Participatory research for person-centred care: Involving undocumented and recent migrants

Carol Rivas, BSc (Hons), MSc, PhD
Professor of Health and Social Care, University College London, London, England,

Abstract

Background

Participatory research is increasingly used to inform person-centred care bottom-up. Nonetheless, researchers often declare it too challenging to include the most underserved groups, a misconception the CICADA study sought to address.

Objectives
To examine a combination of several participatory approaches and research methods that were used to explore COVID-19 pandemic experiences of health and social care among disabled people from minoritised ethnic groups.

Methods

An intersectional mixed-methods study included secondary data analyses, a three-wave survey and semi-structured qualitative interviews with follow-up workshops. Inclusive assets-based participatory methods were deployed. These incorporated focal community members as co-researchers and participants as co-designers of pragmatic outputs.

Results

This approach enabled rich data collection from groups often excluded from health research, such as disabled recent and undocumented migrants. Data exemplify the extent, diversity and intersecting nature of various determinants of health and inequities, and also successful coping strategies. The community of focus was chosen bottom-up with stakeholders, across the UK, with emphasis on locally relevant contexts and local capacity building, with local embedding of co-researchers. To focus on community and individual strengths and assets and contexts has transformative potential. Shared power with and engagement of underserved groups was ensured throughout.

Conclusions
Participatory research methods can effectively inform person-centred care, especially for underserved groups. Different participatory procedures are designed for different ends and should be used strategically. A carefully considered approach with community members as co-researchers and partner collaborators is practical, effective, and efficient. Co-creation and co-design enhances mutual understandings, with outputs likely to be used in practice for and by the underserved.

Correspondence address:
Professor Carol Rivas, Social Research Institute, Institute of Education, University College London, Gower St., London WC1E 6BT, England. Email: c.rivas@ucl.ac.uk

Introduction

The core tenet of person-centred care is its focus on what matters to patients within the context of their individual lives [1]. 'What matters' is complex and encompasses the patient's contextual preferences and needs in relation to their capabilities and resources and broader health service contexts. In other words, it includes consideration of their cultural and personal values and beliefs, their strengths and the assets at their disposal, and national and community constraints, for example in the availability of a service. The goal is better health and wellbeing outcomes and experiences, and a reduction in health inequities. Frequently within healthcare, for example the English National Health Service (NHS) [2], person-centred care operates within a system of 'joined-up' services, adding a further layer of complexity. Bronfenbrenner 's socioecological framework summarises the integration of national and local systems level knowledge with knowledge of the individual, dividing the healthcare ecosystem into the individual (micro), community (meso) and broader (macro) environment [3].

Broader systems level feedback on person-centred care is mainly gathered from patient-reported outcome surveys. These are predicated on the use of retrospective patient input for system change, in a relatively paternalistic top-down healthcare model, and focus on patient satisfaction rather than the patient as person [4]. Complex intervention design frameworks [5] and the realist approach [6] have more positively influenced the evolution of person-centred care. These attend to what works for whom, and in what dynamic and multidimensional contexts (for example time, setting, culture, the patient's informal networks, service availability). They consider the diversity of patients for whom interventions are intended and their lived realities, the mechanisms by which interventions have their effect, which outcomes are relevant, and the local community- or person-centred changes or supports required for patients to engage with and use particular interventions. This moves healthcare from linear outcome-based cause-and-effect models to risk-factor considerations [7]. As Skivington et al (2021) say:

For intervention research in healthcare and public health settings to take on more challenging evaluation questions, greater priority should be given to mixed methods, theory based, or systems evaluation that is sensitive to complexity and that emphasises implementation, context, and system fit…..attention is given not only to the design of the intervention itself but also to the conditions needed to realise its mechanisms of change and/or the resources required to support intervention reach and impact in real world implementation [6, *p 2*].

