

Specialist Centre for Public Health
delivered by Newcastle University and Partners

How do we use lived experience to create research?

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Understanding what we mean by “lived experience”

Form of expertise

Individual, carer, family member, support worker

Physical and/or mental health condition, experience of an issue, situation or service

- Grass roots organisations
- Networks
- Existing partnerships/ programmes

Strategic direction, oversight, plain English translations, design, dissemination of findings

Lived experience experts are not study participants

Knowledge & Insight

Logistics and payments

Very relevant at key stages of research and when decisions need to be made

<https://wellcome.org>

www.sphr.nihr.ac.uk

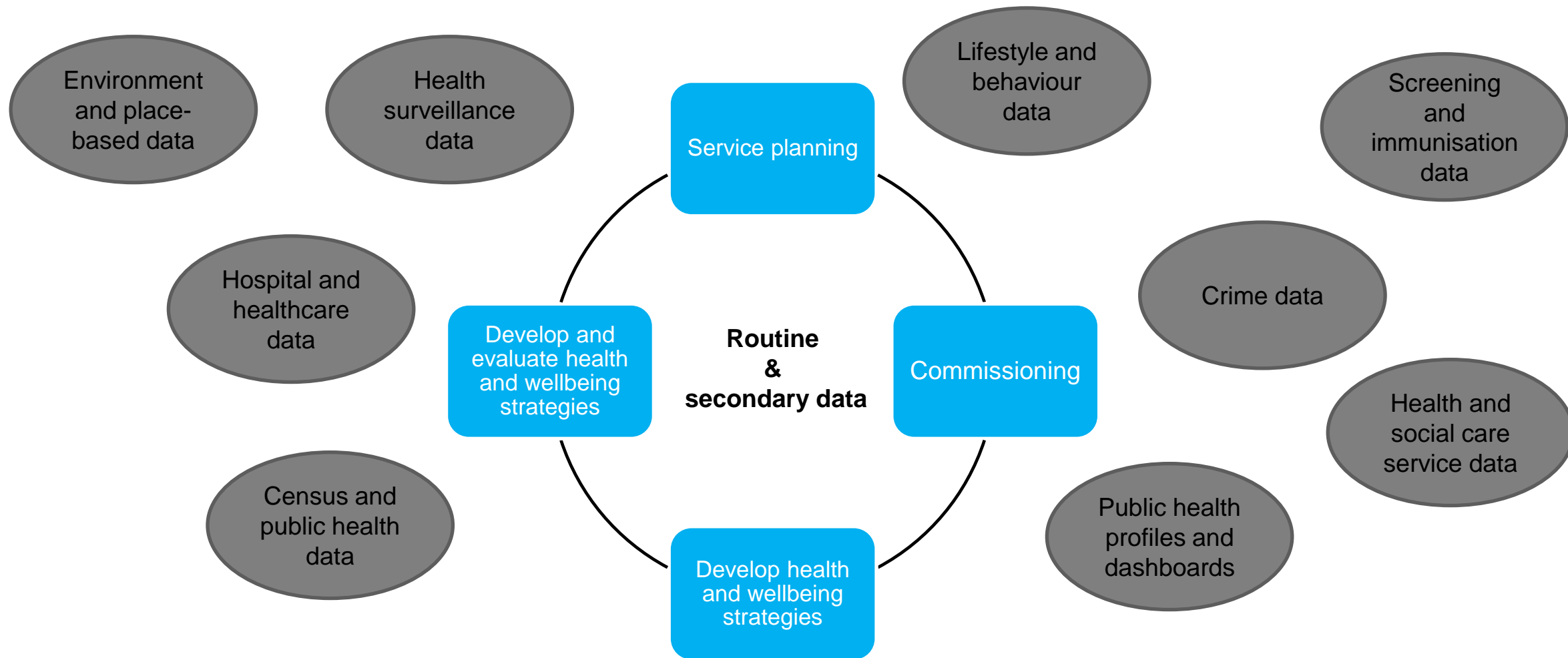
www.healthinnovationnetwork.com

Overview

- Routine and secondary data – uses and limitations
- Stories – patterns and repetition
- What is co-design?
- Qualitative and quantitative examples
- How you might bring the lived experience into your research

How can lived experience enrich research?

