THE INTERSPACE SERIES · SESSION ONE

Defining inclusive and community research

Muhammed Rauf
Founder, Elysium London

Wednesday 11 November 2026



THE MOMENT

Community power, written into the system.

2024	**NIHR** makes inclusion a condition of funding **UKRI** £9m for community research networks
2025	**10 Year Health Plan** care moves into communities **Pride in Place** local people decide spending
2026	**English Devolution Act** empowerment becomes law **UKRI strategy** communities shaping research **Andy Burnham** “the biggest rebalancing of power”

NIHR, Nov 2024. UKRI, Dec 2024. 10 Year Health Plan, 2025. Pride in Place Strategy, 2025. English Devolution and Community Empowerment Act 2026. UKRI Strategy 2026 to 2031. Andy Burnham, 29 June 2026, before becoming Prime Minister.

"The rhetoric around co-production has not been matched by the institutional structures, processes and cultures to facilitate it."

Final report, September 2026

"The systems underpinning academic work do not support this adequately - which often leads to work that claims to be co-produced but actually isn't."

Community Reference Group member, launch report, December 2024



WHO I AM

Muhammed Rauf

- **Lambeth** — Born and raised
- **2020** — Community researcher
- **2023** — Director, Centric
- **2025** — **Founded Elysium London**

20+ health inequalities projects, designed and delivered

WHAT I WAS ASKED, AGAIN AND AGAIN

“We’re writing a bid. Can we write you in?”

They meant recruitment. I meant a partnership.

WHY IT'S PERSONAL

"For too long, people like me have been the subjects of research, not the authors of it."

THE WORDS WE USE

Words used as branding, not as positions.

Three questions show which one you're looking at:

01

Who holds the resources?

02

Who makes the decisions?

03

Whose outcomes are prioritised?

TODAY

2.00 The session

The words we use · Power shared · Power claimed and held

Recorded and published on YouTube

3.00 Five-minute break

3.05 Questions and perspectives

Chatham House Rule

PART 01

01

The words we use

Same words, different power



YOUR TURN · SLIDO

Think of the last project you worked on.

What word did you use for it?

slido.com · #1375483 · one or two words · anonymous

THE WORDS WE USE · WHAT I FOUND

A family of terms. No shared understanding.

PPIE

co-production

involvement

participation

co-design

engagement

inclusive research

lived experience

Of 979 studies using co-production or co-design, a third gave no definition. Masterson et al., Health Expectations (2022).

YOUR TURN · QUIZ ON SLIDO

Three words. Pick the right definition.

01

Engagement

Which definition is correct?

02

Involvement

Which definition is correct?

03

Participation

Which definition is correct?

slido.com · #1375483 · 30 seconds each · pick one each

THE WORDS WE USE · THE ANSWERS

You're all right. It depends who you ask.

Engagement	Sharing information *NIHR* ✓	Two-way, mutual benefit *NCCPE* ✓	Up to co-production *NICE* ✓	A working relationship *Scotland* ✓
Involvement	Research with the public *NIHR · HRA* ✓	From consultation to control *NIHR note 7* ✓	Shaping the options *IAP2* ✓	Informing or consulting *NHS Act* ✓
Participation	Taking part in a study *NIHR · HRA* ✓	Taking part in decisions *NHS England* ✓	Citizens holding power *Arnstein* ✓	Shaping the research *Participatory* ✓

"These terms often overlap, mean different things to different people…" NHS England (2022)

NIHR Briefing notes (2021, 2024). HRA. NCCPE. NICE NG44 (2016). National Standards for Community Engagement (Scottish Government). IAP2 (2018). NHS Act 2006 s.14Z45. Arnstein (1969). Cornwall and Jewkes (1995).