In line with these developments, and in recognition of the diversity in patients and contexts, and the effect of contexts on the realisation of mechanisms of action for interventions,

participatory research is increasingly used to inform person-centred care bottom-up. This means working with, not on, those affected by an intervention. Nonetheless, researchers often declare it challenging to reach the most underserved groups, who may therefore remain excluded [8,9]. This misconception needs addressing [9,10,11] to avoid the underserved experiencing care centred not on their persons but on the norms of better-served groups, something evident in cultural adaptations of mainstream interventions, which assume that:

...the core components of a mainstream form of treatment should be replicated faithfully while adding-on certain ethnic features... based on the idea that the core components are culture-free and even more problematically, that the theory of change involved is universally powerful. [10, p. 295].

It was to challenge assumptions such as this that this research was carried out.

A 'theory of change' operationalises a cause-and-effect approach to intervention provision. It is usually developed by articulating the intended outcomes, then working backwards to connect these to relevant resources and other inputs, challenges and opportunities via the intervention's proposed mechanisms of action. This is then typically illustrated by a linear matrix-based planning tool known as a logic model, which reflects its cause-and-effect origins. As Falicov articulated [12], contextual factors are peripheral considerations, typically represented as a bar below the matrix (Fig 1a), making this type of logic model ill-suited to person-centred care or linked participatory research. Used in cultural tailoring, for example, it leads to so-called surface level changes to the final intervention, such as the language used [13]. Moreover, its linear nature makes it prescriptively inflexible, often necessitating a different logic model for each condition, disability, age, ethnic group, gender or cultural group. A more appropriate non-linear logic model, foregrounding the dynamic interaction between an intervention and its context is shown in Fig 1b.
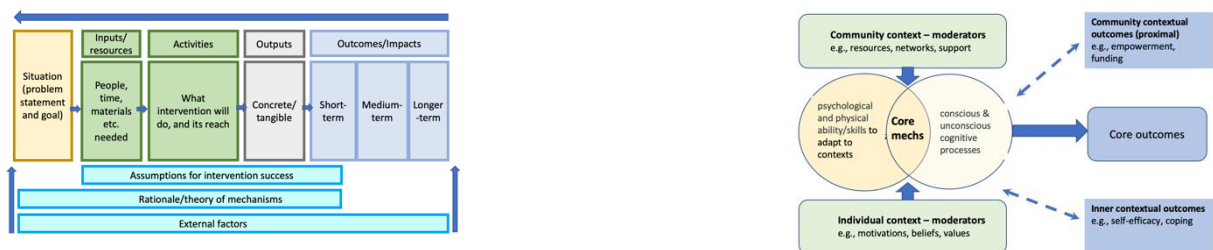
a.   b.

Fig 1a: A traditional linear logic model. 1b: A logic model suited to person-centred care research, adapted from a version developed for staff change [14].

This model still centres on generic core mechanisms [14], those things a clinician must do according to the efficacy evidence-base. But it separates and foregrounds inner (person-centred) and outer (community level) contextual factors. By encouraging reflection on how these affect the core mechanisms in practice it facilitates deeper level transformative changes that are more likely to engage local populations in person-centred care and to require their involvement in associated research.

So how can participatory research populate this non-linear model to holistically inform person-centred care? The following are proposed as necessary components:

- Careful choice of community and focus, bottom-up with various stakeholders in line with Bronfenbrenner's socioecological framework – e.g. patients, clinicians, budget-holders, decision-makers, community, third sector and advocacy groups.
- A focus on locally relevant multiple determinants of health and local capacity building.
- Awareness of community and individual strengths and assets (such as resources and networks) and other relevant contextual features of different settings, that does not position particular groups as deficient or problematic.
- Shared power and engagement throughout the process.
- Bidirectional learning, knowledge exchange.
- A transformative or action-oriented focus and not development of knowledge for knowledge-sake.
- Sustained engagement and feedback loops through an iterative process, such as Plan, Do, Study, Act.

To achieve these components, researchers typically go 'into the field' for months to gain local trust. They may partner with trusted community leaders as gatekeepers, and frequent barbers, nail salons, places of worship, local fairs and local grocery stores.

