the research through trust [R/P]	8
Encourages a sense of partnership (between patients and researchers) and improves patient partner trust of the research community	
Increases self-confidence and the impact of the patient voice	
May increase trainee recruitment/retention, external collaboration, and recruitment [R]	5
There is potential to create external partnerships that are rare for professional engagements	
Improved trainee retention by renewing interest in the real-life implications of their research	

Considerations

Literacy

Health literacy

Digital literacy

Respect

Plain Language

Inclusion

Diversity

Adaptability

Pain levels

Concentration

Comfort

Timing

Travel

Prevention of pain chronification

Improvement in the lives of people living with chronic pain

Impact

Helpful Resources:

Used in this presentation:

Involving patients and the public in research (2019) The Healthcare Improvement Studies (THIS) Institute

Patient and Public Involvement in Health and Social Care Research: A handbook for Researchers (2019) Research National Institute for Health Research, NHS, UK.

Making a start: A Toolkit for charities to begin a PPI relationship. (2020) HRCI & Trinity College Dublin

Buck D, Gamble C, Dudley L, et al. From plans to actions in patient and public involvement: qualitative study of documented plans and the accounts of researchers and patients sampled from a cohort of clinical trials. BMJ Open 2014;4:e006400. doi:10.1136/bmjopen-2014- 006400

Helpful resources on PPI and Patient Involvement:

The European Patients' Academy on Therapeutic Innovation (EUPATI) https://connect.eupati.eu/

The Irish Platform for Patient Organisations, Science and Industry (IPPOSI) https://www.ipposi.ie/

UK Public Participation Charity- INVOLVE https://involve.org.uk/

QSPainRelief

Pain Alliance
Europe

Thank you for your attention

president@pae-eu.eu