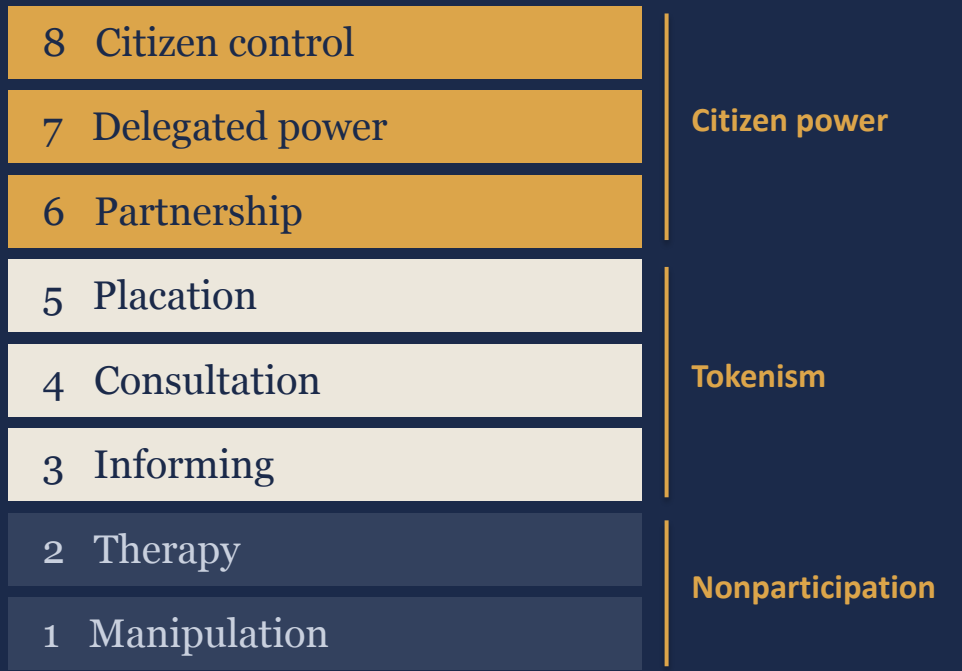
Everyone’s right. That’s the problem.

When one word can mean four things, nobody can be held to it, and communities can’t tell what they’re being offered.

So today: the terms that are explicit about sharing power.

THE WORDS WE USE · THE LADDER WE'LL CLIMB

Sherry Arnstein's ladder of citizen participation, 1969.



"There is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process."

By the end of this hour: every term on it, and your own project.

Arnstein, S. R. (1969). A ladder of citizen participation. Journal of the American Institute of Planners, 35(4), 216–224.

The traditions these terms grew from.

TRADITION	WHERE IT COMES FROM	POWER
Participatory action research	Freire and Fals-Borda, Latin America, 1970s. Research with communities, for change.	*Claimed, through action*
Community-based participatory research	Israel and colleagues, 1998. An equitable partnership at every stage.	*Shared, in partnership*
Disabled people's and survivors' research	"nothing about us without us". Oliver, 1992; Turner and Beresford, 2005.	*Held, in control*
Inclusive research	Walmsley, 2001. Research with people with learning disabilities, covering both strands.	*Shared to held*

What they share: "the location of power". Cornwall and Jewkes, 1995.

PART 02

02

Power shared

Inclusive research



POWER SHARED · CO-DESIGN

Co-design shares power over a part.

Communities and professionals designing something together, with communities sharing power over how it is designed, though not necessarily over what happens next.

WHAT IT LOOKS LIKE

Often a workshop or two, at one moment in a project.

RESOURCES	DECISIONS	OUTCOMES
The institution	Shared, inside the workshop	Not necessarily theirs

Our definition. In the literature, co-design usually means a creative process at the design stage (Vargas et al., 2022). Some, like Newham Council, use it more widely.

THE SHARED SIDE

8 Citizen control
7 Delegated power
6 Partnership
5 Placation
4 Consultation
3 Informing
2 Therapy
1 Manipulation

POWER SHARED · CO-PRODUCTION

Co-production shares power across the whole.

A partnership in which communities and researchers share decisions, resources and responsibility across the whole research life cycle, recognising community knowledge as equal to academic expertise.