Objective

These different components of participatory research were explored in CICADA, a UK-wide study of COVID-19 pandemic experiences of health and social care among disabled people from minoritised ethnic groups. Since CICADA was a pandemic-focused project of relatively short duration (18 months), various relatively innovative methods were necessary.

Methods

CICADA, begun in May 2021 and UK National Institute for Health and Care Research-funded (NIHR132914), captured the impact of changing pandemic contexts through three data collection waves, to address inequities in UK health and social care. One intention was to capture the voices of undocumented migrants and recent asylum seekers. Consistent with the logic model (Fig 1b) and the socioecological framework [3], person- and community-level contexts were considered. Since policy and practice targeted at broad uni-dimensional categories of people often fails [15], the impact on people's experiences of different intersecting identities was explored.

Existing evidence was considered, through a scoping literature review, and secondary analysis of contemporary household panel and UK national cohort study data. The survey had 4,326 valid responses across the UK's four nations at wave 1 (29% attrition by wave 3). People with self-declared chronic conditions or disabilities were interviewed; some attended follow-on co-create workshops five and ten months later. Final mixed stakeholder designer-led co-design workshops generated outputs based on study findings. Interviews with key informants (policymakers, clinicians and community leaders) explored rapid implementation of the co-designed outputs. Throughout this qualitative work, the research team ensured that stakeholders (especially the focal community) had an active and transformative voice in these processes, data and outputs. The ways this was done are

explored below, structured according to the components of participatory research described above.

Results

Choosing the community of focus

Two hundred and seventy one interviews were conducted with people likely to be especially affected by access to care and support during the pandemic. Characterisation of the community of focus required careful thought. The primary criterion for this healthcare study was *patient*-centred: participants had to have an impairment or chronic condition that led to their being disabled in their daily lives [16]. (Some non-disabled comparators were included.) Recruitment was purposive and from the community rather than healthcare services to include people pre-diagnosis and those with 'contested' (hard-to-diagnose) conditions with non-specific symptoms and limited or controversial physical signs. Despite screening interviews, some included participants did not appear disabled in daily life, highlighting different perspectives of disability, that each condition or impairment is not universally disabling, and that not every disabled person is ill. This aligned with the intersectional approach so their data were analysed, contributing informative though unexpected perspectives. For example, the intersection of myopia with recent migratory status disabled one participant for three months, till they obtained spectacles.

Selection by specific disability categories implies their homogeneity and side-lines other intersecting determinants of health, so the study design also foregrounded citizenship status and ethnicity, in a *person*-centred approach, using purposive quota sampling. Characterisation of a community of interest in this way has been called community segmentation [17]. The research team developed this iteratively, informed by community advisors and community co-researchers.

Focal ethnic categories were Arab, Central/East European, African and South Asian to reflect recent migration waves to England and COVID-19 risk statistics; Native white British comparators were added. As with disability, and aligned with the critical intersectional lens, challenges to categories were embraced and categories flexed with feedback from patient and professional advisors, community partners and co-researchers. Participants themselves posed questions such as "I have lived in Nigeria for 10 years, but I migrated there from Syria, am I African or Syrian in your study?"

A core set of 218 interviews were analysed, from participants who fitted the original ethnicity and disability criteria and the analysis tested against the remainder to explore congruence and difference, highlighting how intersecting factors may have different effects in different contexts. For example, socioeconomic status was particularly significant; as Chiarenza [18] says, rather than focusing on traditional cultural groups:

inequalities in health and in access to health care can be best understood in terms of the position of members of [those] different groups within social structures or hierarchies of rights.[18, p.68].