- Provides the why and how behind the what
- Ensures provision, services and research are fit for purpose
- Depth and relevance
- Supports innovation
- Challenges misconceptions and assumptions
- Builds networks between providers, policy makers, commissioners and the community
- Timeliness - what is happening right now?



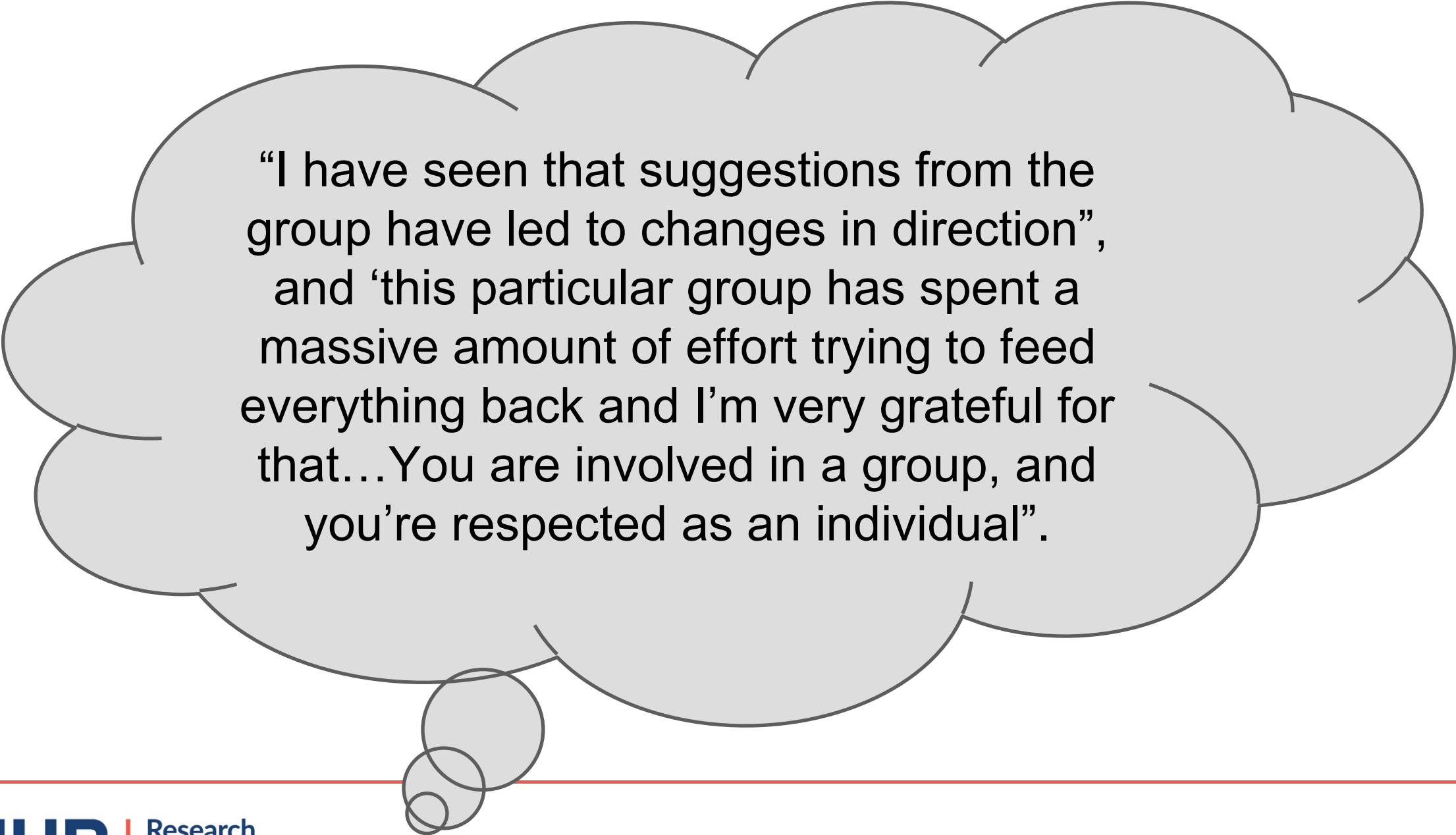
Available data

Limitations of routine and secondary data

- Lack granularity
- Timeliness and frequency
- Lack of demographic detail – sub-group analysis not possible
- Data gaps
- Mismatch between data – data from service use is a proxy for need (underestimates unmet need)
- Unlinked, stored separately. Hard to create a joined-up picture of need
- Mainly QUANTITATIVE – lacks narrative