RESOURCES
Shared, at least in part

DECISIONS
Shared, at every stage

OUTCOMES
Agreed together

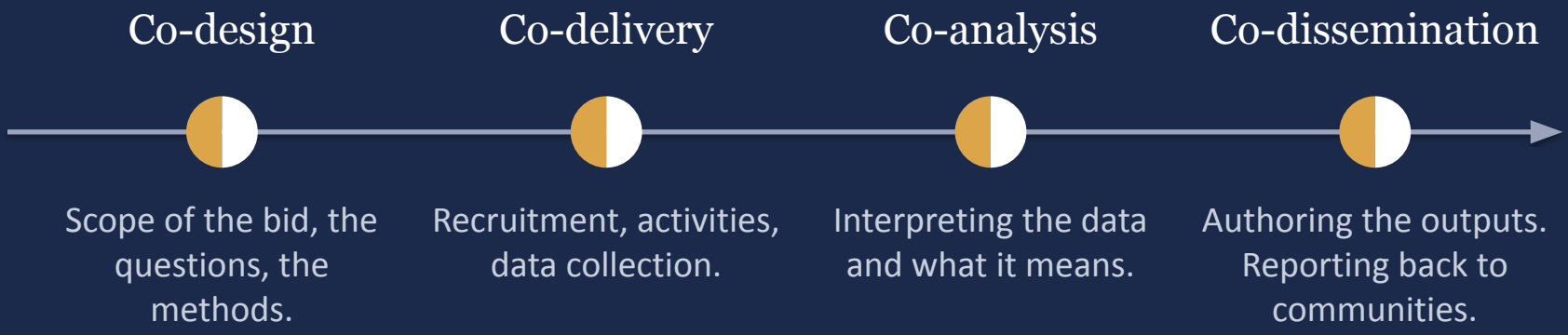
Our definition.

THE SHARED SIDE

8 Citizen control
7 Delegated power
6 Partnership
5 Placation
4 Consultation
3 Informing
2 Therapy
1 Manipulation

THE CONTINUUM MODEL

Power shared at every stage



Same four stages. The question is who leads them.

POWER SHARED · OUR DEFINITION

Inclusive research

An equity-centred, partnership-based approach to generating knowledge that restructures who participates, how decisions are made, and whose knowledge counts.

EQUITY-CENTRED MEANS

Changing the structural conditions under which people take part in research.

- Methods training for partners
- A shared decision framework
- Resources paid up front
- Outputs that matter to communities

Our definition (Rauf, 2025), refined in The Inclusive Research Collaborative white paper. Walmsley (2001) first coined the term.

THE SHARED SIDE

8 Citizen control
7 Delegated power
6 Partnership
5 Placation
4 Consultation
3 Informing
2 Therapy
1 Manipulation



POWER SHARED · A CASE

Mothers' photographs, Sundarbans.

79 mothers took the photos

138 decision makers came

2 commitments: a concrete road, more tube wells

RESOURCES

The university (UK Aid).

DECISIONS

Shared with the mothers.

OUTCOMES

The mothers': their children's health.

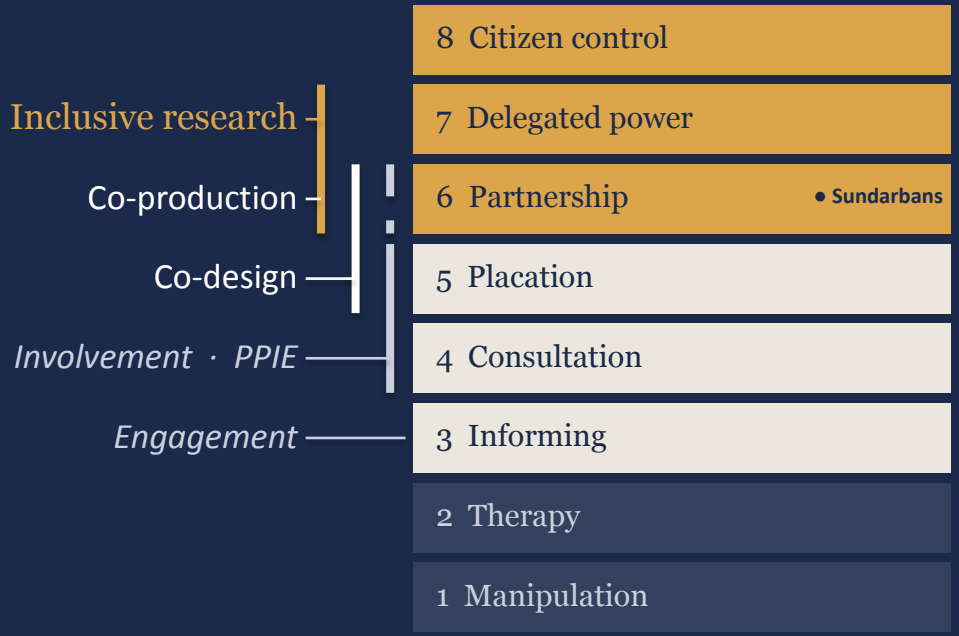
Inclusive research. Partnership, step 6.

Photo: the mothers' own. Ghosh, Bose, Bramhachari and Mandal (2016), BMC Health Services Research 16, CC BY 4.0. IIHMR University; Future Health Systems (UK Aid).

