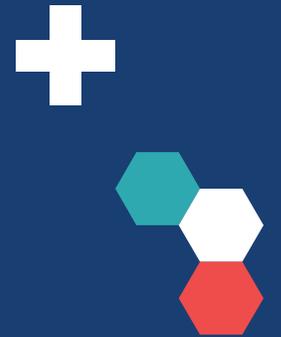


NIHR ARC Wessex



Establishing inclusive and diverse partnerships to better meet the needs of people with MLTCs



Prof Mari Carmen Portillo
Long term conditions theme lead
NIHR ARC Wessex

OPENING QUOTES



“Collaborating together will give opportunities to test initiatives, increase capacity building, establish stronger networks and ensure further visibility to other sources of support in the community” (Voluntary Organisation)”

“I think this is where shared decision making comes in uh, you need to give the chance to the patient to let him describe what he needs and will benefit from and what he's willing to do and set his own goals. You maybe can't take off everything right? But there will be priorities and he perhaps would know quite well what he needs... ...There needs to be something at the strategic level, the ICB to make sure that they've got all the INTERSECTORAL collaboration framework setup to link up to social care and community care and charities in each locality...”
(Practitioner)

ARC Wessex PPIE strategic vision. 2021-24 Strategic aims

1. Listen to voices relevant to our research priorities that reflect the diversity of our local population – ensuring the underserved have a voice (UK Standard Inclusive Opportunities).
 2. Build a culture that respects different perspectives, values contributions and supports mutually respectful and productive relationships (UK Standard Working Together).
 3. Provide health research communities of Wessex (including public) adequate PPI/E training, support and learning opportunities at the right time for their project/programme and/or their own development needs (UK Standard Support and Learning).
 4. Involve the public at strategic and operational levels, ensuring best practice and supporting research transparency (UK Standard Governance).
 5. Use innovative approaches and good communication to expand the reach of our activities, maximising impact by stimulating knowledge-of, and interest-in, our research (UK Standard Communications).
 6. Capture, monitor and share learnings to feedback to those involved, avoid duplication, contribute to the evidence base and build our academic PPI/E (UK Standard Impact).
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ARC Wessex EDI/PPIE Current Strategic developments

1) Building core support and platforms for engaging underserved communities:

- Dedicated Community Engagement Manager
- Raising Voices in Research: NHS England-funded collaboration with ICBs and Voluntary, Community, Faith and Social Enterprises
- Piloting methods for engaging smaller unheard and marginalised groups

2) Strengthened public voice in ARC governance

- Revised and empowered Public Involvement Forum at ARC level
- Refined public voice at Executive and Partnership board level
- Direct involvement in key ARC processes; Annual reporting, work-planning, bid development

3) Professional, on-tap PPIE services

- Efficient contributor sourcing, support and linking across ARC work
- Development of Standard Operating Procedures, quality measures and tailored training for ARC teams

