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1 **From tokenism to transformation:**
2 **lessons from the TOGETHER study**
3 **for building inclusive and equitable**
4 **research**

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1 Plain English summary

2 Children’s health in the UK is getting worse, with rising inequalities that particularly affect
3 racially and socially minoritised families. Yet these families are often left out of research. This is
4 unfair and also means that research findings may not apply to those who need them most.

5 We looked back at the TOGETHER study, a large trial of the *Strengthening Families,*
6 *Strengthening Communities* (SFSC) parenting programme, run in six areas of England. Our aim
7 was to understand what made the study inclusive and how we involved parents and
8 communities in meaningful ways.

9 We analysed information on who joined the trial and who stayed involved and reviewed five
10 years of meeting notes from the study team and public involvement groups. We also held
11 reflection workshops and conversations with parents in the study advisory groups, a lived-
12 experience co-investigator, and the Race Equality Foundation, our third-sector partner.

13 The study recruited 674 parents across 34 groups, meeting the initial study target. The parents
14 were very diverse: 65% were from racially minoritised backgrounds, nearly half spoke a first
15 language other than English, and over half lived in low household incomes. We identified six
16 things that enabled an inclusive study: (1) leadership from lived experience; (2) active parent
17 advisory groups; (3) meaningful community partnerships; (4) community-embedded
18 researchers; (5) the Race Equality Foundation linking researchers and communities; and (6)
19 budgets, resources, and committed leadership.

20 The study showed that inclusive research is not separate from people’s everyday lives. During
21 the COVID-19 pandemic, for example, parents and researchers worked together to create
22 accessible public health newsletters to support families. The TOGETHER study shows that
23 inclusive research is possible when communities are embedded from the start and supported
24 with the right resources.

1 Abstract

2 **Background:** Children’s health in the UK is in decline, with widening inequities
3 disproportionately affecting racially and socially minoritised families. These same communities
4 are often excluded from research, compromising both fairness and scientific validity. Patient
5 and public involvement and engagement (PPIE) has been promoted as a mechanism to address
6 exclusion, but in practice it can replicate existing inequalities. There is limited evidence on what
7 inclusive research looks like in practice. This paper reflects on the TOGETHER study—a large,
8 multi-site randomised controlled trial of the *Strengthening Families, Strengthening*
9 *Communities* (SFSC) parenting programme—exploring the strategies and processes that
10 supported equitable engagement.

11 **Methods:** We used a reflective, retrospective case approach informed by: (i) descriptive
12 analysis of trial baseline data (recruitment, retention, participant demographics); (ii) analysis of
13 five years of study meeting minutes; and (iii) two facilitated reflective workshops with parent
14 advisory groups, the lived-experience co-investigator, and the Race Equality Foundation (third-
15 sector partner).

16 **Results:** The trial successfully recruited 674 parents across 34 programmes, meeting 100% of
17 the target. The sample was both ethnically and socially diverse: 65% of participants identified
18 as Black, Asian, mixed or other minoritised ethnicities; nearly half reported a first language
19 other than English; and over half live with household incomes below £20,000. Attrition rates
20 were 28% at post-intervention and 30% at six-month follow-up. Six key enablers were identified:
21 (1) lived experience leadership through a co-investigator; (2) public involvement via local Parent
22 Advisory Groups (3) relational partnerships with community organisations; (4) multilingual
23 community researchers supporting linguistically and culturally inclusive data collection (5)
24 strategic support from a third sector organisation, the Race Equality Foundation, and (6)
25 investing in inclusion through dedicated budgets, resources, and visible, supportive leadership.

1 These enablers helped ensure high recruitment, strong retention, and meaningful participation
2 with families often excluded from research.

3 **Conclusions:** The TOGETHER study demonstrates that inclusive research is possible when
4 lived experience, community voices, and third-sector expertise are embedded and resourced
5 from the outset. Inclusion required investment of time, money, and infrastructure, as well as
6 leadership that valued relationships and reflexivity and researchers positioned not as detached
7 observers but as relational actors within participants lived contexts. Our reflections highlight
8 the potential and the tensions of embedding equity in research, offering practical insights for
9 researchers, funders, and institutions seeking to move beyond tokenism towards
10 transformation.