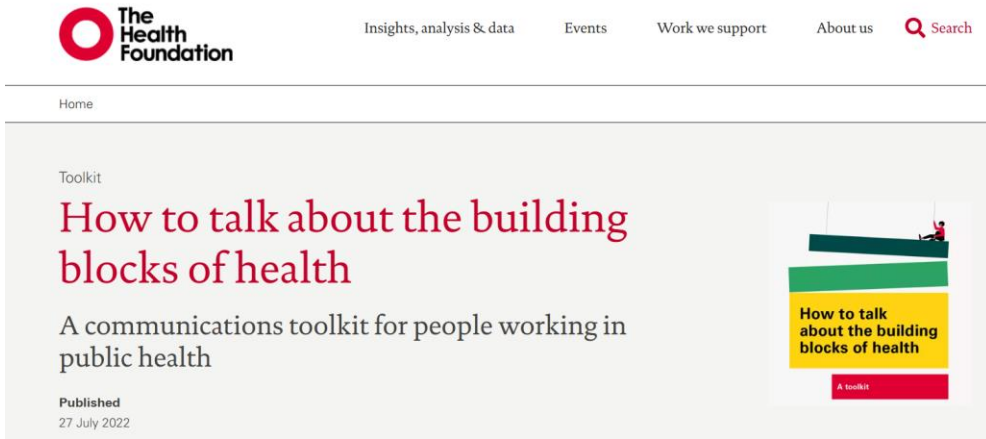
Listening and looking for patterns in the data

- Decisions that are people-centred and contextually relevant
- Causes of behaviour, barriers to access, insight into the problem.....and the solutions
- Explanation of anomalies of trends in the data
- The experience of marginalised groups who aren't visible in the data
- Gaps in provision – accessed by all or few?
- Trust and communication, promotes equity.
- What's working, what's not? Building sustainable services.



“I have seen that suggestions from the group have led to changes in direction”, and ‘this particular group has spent a massive amount of effort trying to feed everything back and I’m very grateful for that...You are involved in a group, and you’re respected as an individual”.

Creating a common purpose and language



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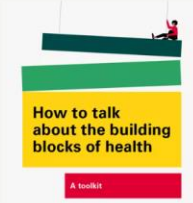
Home

Toolkit

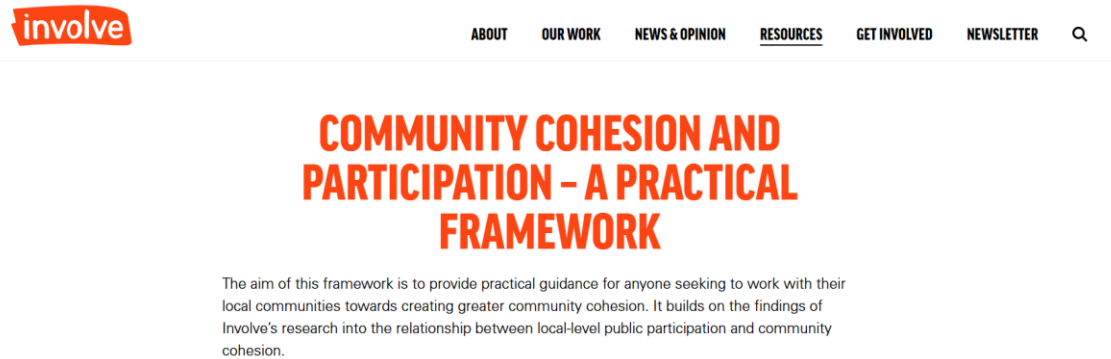
How to talk about the building blocks of health

A communications toolkit for people working in public health

Published 27 July 2022



Look at existing frameworks



involve

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COMMUNITY COHESION AND PARTICIPATION - A PRACTICAL FRAMEWORK

The aim of this framework is to provide practical guidance for anyone seeking to work with their local communities towards creating greater community cohesion. It builds on the findings of Involve's research into the relationship between local-level public participation and community cohesion.