Simultaneously, some aspects of identity over-rode socioeconomic status in specific contexts:

> *The issues people of colour have with police and accessing services, I have not had to deal with. So it comes from the privilege an upper middle-class background …. [After Covid] there have been times when police had stopped…an amount of terror. And because you are Brown, and you hear the stories …even if you have not faced it before, the fear still exists. … When you had to give your details at restaurants or cafes, it felt very much like surveillance. As someone who doesn't trust the authorities, because of where I come from, I did not believe the details would just be used for track and trace (P67, South Asian).*

The demographics of the interview participants broadly represented national data though the study did not aim for representation but for in-depth understanding of experiences. Lay community co-researchers and community partners, working within their local communities, helped access and engage particularly underserved groups. They already had the connections or knew where to put up recruitment posters (such as in which specific local grocer's), and helped researchers develop appropriate communications, study materials and processes. Their success is evident from this data extract:

> *I don't know how to use smart phones or email … [social services] could not help me, no carer, nobody to help with booking appointments, nobody will help me to send emails. …I feel that there were violations of my rights.. Because I am an old lady from minority group and don't speak English, I am deaf so they give up and get frustrated. (P87, North African)*

Nonetheless the study team acknowledged that some groups will have been excluded. For example, people from underserved populations (i.e., with inequitable access to care) tend to have more advanced health conditions. The research team stopped interview sampling once a disability-ethnicity quota was reached, excluding those slowest to respond, who may have been those most disabled by their condition. Others were at least partially excluded from co-create workshops; participants mostly chose remote over face-to-face sessions but were less engaged remotely, because of a desire for anonymity, connection issues, and symptoms that prevented full participation. This illustrates how groups within groups may be particularly silenced, such as technologically impoverished, intellectually disabled and undocumented migrants.

Local relevance and capacity building
For data collection purposes, England was divided into the following regions: London, Yorkshire, Manchester and the Northwest coast, Newcastle and Cumbria, the South East and the Midlands. These reflected different migrant population densities, proportions of European Union (EU) to non-EU migrants, and reasons for migration, enabling the researchers to explore contextual differences in experiences and community capacity-building needs. Interviews were added from the devolved nations part-way; the survey was UK-wide from the start.

Community co-researchers, an important element in the initial study design, were embedded at the different study sites as equal and autonomous partners of the academic research team. When the study began, there were few successful examples of community co-researcher involvement within higher education, because of the extended timelines for institutional bureaucratic processes [19]. In the successful studies, teams had typically tapped into a group established for previous projects, so that some red tape had already been completed. Since the CICADA study team was interested in involving undocumented migrants and recent asylum seekers, this approach was not possible. Serendipitously however, the people who responded to CICADA study adverts for community researchers, via migrant charities, were recent successful asylum seekers who had become charity volunteers to 'put back' into these organisations. This meant they had undergone some checks already, reducing the necessary red tape. A further advantage was their regional reach; a group within academia is more typically based close to the central team. The research team recruited and trained 11 community co-researchers; eight undertook interviews, with some continuing to the project end, doing varied tasks alongside the core team.

Spread across the different England sites, they added research capacity within their local communities, especially impactful given their volunteering roles. The study team validated their importance through letters of recommendation and certificates, empowering them with evidential skills development that could help with job-seeking or promotions. Reciprocally, the author of this manuscript took up positions on the advisory committees of two of the relevant charities, directly impacting on local health care in their regions (London and Manchester).

The study lead also built local capacity by funding and assigning full control to collaborator partners, in Yorkshire and London, for two small 'studies within a project'. Each was asked to collect, analyse and report back on 20-30 local community interviews, adhering to the overall study design. One used this in a business case, procuring funding to undertake one of the intervention solutions developed from the co-design work.

Strengths and assets
A participatory research orientation to individual and community strengths and assets is empowering, through its holistic emphasis on positives. When this is incorporated in study outputs the empowerment is magnified, leading to great transformative potential. The more commonly used deficit-focused approaches tend to be ableist and white-centric, assuming failed interventions occur because the individual did not engage or try hard enough. The strengths-based work refuted this, learning from and building on what participants said worked well when coping with issues or managing their health within their personal contexts.