11 **Keywords:** health inequalities; inclusion; public involvement; equity; PPIE; EDI; RCT;
12 community engagement; parenting; third sector.

1 Background

2 Improving children’s health is a vital foundation for lifelong wellbeing and population health [1].
3 Yet in the UK, children’s health is in worrying decline. One in five children now experiences a
4 probable mental health disorder [2], and over 4.5 million live in poverty, with racially minoritised
5 families disproportionately affected [3]. These stark inequities are not simply the result of
6 individual choices but are shaped by the wider determinants of health, the conditions in which
7 people are born, grow, live, work, and age [4]. For ethnically and socially diverse communities,
8 these conditions are often defined by entrenched inequalities [5]. Yet these same communities
9 are often excluded from the health, social care, policy and research systems meant to
10 understand and address their needs—including research.

11 Health research plays a vital role in generating evidence to inform policy, drive
12 innovation, and improve population outcomes [6]. However, ethnically and socially diverse
13 populations remain persistently underrepresented in health research [7–10]. In the UK, an
14 analysis of 148 research trials published by the National Institute for Health and Care Research
15 (NIHR) between 2019 and 2021 found that 86% of participants were White [10]. Just 4% were
16 Black and 5% Asian, figures that fall short of reflecting the ethnic diversity of the population.
17 Only 60% of trials even reported participants’ ethnicity. Underrepresentation extends beyond
18 recruitment and many studies also struggle to retain participants from minoritised groups,
19 further threatening the validity and relevance of findings [11]. To understand what works to
20 reduce inequalities, we cannot continue to study only the privileged.

21 The reasons for underrepresentation in research are complex and deeply embedded in
22 structural and institutional systems [12]. Historical and contemporary experiences of
23 exclusion, exploitation, and racism have led to deep mistrust of research institutions [13].
24 Language barriers, inflexible protocols, and inaccessible recruitment strategies continue to
25 marginalise communities. People from ethnic minority backgrounds report previous negative

1 experiences with health or social services, reinforcing a sense of alienation [8]. The
2 consequences of this exclusion are about both fairness and scientific rigor. From an ethical
3 perspective, the exclusion of ethnically and socially diverse communities from research limits
4 whose experiences count and whose needs are prioritised. From a scientific perspective,
5 research based on unrepresentative samples produces evidence that is narrow, non-
6 generalisable, and potentially ineffective for the communities most affected. Inclusive research
7 is therefore not simply about diversity for its own sake—it is essential to producing actionable,
8 equitable evidence.

9 Patient and Public Involvement and Engagement (PPIE)—research carried out *with or by*
10 members of the public rather than *to, about, or for* them—is now widely recognised as a core
11 element of high-quality research [14–16]. Done well, it can challenge assumptions, reshape
12 priorities, and improve research design and representation. It is also increasingly seen as a way
13 to build trust and address exclusion—particularly for underserved or racially minoritised
14 communities [17]. Yet PPIE is not immune to the inequalities it seeks to address. Public
15 contributors remain largely drawn from narrow demographics—most often older, White,
16 middle-class, and professional [18]. Diversity in PPIE panels is rarely reported, and groups
17 facing the greatest health inequalities are often least likely to be included in PPIE [19]. As a
18 result, PPIE that is not intentionally structured to include racially minoritised and
19 socioeconomically disadvantaged communities risks reproducing existing inequities within
20 research systems [7,20].

21 Many of the barriers faced by racially minoritised and socioeconomically disadvantaged
22 groups, such as discrimination, mistrust of institutions, and structural disadvantages [4,5,21],
23 are reproduced within research systems [7,20,22,23]. These same barriers affect both research
24 participation and involvement in PPIE roles and activities. One review found that lack of trust,
25 poor communication, and the dismissal of cultural concerns were key obstacles for racially

1 minoritised communities [7]. Others experience digital exclusion or receive inadequate support
2 for cognitive or communication needs, while many struggle to balance PPIE roles with complex
3 personal, work, and caregiving responsibilities [20]. Some contributors also carry the invisible
4 emotional labour of representing communities under strain—often without adequate
5 recognition or support [24]. While some of these challenges stem from time and resource
6 constraints, they also reveal a deeper lack of understanding among researchers about the lived
7 realities and needs of diverse contributors [20].

