Collated Co-production, Involvement and Engagement (PPIE) Resources. HRC Brain Health Event 12.11.2025

UK Guidance	
NHS England - (2023) The Co-production and Quality Improvement Resource Guide	https://www.england.nhs.uk/publication/co-production-resource-guide/
NICE - National Institute of Health and Care Excellence – Public Involvement Policy	https://www.nice.org.uk/get-involved/people-and-communities/patient-andpublic-involvement-policy
SCIE - Co-production training and resources to help health and social care staff, service users, and carers work together to improve services	https://www.scie.org.uk/co-production/

NIHR	
NIHR - UK Standards for Public Involvement	https://sites.google.com/nihr.ac.uk/pi-standards/home
NIHR - (2024) Going the extra mile: Improving the nation's health and wellbeing through public involvement in research	https://www.nihr.ac.uk/going-the-extra-mile
NIHR - (2021) Good practice guidelines on the recruitment and involvement of public members on trial and study steering committees.	https://www.nihr.ac.uk/good-practice-guidelines-recruitment-andinvolvement-public-members-trial-and-study-steering-committees
NIHR - (2022) The Race Equality Framework for public involvement in research. A self-assessment tool to help organisations improve racial equity in health and care research.	https://www.nihr.ac.uk/nihr-race-equality-framework
NIHR – (2018) INVOLVE. Community Engagement Toolkit - Guidance on co-producing a research project	https://research.hscni.net/sites/default/files/Copro_Guidance_Mar18.pdf
NIHR – (2024) Payment guidance for members of the public considering involvement in research	https://www.nihr.ac.uk/payment-guidance-members-public-consideringinvolvement-research
NIHR – (2023) Payment for public involvement in health and care research: a guide for organisations on employment status and tax	https://www.nihr.ac.uk/payment-public-involvement-health-and-careresearch-guide-organisations-employment-status-and-tax
NIHR Policy Research Unit. DeNPRU Exeter - What works when working together? A practical guide for involving people with different neurodegenerative conditions in policy research	https://www.learningforinvolvement.org.uk/wpcontent/uploads/gravity_forms/6-341881053f9095fe395a1f986cd7085c/2025/01/DeNPRU-Exeter_What-workswhen-working-together_Digital-guide.pdf

Applied Research Collaborations (ARC)

NIHR ARC East of England (E of E) - Public Involvement & Research Inclusion	https://arc-eoe.nihr.ac.uk/public-involvement-research-inclusion
NIHR ARC East Midlands - (2024) Lunch and Learn session introducing co-production e.g., what it is (and isn't), why it matters, and practical tools and tips	https://www.youtube.com/watch?v=a-vfm55bb5A
NIHR ARC South London - Resources to support involvement in research.	https://arc-sl.nihr.ac.uk/involving-patients-public/resources-supportinvolvement-research
NIHR ARC South West Penisula (PenARC) - Patient & Public Involvement & Engagement	https://arc-swp.nihr.ac.uk/patient-public-involvement-engagement/
NIHR ARC West - Resources and training to support people working together in co-produced health and social care research	https://arc-w.nihr.ac.uk/research/projects/training-and-resources-forsharing-power-in-co-produced-research/
NIHR ARC West - A map of resources for co-producing research in health and social care.	https://arc-w.nihr.ac.uk/Wordpress/wp-content/uploads/2020/05/Map-ofresources-Web-version-v1.2.pdf

Dementia Networks Plus

SPIN-Dementia Network Plus (SPIN-D) - Co-production and Involvement Resource.	https://spindementianet.org/co-production-and-involvement-resource/
Empower Dementia Network Plus - Co-production Training Video	https://empowerdementia.co.uk/co-production-training/
Empower Dementia Network Plus - Co-production Toolkit	https://www.dementiaresearcher.nihr.ac.uk/wp-content/uploads/2025/08/Co-production-booklet-EMPOWER.pdf

Dementia Focused

Alzheimer's Society - Guidance on running co-production with people with dementia, including pros, cons, and practical resources	https://www.alzheimers.org.uk/dementia-professionals/dementiaexperience-toolkit/research-methods/dementia-friendly-co-production
Dementia Enquirers - Provides Gold Standards for co-research and ethical research with people living with dementia	https://dementiaenquirers.org.uk/
MinD - Supports co-design and wellbeing - focused design for people with dementia, mental illness, and neurodiverse conditions	https://designingfordementia.eu/network

Miscellaneous	
Co-production Collective (UCL) A continuously updated library of case studies, toolkits, articles, and videos.	https://www.coproductioncollective.co.uk/
IMPACT - A programme that co-produces care and support research and services with people who draw on care and carers	https://impact.bham.ac.uk/our-mission/co-production/
KCL Digital Health Hubs - Flexible training in digital health, cocreation, and data skills	https://digitalhealthtraining.kcl.ac.uk/
Patient Engagement Management Suite - Practical How-to Guides for Patient Engagement	https://pemsuite.org/how-to-guides/
Public Involvement Front Door - Values-based approach and practical tips and resources for public involvement	https://www.publicinvolvement.co.uk/
PIRIT – Public Involvement In Research Impact Toolkit	https://walescancerresearchcentre.org/free-public-involvement-in-researchimpact-toolkit-pirit-launched-for-public-use/
Russel et al (2020) - The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it?	https://pubmed.ncbi.nlm.nih.gov/33133636/
Sensory Trust - Looking at access from the perspective of the visitor. A tool to review access improvements, plan events, and frame visitor information.	https://www.sensorytrust.org.uk/resources/guidance/access-chain-aninclusive-design-tool
SPARTIES - Guide on key points about co-producing research with people living with dementia	https://health.ed.ac.uk/research/current-research/edinburgh-centre-forresearch-on-the-experience-of-dementia/the-smarties
Stronger Together (2021) - A toolkit co-created with older people to share learning, stories, and resources	https://agefriendlysheffield.org.uk/news-and-blogs/stronger-together-a-coproduction-toolkit-from-ageing-better/
VOX Scotland - Guidance to help genuinely coproduce mental health policy and practice with people who have lived experience	https://voxscotland.org.uk/wp-content/uploads/2022/11/Making-CoProduction-Work.pdf
CARE Network - PPI Group associated with HRC in Brain Health	https://www.kcl.ac.uk/research/community-ageing-research-acrossethnicities-care-network-1