Importantly, in the co-design workshops, stakeholders were asked to develop person-centred care-relevant outputs based on these identified assets and strengths. The outputs did not suggest the community should do more but rather how clinicians and communities might work together more effectively in everyday practice, adjusting to varying contexts. Thus they did not relocate responsibilities and accountabilities from policymakers and health and social care systems to the community or deproblematise or shift the focus from

structural causes of inequalities [20]. Nor did they marginalise implementation contexts; successful strategies may not work to scale and in person-centred care it is important to understand why and how they work in particular circumstances, not just what was done during the pandemic. Study solutions aimed for the sustained empowerment of communities and individuals.

Power-sharing and engagement
True power sharing is rare in academic research. Even when funding is shared between the community and academic partner, removing one source of antecedent researcher power, deliberative and equitable negotiation of differences in expertise, values, incentives, priorities, working cultures, standards, resources, timescales and language is necessary [21]. In CICADA, researchers had to redefine their expectations of data quality; their community co-researcher interviews tended to less depth than those of the core team, but enhanced study quality by giving voice to the underserved and seldom heard, extending their reach and providing new perspectives and insights. Co-researchers guided the core researchers as much as the core researchers guided them in appropriate study processes, as respected autonomous decision makers in the field, whose work had the same valency as and was analysed with that of the core researchers.

The study's community advisors were initially not decision makers; their perspectives and advice could be over-ruled at any time. The study lead decided to transform them into additional co-researcher 'leaders and controllers' [22], a highly successful move. They were particularly invested in study processes, compared to the locally embedded co-researchers, perhaps because the continuing advisory group meetings reinforced their contributions:

The project leaders prepared me and fellow facilitators with sufficient information and knowledge to ensure that we felt confident and competent to carry out the tasks. This meant that I not only contributed to a worthy and important study, but also learnt new skills, met new friends and grew in myself. (Community advisory group member)

Sharing power with partners in Yorkshire and London both empowered them locally and provided balance in this research; their outputs could be triangulated with the core team's own work. One partner also held with the core team a national knowledge exchange webinar, reaching 240 healthcare professionals and community members. Delegates heard about the CUCADA research findings and shared their own data and experiences; a community of practice formed. Including partnerships in the initial study design increased funder confidence in the feasibility of the study, in an interesting reflection on distributed power.

Action-oriented knowledge exchange
It has been claimed that knowledge exchange pathways for participatory research and healthcare based person-centred research should be differentiated. The former, it is argued, emerged from a tradition of community action for change and focuses on community behavioural and lifestyle interventions, while the latter feeds into healthcare systems [23]. CICADA showed this to be an artificial distinction, targeting both pathways to empower communities whilst locating their care needs within service provisions.

The study design included co-creation research workshops, mixed stakeholder designer-led co-design workshops leading to patient and community-based outputs, and partnerships with third sector groups connected to healthcare systems. In particular the study lead partnered with a group feeding into clinical practice in Bradford, Yorkshire, and the Bromley-by-Bow Community Centre, which was allied with an adjacent London Health Clinic. Key informant interviews were knowledge exchange events designed to develop pathways to use for the outputs of the study.

Knowledge exchange was the raison d'être of the co-creation workshops, designed for *'the collaborative generation of knowledge by academics working alongside stakeholders from other sectors'* [24. p 393]. One hundred and thirty four interviewees were invited to these, with 104 attending at five months, 35 at 10 months. Preliminary analyses were discussed in these workshops, with photographs, videos enacted by community advisors and typewritten summaries, for accessibility across disabilities. Participants fed back, then contrasted more recent relevant experiences. Recruitment at 10 months was challenging because 'normal' post-pandemic life and priorities had resumed.