8 These gaps point to a wider structural problem. PPIE is frequently promoted as a
9 solution to exclusion, yet a growing body of literature highlights concerns about tokenism,
10 performative engagement, and the reproduction of existing power hierarchies within research
11 systems [22,25]. Without intentional strategies to address structural inequities, PPIE risks
12 becoming a procedural requirement rather than a transformative practice. Similar critiques
13 have been raised in relation to diversity in clinical trials, where recruitment targets may be
14 pursued without addressing the underlying relational and structural barriers to equitable
15 participation [13,25,26]. To move beyond symbolic inclusion, we need clearer evidence of what
16 inclusive research looks like in practice [8,14]. Real-world case studies offer valuable insights
17 into the challenges, tensions, and enablers of inclusion. Rather than relying on generalised
18 commitments to diversity, researchers and funders must examine the mechanisms that
19 underpin effective community engagement. This paper explores how inclusive research was
20 realised in practice through PPIE and other strategies in the TOGETHER study—a large-scale
21 trial of the Strengthening Families, Strengthening Communities (SFSC) parenting programme
22 (funded by the National Institute for Health and care Research [NIHR]).

23 **Overview of the TOGETHER study**

24 The TOGETHER study was a national, multi-centre randomised controlled trial (RCT) [27]—
25 widely regarded as the most rigorous design for evaluating the effectiveness of interventions

1 and is frequently prioritised within evidence hierarchies [28]. RCTs randomly allocate
2 participants to an intervention or control group, allowing for rigorous causal inference while
3 minimising bias. RCT evidence is frequently prioritised within funding and
4 policy/commissioning decisions so plays an influential role in determining which interventions
5 are adopted, scaled or discontinued. This makes RCTs particularly important in the context of
6 inequality where if trials do not adequately include racially and socioeconomically marginalised
7 groups, the evidence base guiding policy may systematically overlook those most affected. The
8 issue is therefore how we can design and deliver RCTs in ways that ensure inclusive
9 participation and equitable representation.

10 The TOGETHER study set out to evaluate the effectiveness and cost-effectiveness of the
11 *Strengthening Families, Strengthening Communities* (SFSC) parenting programme in improving
12 parental mental well-being and children’s social and emotional development up to six months
13 post-intervention [27]. The SFSC programme is a universal, evidence-informed programme
14 deployed by the Race Equality Foundation—a third-sector organisation dedicated to race
15 equity. Designed to meet the needs of racially and culturally diverse families, particularly Black,
16 Asian, and minoritised ethnic communities, SFSC focuses on promoting protective parenting
17 factors, positive behaviour change, and stronger community ties. While systematic reviews
18 have shown that universal parenting programmes can support parenting skills, parental
19 wellbeing, and child behaviour [29–31], such programmes can be less effective at engaging
20 ethnically and socially diverse families [32]. SFSC stands out for its inclusive, community-
21 focused model, and earlier evaluations have shown promising outcomes—but large-scale trials
22 assessing its impact across diverse groups have been lacking.

23 Led by Professor Richard Watt at UCL, TOGETHER was conducted across six urban sites
24 in England—Calderdale, Hull, Kirklees, Leeds, London, and Luton—chosen for their social and
25 ethnic diversity and alignment with real-world SFSC delivery contexts. The study launched in

1 April 2019 and included an internal pilot, a full RCT, a cost-effectiveness evaluation, and an
2 embedded process evaluation [27]. Recruitment was conducted through a mix of Local
3 Authorities, community groups, and trusted local settings such as schools, children’s centres,
4 and places of worship. A collaborative study team included academic researchers, a lived
5 experience co-investigator, the Race Equality Foundation, and three Parent Advisory Groups
6 (PAGs), composed of parents from participating communities (see Figure 1).

7 The trial findings offer critical insights into how SFSC can reduce health inequalities, the
8 study also sheds light on what it takes to conduct an inclusive, large-scale research project in
9 practice. This paper focuses on the strategies and processes that enabled inclusive
10 participation across a complex, multi-site trial.