Set up a community stakeholder engagement group



Have conversations in neutral spaces about how people are affected by housing, transport, barriers to services – influence on health behaviours



Challenges



- Representation and inclusion
- Practical barriers
- Trust and Engagement
- Data reliability
- Diverse needs
- Organisational barriers

Opportunities



- Co-production and participatory methods
- Partnership models for long-term engagement
- Transparency and feedback loops
- Strengthen communication, skills, knowledge, relationships and structures. E.g. create common languages and acknowledge diversity in perspectives. Help grassroots organisations apply for funding.

What is co-design and why is it important?

- Working in partnership with those affected by your research
- Setting the question – relevance, importance, inclusive
- Involvement at the beginning, middle and end

[NIHR Guidance](#)
[UK Standards for Public Involvement](#)

- Increasingly a condition of funding
- Knowledge mobilisation, dissemination and impact
- Develop something valued by communities, rather than as defined by the system

A participatory approach where service users and other stakeholders actively collaborate in designing services, with professionals **sharing power and decision making** with them

Three examples

- BootStRap Study – problematic use of the internet in young people.
- Development of a self-reported measure of “self-management” for use with kidney patients on haemodialysis.
- Community insights into a large NIHR programme development grant – comprehensive geriatric assessments in people with kidney disease and frailty.

The BootStRap Study



Resilient in times of change: join the Digital Revolution for Mental Health and Adaptation

The BootStRaP project is a pioneering Europe-wide study to address and reduce the risks of harmful internet use among teenagers – the online generation.

It is important to help young people develop healthy internet use before it causes harm, as well as supporting parents, carers, teachers, and medical professionals, to understand the risks.



The Lundy Model of Participation

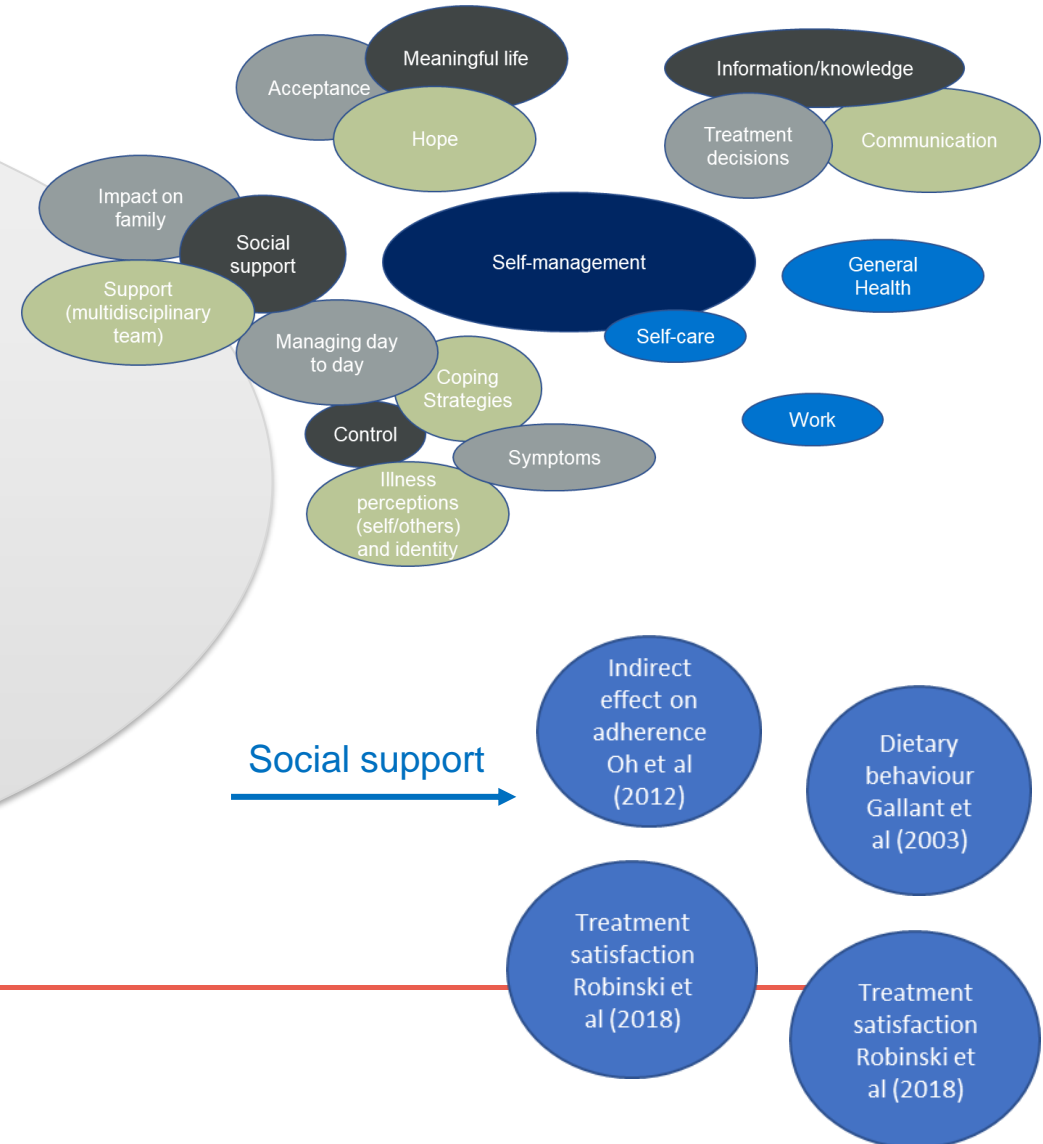
- **SPACE:** CYP must be given the opportunity to express a view
- **VOICE:** CYP must be facilitated to express their views
- **AUDIENCE:** CYP views must be listened to.
- **INFLUENCE:** CYPs views must be acted upon, as appropriate