In September 2022, the author of this manuscript produced CICADA Stories, a knowledge exchange event with members of the public, performed at the Bloomsbury Theatre, London. This dramatisation of the data, co-produced with the community advisory group, ended with a Q & A and was positively received:

The CICADA Stories performance was absolutely brilliant. The team managed to combine beautiful spoken word poetry, with dance, drama and incredible qualitative data to create an extremely moving evening of theatre. I cannot imagine how much work went into this but it is an absolute model of how to make research come alive to an audience. Public engagement at its best. (Academic audience member)

The designer-led co-design workshops were attended by health professionals, community leaders, charity leads and members of the public (16 people in total) to share knowledge to co-design rapid-impact outputs**.** Designer-led co-design is appropriate when expected outputs are tangible, such as a report, map, website, guidance or infographic and need to be of a professional standard, practical to develop, affordable and sustainable [24]; this study was too short to develop more complex interventions. Design-based approaches without a trained designer are an alternative often used in healthcare settings and developed to embed transformative thinking into the mindset of staff undertaking PDSA cycles [25].

Typically in co-design, stakeholders are asked to negotiate amongst themselves modifications to a prototype or existing intervention or clinical aid so it is relevant, acceptable and appropriate across the stakeholder groups. Instead, in the CICADA study, co-design participants began with summaries of the interview data, from which prototypes were developed for modification in a later workshop. Designers in designer-led workshops use techniques, called generative methods or ideation tools, which typically involve using, handling or making something [24]. These aim to release participants from conventional ways of thinking, to explore, reflect on, reimagine, express and share experiences and thoughts that usually lie in the subconscious. The approach is inclusive; each individual

contribution has a physical presence that is not dependent on different verbal communication norms and is difficult for others in the group to ignore – this means that everyone feels listened to [24]. In CICADA, participants made plasticine models inspired by strategies revealed in the data. Few people are expert plasticine modellers, so this also demolished power differences in the room. To explore tacit (subconscious) knowledge, facilitators asked questions about the modelling; conversations were audio- recorded and illustrated by an artist, combining the 'made' and the communication it engendered [25].

The researchers split participants into groups of 4-5 mixed stakeholders to facilitate sharing, learning and different variations of new understandings. These were incorporated into new negotiated group models, that incorporated the attributions and meanings of the individual models and were displayed with descriptions of the relevant thought processes, alongside the artist's impressions of discussions. This meant the shared negotiated process was visible and could be examined, and helped demonstrate authenticity of the process for funders, too.

Sustained engagement
CICADA was too short to explore sustained engagement. However, the study lead plans to use seed funding to continue to involve participants, researchers, the community advisory group and co-researchers in iteratively developed outputs.

Discussion
Participatory research methods are invaluable in developing the evidence-base for person-centred care, driving a greater sensitivity to diversity and the contexts in which intervention mechanisms of effect do or do not operate. Yet, researchers often fail to utilise participatory approaches that include the most underserved groups, wrongly believing them to be resource-heavy. The CICADA study has shown the fallacy of this with its methods, enabling good representation from some of the most underserved groups, such as undocumented migrants. This is critical to reduce inequities in person-centred care, as elsewhere in healthcare.

The commonly used participatory methods are predicated on the idea of the citizen as a consumer with a right to be involved in decisions about their care. However, the CICADA study lead was interested in the experiences of those with uncertain citizenship status, and in replacing siloed categorizations of people by disability or by ethnic group with an intersectional approach that is rare in participatory healthcare research. The CICADA study was therefore designed to be inclusive of, and focused on the intersection of, citizenship status, minoritised ethnic group identity and disability within different contexts. In keeping with a risk-based rather than more usual outcomes-based logic model, and socioecological considerations, foregrounded person-centred and community contexts, strengths and assets were foregrounded. This enabled the research team to co-design, with relevant stakeholders, person-centred outputs, either based on pragmatic strategies that participants had used successfully during the pandemic, or that could support their use. This approach is more likely to help underserved groups than a top-down or a deficit-focused orientation. Simultaneously it was important to emphasise that services could not be replaced by community efforts, to avoid what Fotaki [26] called producing 'hapless constituents' rather than the empowered consumer ideal of participatory methods.