11 Aims and objectives

12 This paper offers critical reflections from the TOGETHER study and the key enablers to
13 designing and delivering an inclusive research study in practice. Our specific objectives are to:

- 14 1) Explore participant recruitment and retention patterns and their links with specific
15 inclusion strategies.
- 16 2) Examine the relational partnerships between academic researchers, the lived
17 experience co-investigator, advisory groups, and the Race Equality Foundation.
- 18 3) Scrutinise the broader academic landscape in supporting or hindering strategies and
19 practices for inclusive research.
- 20 4) Offer recommendations for researchers and funders to support equity and inclusion in
21 research strategies and practices.

1 Methods

2 Study design

3 This paper presents a retrospective, critical reflective case analysis of the inclusive practices
4 embedded within the TOGETHER study. The study began in early 2019 and during the study
5 there had been interest to capture learning about the PPIE ‘work’ underway (i.e. with a regular
6 survey with the advisory groups). The realities of delivering a complex trial meant that a formal
7 evaluation was not planned but there was continued interest in drawing out insights,
8 nonetheless. As such, this paper was developed following completion of the study as a critical
9 reflective analysis of those involved, rather than a formal separate sub-study of the TOGETHER
10 study. Rather than evaluating effectiveness through formal qualitative methods or fixed
11 metrics, we sought to surface insights into the realities, and at times, the ‘messiness’ of
12 conducting a large-scale community trial through our own reflections.

13 Data sources

14 Our reflections were informed by multiple sources. First, we drew on descriptive trial data
15 generated and overseen by the North Wales Organisation for Randomised Trials in Health and
16 Social Care (NORTH) Clinical Trials Unit (CTU), which held responsibility for trial data
17 management and analysis. We relied on existing planned analyses of recruitment, withdrawal,
18 attrition, and outcome data, and supplemented this with additional descriptive analyses
19 relating to referral pathways into the study (i.e. from statutory services and community
20 organisations) to uncover patterns of inclusion and engagement. We then reviewed five years of
21 study team and PPIE meeting minutes. These documentary materials, originally generated for
22 governance and operational purposes, were examined to identify how public involvement was
23 discussed and enacted within study. We went on to share and discuss some of the insights
24 from the trial data and documentary materials in two structured reflective sessions with the
25 lived experience co-investigator and members of the PAGs. The sessions were documented
26 and visually captured by a professional graphic illustrator (see

1 Figure 2). In addition, some PAG members volunteered to participate in individual video
2 interviews, which were compiled into a short film (see
3 <https://www.youtube.com/watch?v=x4cb71K9mUU>) to support dissemination and knowledge
4 mobilisation. These materials were intended to promote shared learning and visibility of the
5 study rather than to serve as formal qualitative research data. All these forms of data were
6 drawn on for the purposes of our critical reflections and findings presented in this paper.

7 Analysis

8 The analytic process we followed was iterative, collaborative, and reflexive. AM first reviewed
9 study documentation and descriptive trial data, including recruitment, retention, and referral
10 patterns, to identify preliminary observations relating to inclusion and engagement across
11 sites. These observations formed the basis for structured discussions with LB and KM, drawing
12 on their sustained involvement in public involvement leadership and lived experience roles
13 within the trial. These early conversations surfaced provisional themes relating to relational
14 practice, infrastructure, leadership, and community partnership. These emerging insights were
15 then taken into the first facilitated reflective session with PAG members in early 2024. The
16 session was designed as a collective sense-making exercise, inviting participants to reflect on
17 their experiences, perceived contributions, challenges, and impacts across the study journey. A
18 second session focused on synthesising these reflections, identifying shared experiences, and
19 articulating what PAG members considered to be important factors in supporting their
20 meaningful inclusion and impact on the study. A professional visual scribe was engaged to
21 document this process graphically to support collective reflection and knowledge sharing.
22 Alongside this, PAG members, LB, KM, and AM discussed strategies for disseminating learning
23 from the study. This included co-producing audiovisual outputs, such as a short film featuring
24 consenting PAG members and key contributors. While primarily intended for dissemination and
25 knowledge mobilisation, these materials also reinforced and clarified shared reflections about
26 inclusion.