Development of the PRIESM CKD-HD Scale – listening to the lived experience

“I’m not on dialysis so that means 99% of the time I am self-managing and once every three months I go for a hospital appointment and my um, blood pressure medication is adjusted or what have you. I am self-managing. I would assume that the more ill I become that balance might change a little bit, but the reality is unless you’re in 100% hospital care or care home care, we are self-managing most of the time”

Pre-dialysis patient



**KidnEy oLder person
Assessment (EDNA) study
development:**
understanding what matters
to older people living with
frailty and chronic kidney
disease, their caregivers
and healthcare
professionals

Comprehensive geriatric assessment

Terminology

Acceptability

Purpose

- What matters most?
- What should we measure?
- Tasks – script for focus groups, reviewing findings, communicating our ideas (PES), shaping the next bid.

How can you bring lived experience into your own research?

- Produce guides for conducting focus groups and interviews
- Design ethics and consent templates suitable for low-risk research
- Provide tailored training to key staff, help them develop ideas, collect data and interpret findings
- Engage local community in identifying barriers to accessing local health assets such as clinics, parks and food banks.

- Monitor access to services. Who is using what and when, which communities appear to lower access levels and why?
- Encourage small low-cost projects or support staff to look for funding opportunities
- Track local indicators and compare with areas with a similar demographic profile
- Set up a journal club.

How the RSS SCPH can help you

- There is funding for Local Authority Research Practitioners (LARPs) and Grassroot awards.
- The Public Health Research (PHR) Programme **funds research that generates evidence** to improve the health of the public and reduce health inequalities.
- The Public Health Intervention Responsive Studies Teams (PHIRST) has **funding available to evaluate local authority projects.**
- NIHR Local Authority Short Placement Award for Research (LA SPARC) are designed to **support individuals working in local authority settings** and NIHR Academy members to design and apply for funds to undertake short placements.
- One to one design advice and support (if intending to apply for external funding)

Top tips (for writing grant applications but also generally)

- Be clear on the importance of the research and its potential impact
- Make sure it's clear how public involvement has shaped your research idea and how the public will continue to be involved in your project
- Consider how to make your research as inclusive as possible
- Think about your pathway to impact
- Get feedback – draft and redraft your idea and where possible involve public representatives and engage other stakeholders.
- Write and communicate in plain English, using shared language.

REMEMBER!

Research inclusion (hearing the lived experience) is important at every step



Summary

Engaging with community members and relevant stakeholders is essential for understanding local need and shaping service provision – context, relevance, trust and sustainable partnerships

Routine and secondary data is often quantitative and may lack granularity, local narrative and work that takes a co-design approach can provide further insight

Working with local communities and stakeholders is unlikely to be a quick win and can pose challenges, but can have long-term benefits and help shape a common language

There are an increasing number of options for funding and supporting research in local authority public health teams

Small scale projects and ideas that may come from patterns or divergence in experience, can lead to important local change in the way services are commissioned, their reach into local sub-groups and reducing inequity

Questions?