POWER SHARED · ON THE LADDER

Power shared, on the ladder.

INCLUSIVE RESEARCH TERMS



Arnstein (1969) in the middle. Our terms (white, gold) placed by our definitions; sector terms (grey) by where they most often show up in practice, dotted where they can reach.

PART 03

03 Power claimed and held

Community research



Community research starts as a movement for social and racial justice.

Authorship

of our own stories

Ownership

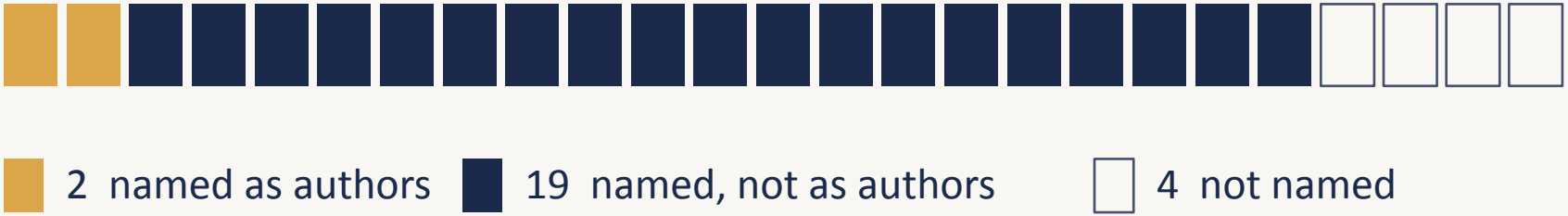
of our data and evidence

Change

so the next generation doesn’t face the same inequalities

2 in 25

reports named community researchers as authors.



Elysium London scan of 25 London community and peer research reports, 2022 to 2026.

POWER CLAIMED AND HELD · COMMUNITY-INFORMED

Community-informed: communities share their views.

Research that seeks the views of communities affected by the issue under study, with the institution leading the research and deciding how resources are used.

WHAT IT LOOKS LIKE

A survey, a consultation or a listening event.

RESOURCES	DECISIONS	OUTCOMES
The institution	The institution	The institution's

THE HELD SIDE

8 Citizen control
7 Delegated power
6 Partnership
5 Placation
4 Consultation
3 Informing
2 Therapy
1 Manipulation

Our working definition. Often called community-engaged research, a wider term whose own guidance runs from outreach to shared leadership (Principles of Community Engagement, 2011).

POWER CLAIMED AND HELD · CENTRED AND LED

Centred isn’t the same as led.

COMMUNITY-CENTRED

Research centred on community experience, with people affected delivering the research and influencing how resources are used.

COMMUNITY-LED

The sector’s most common term for the top of this side. Communities hold the resources, make the decisions and set the priorities.

THE DIFFERENCE

Resources	Often the institution	Communities
Decisions	Shared, at best	Communities
Outcomes	Often the institution’s	Communities’

Our working definitions.

POWER CLAIMED AND HELD · OUR DEFINITION

Community research

Research that starts from community experience and priorities, with people affected leading the research and deciding how resources are used.

Power claimed and held by communities.

Our definition. It grows from participatory action research (Freire; Fals-Borda). Who holds the resources is at the centre.

THE HELD SIDE

- 8 Citizen control
- 7 Delegated power
- 6 Partnership
- 5 Placation
- 4 Consultation
- 3 Informing
- 2 Therapy
- 1 Manipulation

POWER CLAIMED AND HELD · THE CONTINUUM MODEL

Rebuilding Trust, stage by stage.



Priorities from our earlier work, agreed with the council.

Six residents, trained as community researchers, delivered it.

Community researchers and participants interpreted the data together.

Residents authored the report, and a video went back to participants. Findings to Cabinet.

Same four stages. This time, communities led every one.

My account; report December 2022.



POWER CLAIMED AND HELD · A CASE

Rebuilding Trust, 2021 to 2022.

6 community researchers trained

70 residents took part

1 definition adopted by the council

RESOURCES

A community organisation.

DECISIONS

Residents, as community researchers.