1 Following these sessions, AM, LB, and KM revisited all sources (documentary materials,
2 descriptive data, reflective session outputs, and audiovisual transcripts) to identify recurring
3 patterns which might be linked to equity, diversity, inclusion, and lived experience involvement
4 and trial participation. Through iterative discussion and comparison across sources, five
5 interrelated ‘enablers’ were identified as consistently underpinning inclusive participation and
6 representation within the trial. A subsequent period of collaborative refinement involved
7 additional researchers (AL, DC, and TBP) offering further reflections and an additional enabler.
8 The study lead (RGW) and third sector co-investigator third sector lead (JB) also provided
9 critical reflections as well as reflection on wider system-level factors that facilitated or
10 constrained their enactment.

11 Positionality and reflexivity

12 We acknowledge that our reflections are shaped by our positionalities, relationships, and
13 proximity to the work on the TOGETHER study including our different roles, responsibilities, and
14 forms of authority within it. The findings presented in this paper were primarily developed by
15 three authors (AM, LB and KM), who worked closely together throughout different stages of the
16 TOGETHER study and in the analysis presented here. AM is an academic researcher who held
17 roles within the study; LB is Deputy CEO of the Race Equality Foundation and worked closely
18 with delivery partners and community organisations; and KM is a parent co-investigator with
19 lived experience who contributed to the study from its early stages through to dissemination.
20 We connected through our respective roles in the study and developed an ongoing reflective
21 dialogue about the PPIE processes and relationships that unfolded across the project. As
22 women from minoritised ethnic backgrounds working across academic, third sector and lived-
23 experience roles, we recognised both differences and commonalities in how we navigated the
24 spaces surrounding the study. While our roles carried different forms of authority and power
25 within the research process, we also shared experiences of working within racialised
26 institutional contexts, including academic and research environments, which shaped how we

1 understood issues of trust, representation and inclusion in the study. For LB and KM,
2 reflections were also shaped by their positions as parents engaging with research concerning
3 family life, while AM's position as an academic researcher shaped how these insights were
4 interpreted within broader research frameworks. Over time, including after AM had moved on
5 from a formal role within the study, our continued collaboration across other research activities
6 provided space to reflect more critically on these experiences. Towards the end of the study, we
7 therefore sought to bring these reflections together in a more structured way as part of the
8 analysis presented in this paper. While our own perspectives were an important starting point,
9 we were also attentive to the limitations of relying solely on personal reflection. We therefore
10 drew on additional sources including trial data, meeting minutes and reflections with the PAGs
11 to situate, challenge and extend our interpretations. We also sought input from other members
12 of the research team and study partners to sense-check the themes that emerged from these
13 reflections. In particular, senior leads within the research (RW) and partner organisation (JB)
14 contributed perspectives on how these insights resonated with broader context of research.
15 Researchers involved in key roles on the study (AL, DC and TBP), including leading PPIE work
16 during the study, also reviewed and reflected on the emerging themes to sense-check how
17 these resonated with their own experiences of delivering and supporting the research. The
18 findings in the paper therefore represent a situated interpretation shaped by our positions
19 within and around the study rather than a neutral or exhaustive account of the PPIE processes.
20 We therefore do not claim objectivity or completeness, but instead offer a situated perspective
21 that embraces reflexivity, humility, and transparency. Our intention is not to present a definitive
22 account, but to illuminate the key practices, tensions, and learning moments that supported
23 inclusive research in this context. In the following section, we present key insights from these
24 reflections, followed by a discussion around implications and recommendations for
25 researchers and funders.