MULTIPLE LONG-TERM CONDITIONS

01

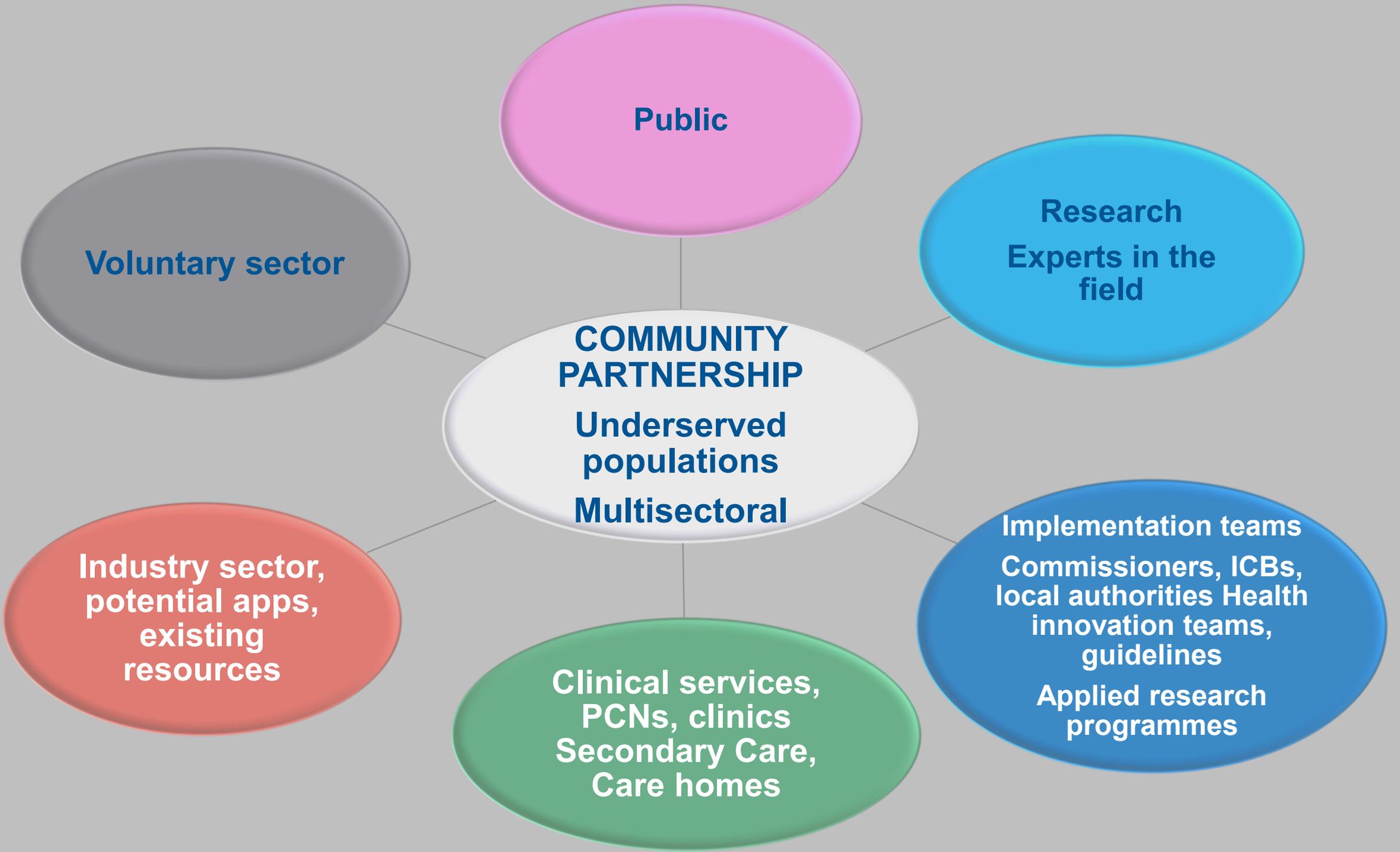
Identification of problems and outcomes that matter most to patients and carers and how they would like to see services configured to meet their needs

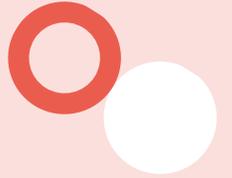
02

Research that enables the health and social care system to take a less fragmented, patient-centred, whole person approach to the treatment and care for people with MLTCs, including quality of life and well-being

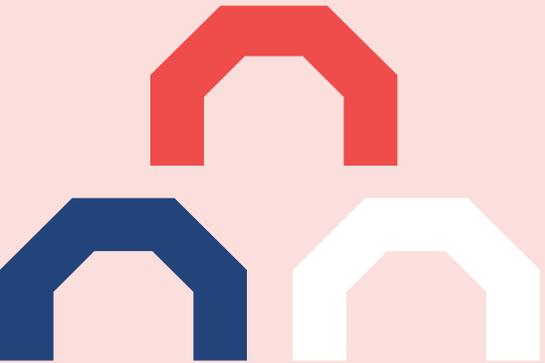
03

Multi-disciplinary workforce + a new generation of researchers working beyond usual single disease specialisms and typical less inclusive research environments





Some examples...



EXAMPLE I. Multidisciplinary Ecosystem to study Lifecourse Determinants and Prevention of Early-onset Burdensome Multimorbidity (MELD-B)

To develop an Artificial Intelligence (AI)-enhanced epidemiological analytic system in which optimal lifecourse time points and targets for prevention of burdensome, mid-life MLTC-M are identified through multidisciplinary synthesis and analysis of birth cohorts and electronic health records.

MIXED METHODS (public health, life course, prevention perspective on MLTCs)

Key messages

- Prevention approaches are under-explored but have significant potential to reduce health inequalities
- Early life focus with potential to reduce the inequitable distribution of burdensome MLTCs seen at mid-life
- Early life determinants of multimorbidity that recognise the interacting multiple identity dimensions contributing to disadvantage leading to multimorbidity-related health inequalities.

PPIE: 11 members with significant diversity in terms of age (20s to 80yrs), gender, ethnicity (Asian, Black, White), geography (Hampshire, Dorset, London, Wales, Scotland (deprived areas in Glasgow), North of England, Midlands), neurodiversity and socioeconomic status.