The research lead was especially interested in efficient use of methods, as this was an ambitious study, repeatedly engaging numerous participants, within a relatively short period, for such participatory work, of 18 months. In this paper the author has described how a combination of several participatory approaches might best be used in an inclusive participatory research project involving the underserved. The go-to of participatory research is often a simple community arts-based workshop with outputs that are interpreted by researchers, or a consultation process in which final decisions are made by the research team [10]. It is necessary to move beyond these approaches to what works best in what part of the research process to achieve different objectives and satisfy different needs.

In CICADA, the researchers trained community co-researchers who increased their reach within underserved groups better and more efficiently than the researchers themselves could have achieved if they had spent time in the field gaining community trust. Partnerships were formed with third sector groups linked to healthcare teams, who worked in parallel on smaller versions of this study. As with the co-researchers, this shifted work from the core team, and increased study feasibility through a redistribution of power and accountability that increased local commitment and investment. The research team used co-create workshops, key informant interviews, a practitioner webinar and a public theatre show for knowledge exchange, to develop mutual understanding across and between researchers, practitioners and communities. Local capacities were built and communities and individuals were empowered. Throughout, the researchers showed flexibility in their expectations and understandings of data quality, categorisations and recruitment criteria, intersecting identities and other aspects of this study's design and processes, responding to the input of the co-researchers, advisors and participants as equal controllers of the study. The mixed stakeholder designer-led co-design workshops led to several practical and transformative strengths-based outputs, acceptable to all relevant stakeholders, that encourage person-centred care. Without these different participatory research components, the data would have been incomplete, less rich and less likely to result in impactful outputs and evidence. Careful thought about participatory methods can reap significant rewards.

Conclusions

Participatory research methods are effective in informing person-centred care, especially for underserved groups. However, those served least well are least likely to be engaged in such research when it uses a basic and prescriptive approach that does not consider their particular needs, values, beliefs and assets in relation to their individual and community contexts. Different participatory procedures are designed for different ends, and should be used strategically. Training people from underserved communities to act as autonomous decision-making co-researchers, and commissioning small studies from partners and collaborators, improves the reach and sensitivity of a study, empowers the individuals and communities concerned, and provides checks on the core team's work, to validate or challenge this. Co-creation knowledge exchange activities and mixed stakeholder co-design work, equitable across different groups, enhance mutual understandings, with outputs that are likely to be taken up in practice for better person-centred care of the underserved.

References
1. World Health Organization (WHO). *People-centred health care: a policy framework*. WHO: Regional Office for the Western Pacific. 2013. ISBN: 9789290613176**.** Available at: https://www.who.int/publications/i/item/9789290613176.
2. NHS England. Universal Personalised Care: Implementing the Comprehensive Model. Version:1. Publications Gateway Reference: 08193, 2019. NHS England. Available at: https://www.england.nhs.uk/publication/universal-personalised-care-implementing-the-comprehensive-model/
3. Bronfenbrenner U, Evans GW. Developmental science in the 21st century: Emerging questions, theoretical models, research designs and empirical findings. *Social development,* 2000; 9 (1):115-125.
4. Mezzich JE, Levent Kirisci, Ihsan M Salloum, Jitendra K Trivedi, Sujit Kumar Kar, Neal Adams, Janet Wallcraft. Systematic conceptualization of person centered medicine and development and validation of a Person-centered Care Index. *Int J Person Centered Medicine* 2016; 6 (4):219-247.
5. Skivington K, Matthews L, Simpson S A, Craig P, Baird J, Blazeby J M et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance *BMJ* 2021; 374:n2061 doi:10.1136/bmj.n2061
6. Pawson R, Tilley N. *Realistic evaluation*. 1997. London: Sage.
7. Rothman KJ, Greenland S, Lash TL. *Modern epidemiology.* Third edition. Philadelphia: Lippincott Williams & Wilkins; 2008. p. 758.
8. Halvorsrud K, Kucharska J, Adlington K, Rüdell K, Brown Hajdukova E, Nazroo J, Haarmans M, Rhodes J, Bhui K. Identifying evidence of effectiveness in the co-creation of research. *J Public Health (Oxf).* 2021 Apr 12;43(1):197-208. doi: 10.1093/pubmed/fdz126.
9. Darko N. Engaging black and minority ethnic groups in health research: 'hard to reach'? Demystifying the misconceptions. United Kingdom: Policy Press, 2021, ISBN/EAN 1447359127/9781447359128
10. Harris J, Cook T, Gibbs L, Oetzel J, Salsberg J, Shinn C, Springett J, Wallerstein N, Wright M. Searching for the impact of participation in health and health research. *BioMed Research Int*, 2018: 9427452.
11. Evans A, Potochnik A. Theorizing participatory research. In Emily Anderson (Ed.), *Ethical issues in stakeholder-engaged health research*, pp11-26, 2023. Springer.