OUTCOMES

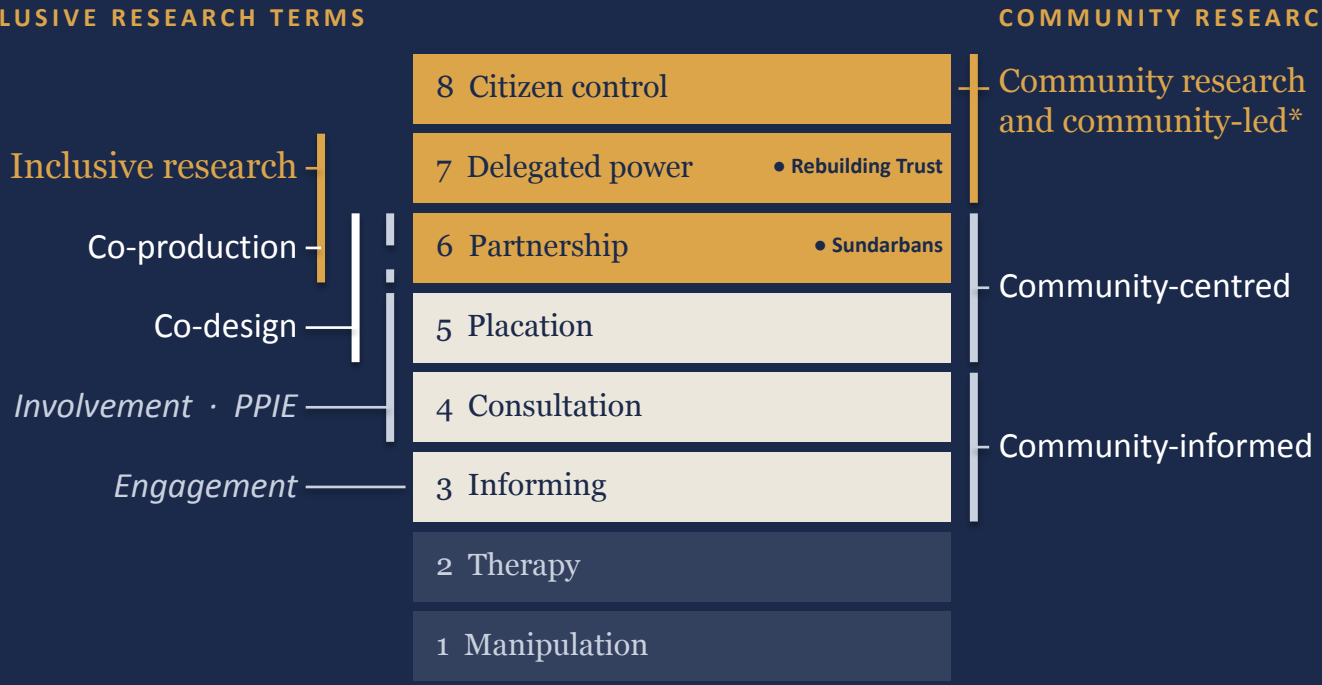
Residents', taken to Cabinet.

Community research. Delegated power, step 7.

Not citizen control: the priorities were agreed with the council. My account; report December 2022.

POWER CLAIMED AND HELD · ON THE LADDER

One ladder. Two sides.



*Arnstein (1969) in the middle. Our terms (white, gold) placed by our definitions; sector terms (grey) by where they most often show up in practice, dotted where they can reach. *Only when communities hold all three.*

YOUR TURN · SLIDO

Back to that project.

1 Where did it actually sit? Ask the three questions, then pick a step on Slido.

2 For your next project: name one thing you'd change.

slido.com · #1375483 · anonymous

FROM YOUR SEAT · FUNDERS

When you assess a bid.

WHO HOLDS THE RESOURCES?

1 How much of the award goes to communities?

A costed community line, shown as a share of the award.

WHO MAKES THE DECISIONS?

2 How much say will they have over how it's used?

A decision plan, stage by stage.

WHOSE OUTCOMES ARE PRIORITISED?

3 Whose ideas is it built on?

Communities shaped the questions, and the findings go back to them.

Inclusive research shares all three. In community research, communities hold all three.

FROM YOUR SEAT · RESEARCHERS

When you design a bid.

WHO HOLDS THE RESOURCES?

1 What share of the budget goes to community partners?

Costed in the first draft, line by line, with their overheads.

WHO MAKES THE DECISIONS?

2 Which decisions will communities make, and when?

Written into the plan, stage by stage.

WHOSE OUTCOMES ARE PRIORITISED?

3 Whose questions are these?

Shaped with communities before you write. Community researchers as authors.

Inclusive research shares all three. In community research, communities hold all three.