EXAMPLE II. Optimisation of community resources and systems of support to enhance the process of living with Parkinson's Disease: a multi-sectoral intervention



Determine the feasibility of a multisectoral intervention to improve the living with PD for patients and family caregivers, **optimising community resources and systems of support.**

Intervention start

Intervention as needed

Follow-up at "exit"



Coordinator/
Community hub

Telephone

Follow-up
3 months

- Linked up approach across health, social care, and voluntary support through a single point of contact-across countries.
- Training for key agents in pathway. Partnerships and communication channels.
- Disadvantaged populations priority.
- Reach, upskilling and wide settings including voluntary organisations



PwPD included in study

Coordinator logs agreements on

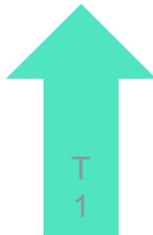
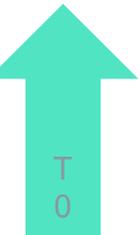
- Resources
- Follow-up visits
- Identified needs

Consultation in the participants homes or at the clinic.

- Together with FC, if appropriate, or separately.
- Duration: 1 – 1 ½ hours.

Log for recording:

- Time spent
- Agreements made
- Identified needs
- Number of visits
- Type of visit (phone, at home, in clinic)

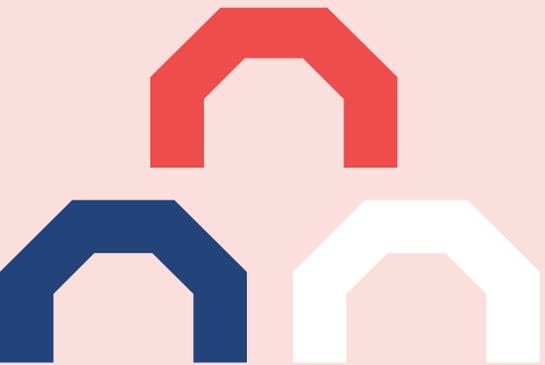
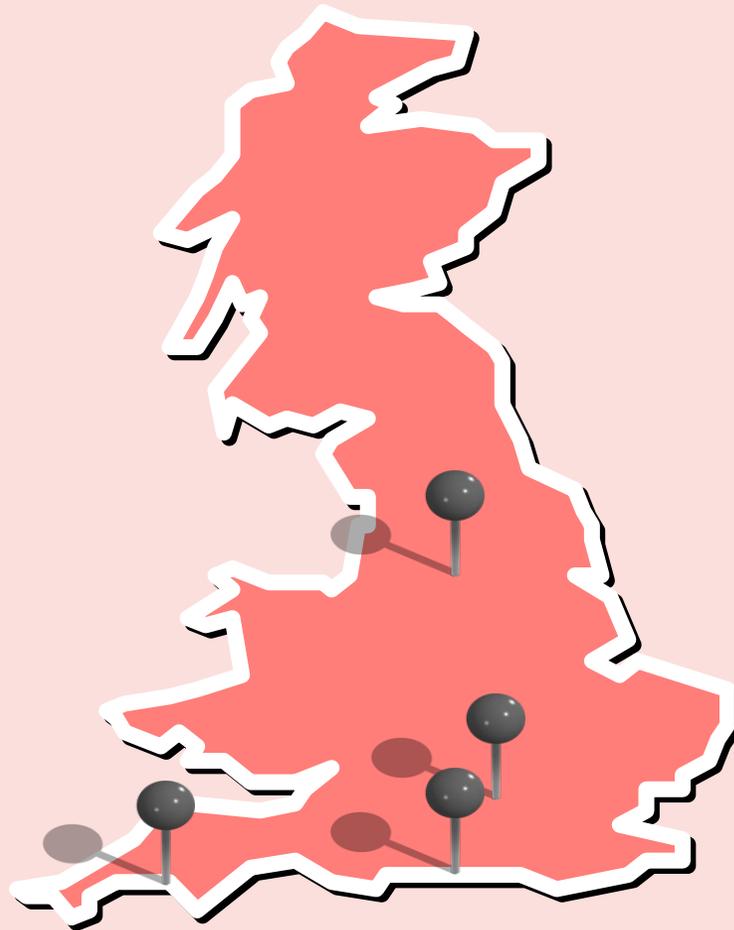
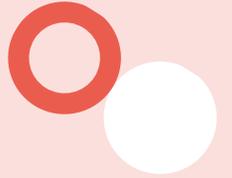


T0

Data collection

T1

EXAMPLE III. NIHR PGfAR. CO-ACTION. Adapt, test and implement a multisectoral personalised social and self-management intervention to support better living with MLTCs in the community.



ARC Wessex: Fostering fair partnerships to better meet the needs of people with MLTCs.

- Tailoring interventions and training to clinical reality and needs.
- Game changer for social connectedness and higher reach and participation of people with LTCs and family carers.
- Enhanced chances of EDI success, potential impact, shifting from a biomedical to person centred approach.

Thanks!!!!

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