12. Falicov CJ. Commentary: On the wisdom and challenges of culturally attuned treatments for Latinos. *Fam Process*. 2009 Jun;48(2):292-309. doi: 10.1111/j.1545-5300.2009.01282.x. PMID: 19579910.

13. Hawkins RP, Kreuter M, Resnicow K, Fishbein M, Dijkstra A. Understanding tailoring in communicating about health. *Health Educ Res*. 2008 Jun 01;23(3):454–66. doi: 10.1093/her/cyn004.

14. Mills T, Lawton R, Sheard L. Advancing complexity science in healthcare research: the logic of logic models. *BMC Med Res Methodol* 19, 55; 2019. https://doi.org/10.1186/s12874-019-0701-4

15. Hankivsky O, Cormier R. Intersectionality and public policy: some lessons from existing models. *Political Research Quarterly*, 2011; 64(1), 217-229. https://doi.org/10.1177/1065912910376385

16. UK Government. The Equality Act 2010. In: https://www.legislation.gov.uk/ukpga/2010/15/contents; 2010

17. Andersson N. Participatory research-A modernizing science for primary health care. *J Gen Fam Med.* 2018 Jul 11;19(5):154-159. doi: 10.1002/jgf2.187.

18. Chiarenza A (2014) Standards for equity in health care for migrants and other vulnerable groups: self-assessment tool for pilot implementation. International Network of Health Promoting Hospitals, Reggio Emilia: AUSl of Reggio Emilia.

19. Marks S, Mathie E, Smiddy J. et al. Reflections and experiences of a co-researcher involved in a renal research study. *Res Involv Engagem* 2018;4,36.

20. Foley W, Schubert Lisa. Applying strengths-based approaches to nutrition research and interventions in Indigenous Australian communities. *J Critical Dietetics* 2013:1(3):15-25.

21. Bergold J, Thomas S. Participatory research methods: a methodological approach in motion. *Forum Qualitative Sozialforschung* 2021;13(1). https://doi.org/10.17169/fqs-13.1.1801Bigby

22. Sofolahan-Oladeinde Y, Mullins CD, Baquet CR. Using community-based participatory research in patient-centered outcomes research to address health disparities in under-represented communities. *J Comparative Effectiveness Research*. 2015;4(5):515–523. doi: 10.2217/cer.15.31.

23. Brown T. Design Thinking. Harv Bus Rev. *2008;* June; available at: http://5a5f89b8e10a225a44ac-ccbed124c38c4f7a3066210c073e7d55.r9.cf1.rackcdn.com/files/pdfs/IDEO_HBR_DT_08.pdf

24. Robert G, Locock L, Williams O, Cornwell J, Donetto S, Goodrich J. Co-Producing and CoDesigning. In: *Elements of Improving Quality and Safety in Healthcare.* Cambridge University Press, Cambridge, 2022. https://doi.org/doi:10.1017/9781009237024

25. Langley J, Wolstenholme D, Cooke J. 'Collective making' as knowledge mobilisation. *BMC Health Serv Res* 18, 585 (2018). https://doi.org/10.1186/s12913-018-3397-y

26. Fotaki M. Towards developing new partnerships in public services. *Public Administration* 2011;89:933-955. https://doi.org/10.1111/j.1467-9299.2010.01879.x