FROM YOUR SEAT · COMMUNITY ORGANISATIONS

Before you say yes.

WHO HOLDS THE RESOURCES?

1 What share of the budget comes to you?

Your own costed line, paid on a schedule your cash flow can carry.

WHO MAKES THE DECISIONS?

2 Which decisions will you make, and when?

In writing. If it’s only recruitment, price it as recruitment.

WHOSE OUTCOMES ARE PRIORITISED?

3 What comes back to your community?

Your questions in the bid, findings shared back, credit, and something that stays.

Inclusive research shares all three. In community research, communities hold all three.

TO CLOSE

“Using our voice is the first way we claim power.”

Start with the words we use, and make them match the work.

Quote: Rauf (2026), The Interspace Essays, Issue 01.

BEFORE YOU GO

Thank you.

for joining session one.

01 Evaluation form, by email

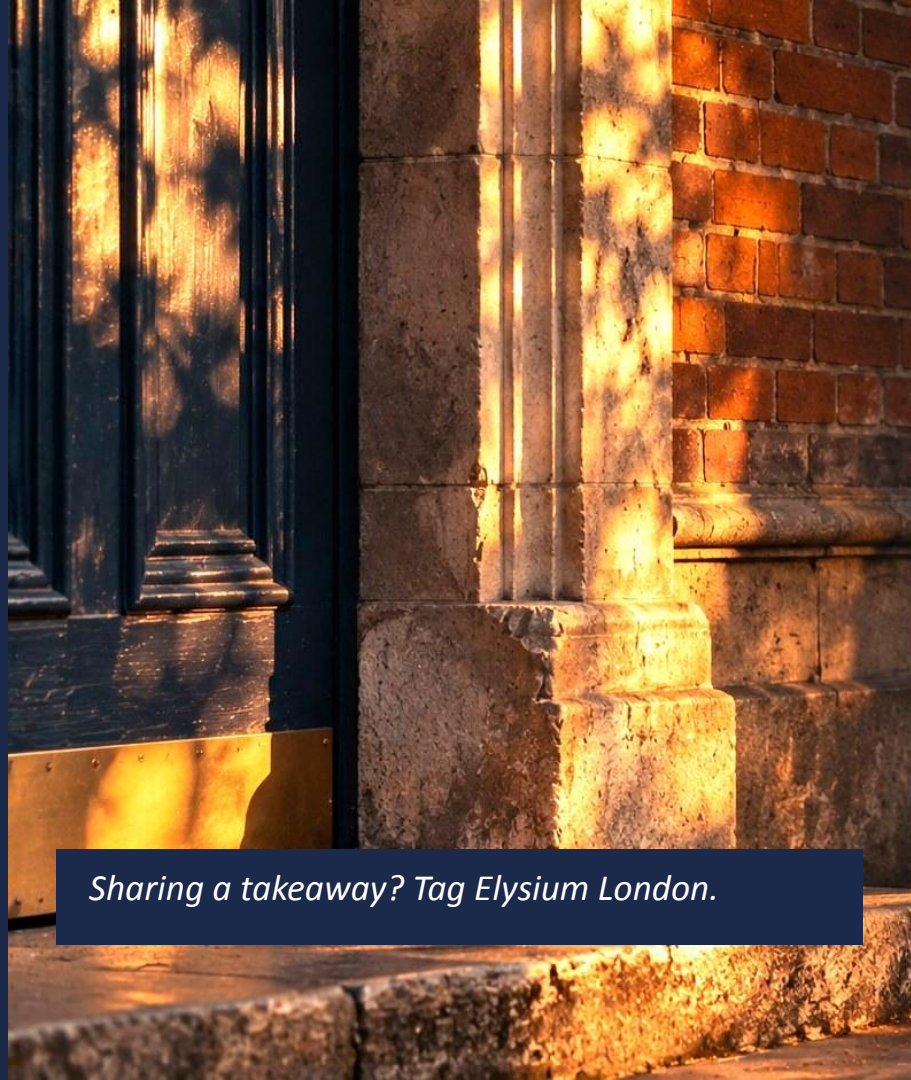
02 Session two: Jan or Feb 2027

03 Power study: register interest

04 Working definitions, by email

LinkedIn: Muhammed Rauf · Elysium London

YouTube @elysium.london · elysium.london



Sharing a takeaway? Tag Elysium London.

WHAT WE DREW ON

References.

