



From consultation to co-ownership

Making lived experience count in mental-health research, policy and implementation

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LIVED EXPERIENCE → DECISIONS

Rights-based practice must transfer power

**People are not the setting in which implementation happens.
They are partners in deciding what good implementation means.**

Dignity

Equity

Decision rights

Meaningful engagement is not attendance. It is a route into power.

GAMIAN-Europe at a glance

35+

Members

Patient organisations in the European network.

25+

Countries

Local experience informs European discussion.

20+

Partners

Partner associations extend collaboration.

Patient-driven since 1998, grounded in member organisations.

What GAMIAN-Europe does

01

Advocacy

Bring lived experience into EU mental health policy and engage decision-makers.

02

EU research

Shape European research from design through implementation and dissemination.

03

Awareness

Challenge stigma and improve mental health literacy through campaigns and resources.

The patient voice runs through policy, research and public understanding.

Lived experience strengthens implementation

Better questions
More acceptable
methods
Sharper interpretation

1.16x

odds of trial enrolment with public
involvement
(26-study meta-analysis; modest effect)

Promising, not magic: impact evidence remains uneven and context-dependent.

REMESOS: lived experience across the project

01



Shape project design

Advisory board brings lived experience into priorities and design.

02



Adapt peer support

Members inform the rollout of peer support in four countries.

03



Share findings

Board helps make results clear and relevant to communities.

— Lived experience informs design, delivery and learning.

Match the involvement route to the decision

Psych-STRATA

A 10-person European patient board shapes decision tools and digital-health evaluation.

TRUSTING

Patient and clinician user boards guide ethically sensitive speech-based AI research.

PSY-PGx

A patient board gives continuous feedback on study design and participant materials.

Experts by Experience

A standing pool makes involvement reusable, diverse and available earlier.

Lived experience must shape policy, too

Set priorities

Put lived priorities and overlooked harms on the policy agenda.

Design policy

Test rights, language, feasibility, access and unintended effects.

Implement

Track whether commitments reach people, services and communities.

Hold to account

Make gaps visible—and give people a route to demand correction.

Inclusion without influence is tokenism

Participation theatre

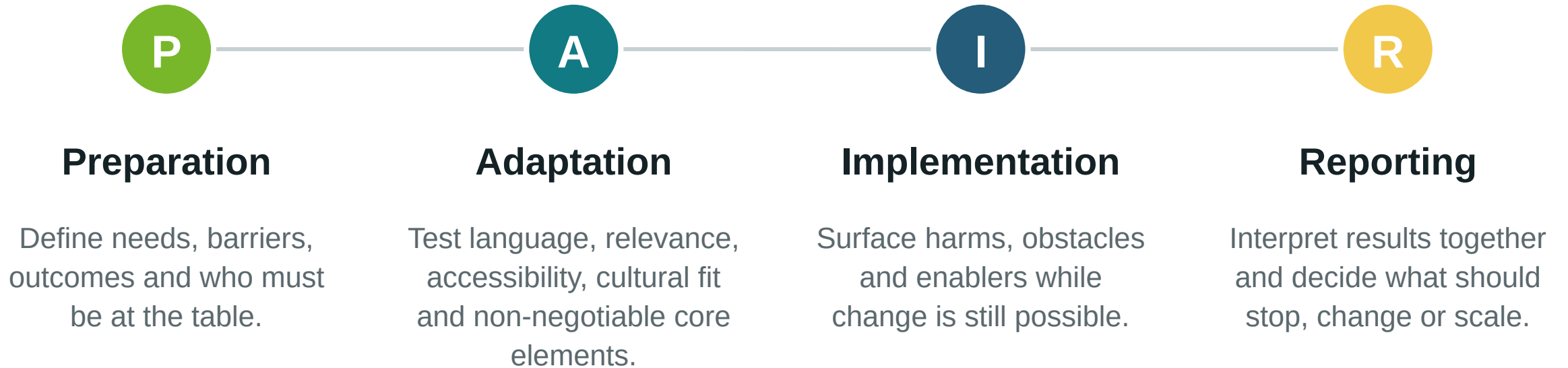
1. One person invited after decisions
2. A story requested—but not judgement
3. No authority, feedback or visible change

Meaningful influence

1. People enter before choices harden
2. Decision rights are explicit
3. The work reports what changed

Presence is visible. Influence is traceable.

Build lived experience into every PAIR phase



Around 60 implementation sites in 20 countries = around 60 opportunities to build influence into routine practice.

Use one anti-tokenism standard across every site

- 01** — Start before the protocol or adaptation is fixed
- 02** — Name the decisions people can influence
- 03** — Resource participation: pay, prepare, support and make access possible
- 04** — Seek diversity without pretending anyone represents everyone
- 05** — Close the feedback loop after every contribution
- 06** — Evaluate and report the changes, disagreements and limits

Build the route. Fund it. Record the decision. Report the change.

Judge involvement by what changes



What changed because people were involved?

Ask it in research. Ask it in policy. Ask it in implementation. Then report the answer.

THANK YOU