Arnstein, S.R. (1969). A ladder of citizen participation. Journal of the American Institute of Planners, 35(4), 216-224.

Burnham, A. (2026). Speech at the People's History Museum, Manchester, 29 June 2026.

Clinical and Translational Science Awards Consortium (2011). Principles of Community Engagement. 2nd edition. NIH Publication No. 11-7782.

Cornwall, A. and Jewkes, R. (1995). What is participatory research? Social Science & Medicine, 41(12), 1667-1676.

Department of Health and Social Care (2025). Fit for the Future: 10 Year Health Plan for England.

Durose, C., Perry, B., Richardson, L. and Vince-Myers, B. (2026). Doubling Down Not Ducking Out: Why Co-Production of Research Matters Now. Universities of Liverpool, Manchester and Sheffield.

Elysium London (2026). Scan of 25 London community and peer research reports, 2022 to 2026. Unpublished data.

English Devolution and Community Empowerment Act 2026.

Fals-Borda, O. and Rahman, M.A. (eds) (1991). Action and Knowledge: Breaking the Monopoly with Participatory Action-Research. New York: Apex Press; London: Intermediate Technology Publications.

Freire, P. (1970). Pedagogy of the Oppressed. Herder and Herder.

Ghosh, U., Bose, S., Bramhachari, R. and Mandal, S. (2016). Expressing collective voices on children's health: photovoice exploration with mothers of young children from the Indian Sundarbans. BMC Health Services Research, 16(Suppl 7), 625.

Health Research Authority (n.d.). Public involvement. hra.nhs.uk.

International Association for Public Participation (2018). IAP2 Spectrum of Public Participation. IAP2 International Federation.

Israel, B.A., Schulz, A.J., Parker, E.A. and Becker, A.B. (1998). Review of community-based research: assessing partnership approaches to improve public health. Annual Review of Public Health, 19, 173-202.

Local Government Association (n.d.). Co-design in transformation: Newham's co-design standards. Transformation roundtable.

Masterson, D., Areskoug Josefsson, K., Robert, G., Nylander, E. and Kjellström, S. (2022). Mapping definitions of co-production and co-design in health and social care: a systematic scoping review providing lessons for the future. Health Expectations, 25(3), 902-913.

WHAT WE DREW ON

References, continued.

Ministry of Housing, Communities and Local Government (2025). Pride in Place Strategy.

National Co-ordinating Centre for Public Engagement (2025). Introducing public engagement.

National Health Service Act 2006, s.14Z45, inserted by the Health and Care Act 2022.

NHS England (2022). Working in partnership with people and communities: statutory guidance.

NICE (2016). Community engagement: improving health and wellbeing and reducing health inequalities. NICE guideline NG44.

NIHR (2021, updated 2024). Briefing notes for researchers: public involvement in NHS, health and social care research.

NIHR (2024). Inclusive research design to become an NIHR condition of funding. 24 July 2024, updated 27 November 2024.

Ocloo, J. and Matthews, R. (2016). From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. BMJ Quality & Safety, 25(8), 626-632.

Oliver, M. (1992). Changing the social relations of research production? Disability, Handicap & Society, 7(2), 101-114.

Perry, B., Durose, C. and Richardson, L. (2024). Getting our house in order: improving conditions for co-produced research in UK higher education. Co-Production Futures Inquiry, Briefing Note 1. Universities of Liverpool, Manchester and Sheffield.

Rauf, M. (2025). Strategic Frameworks for Inclusive Research: A Practice-Informed Contribution to Institutional and Community Systems. Elysium London.

Rauf, M. (2026). Community research has to claim power. The Interspace Essays, Issue 01. Elysium London.

Rauf, M. (2026). The Inclusive Research Collaborative: An Evidence-based Case for New Infrastructure in South London. Elysium London.

Scottish Community Development Centre (2016). National Standards for Community Engagement. SCDC, commissioned by the Scottish Government.

Turner, M. and Beresford, P. (2005). User Controlled Research: Its Meanings and Potential. INVOLVE.

UK Research and Innovation (2024). Investment to address regional priorities with UK communities. December 2024.

UK Research and Innovation (2026). UK Research and Innovation Strategy 2026 to 2031.

Vargas, C., Whelan, J., Brimblecombe, J. and Allender, S. (2022). Co-creation, co-design, co-production for public health: a perspective on definitions and distinctions. Public Health Research & Practice, 32(2), e3222211.

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. Disability & Society, 16(2), 187-205.