1 Results

2 Ethnically and socially diverse representation in the study

3 The TOGETHER study successfully recruited 674 participants and delivered 34 SFSC parenting
4 programmes, meeting 100% of the target. The sample was both ethnically and socially diverse:
5 65% of participants identified as Black, Asian, mixed, or other minoritised ethnicities; nearly
6 half reported a first language other than English; and more than half had household incomes
7 under £20,000. 16% (n=107) completed questionnaires in a language other than English.
8 Retention was also strong: only 11% formally withdrew from the trial, with attrition rates of 28%
9 at the post-intervention assessment and 30% at the six-month follow-up. There was no
10 statistically significant difference in withdrawal or attrition rates by ethnicity, household
11 income, age of child, site or language. Findings (due to be published) showed that SFSC
12 significantly improved parental mental wellbeing and had positive effects on secondary
13 outcomes including children's socio-emotional wellbeing, parenting practices, and family
14 relationships. These benefits were observed across ethnic and socioeconomic groups,
15 suggesting the programme's potential to reduce rather than reinforce inequalities.

16 Key enablers for inclusivity

17 We identified six key enablers that were critical to the inclusive and successful delivery of the
18 TOGETHER study. These reflect the relational, structural, and institutional factors that shaped
19 how the research was conducted and who it reached. These key enablers include:

- 20 1) Leading with lived experience: Navigating power, emotion and endurance.
- 21 2) Disrupting from within: Parent Advisory Groups as agents of change.
- 22 3) Roots into the community: Building strong relational partnerships with local community
23 organisations.
- 24 4) Speaking the same language: Community researchers supporting culturally and
25 linguistically inclusive data collection.

1 5) Connecting the dots: The third sector as powering inclusion.

2 6) Investing in inclusion: Budgets, resources, and leadership

3 1) Leading with lived experience: Navigating power, emotion and 4 endurance

5 A core feature of the TOGETHER study was the appointment of a lived experience co-
6 investigator, whose role spanned the full lifecycle of the research. Her contribution was
7 pivotal—not only in supporting inclusive practices, but in bringing consistency, challenge, and
8 lived insight to a complex trial. Having previously completed the SFSC programme herself, she
9 offered a unique perspective that bridged participants and researchers. Her sustained
10 involvement added depth and credibility to the research process, ensuring it remained
11 grounded in the realities of the communities it aimed to serve.

12 The co-investigator was identified by the Race Equality Foundation during the early
13 conception of the study. The team was keen to draw on a public contributor who had the lived
14 experiences to contribute meaningfully to the study rather than draw on the ‘usual suspects’
15 [19]. She was not a ‘professionalised’ PPIE contributor although had some prior involvement on
16 an advisory group for a smaller study. She brought lived experience as a Black parent raising a
17 neurodiverse child. She is also neurodiverse herself.

18 Over the five-year duration of the study, she attended nearly all of the Trial Management
19 Group (TMG) meetings, co-facilitated 25 PAG sessions, and took part in numerous planning and
20 debriefing discussions with the research team. All of this was carried out alongside her
21 professional work, voluntary responsibilities, and family life. The time commitment was
22 significant and to support her role, the Race Equality Foundation offered consistent
23 infrastructure and care. This included regular preparatory talks ahead of meetings and
24 maintaining open lines of contact with other dedicated staff on the research team.

1 These relationships formed a support network that enabled her to stay engaged in what
2 was often a demanding role. She had been instrumental in raising issues of power imbalance—
3 reminding the team that the subject matter under study was not abstract or theoretical for the
4 families involved. It was lived, personal, and at times painful. She reflected in an individual
5 interview:

6 *“This is not theory stuff for us...it affects my mental health... this is real for us.”*

7 She frequently spoke to the discomfort of navigating academic spaces, where research
8 language, professional hierarchies, and institutional norms could feel alienating. She continued
9 where she reflected:

10 *“I feel it’s not always been comfortable because sitting with researchers and different types of*
11 *people around the table you actually question, can I say this? Can I be a part of this?”*

12 There were moments where the emotional labour and role led her to consider stepping back.
13 However, having a key contact point at the Race Equality Foundation was an important support
14 function. This support included regular structured meetings, often prior to formal meetings as a
15 space where she could ask questions, clarify terminology, and raise any emerging concerns in a
16 supportive environment. These pre-meetings were not token gestures—they provided
17 psychological safety and built confidence for full participation in formal research governance.
18 There was also opportunity for informal and ad-hoc check-in’s which suited her schedule and
19 needs. She reflects on this support:

20 *“If it wasn’t for you guys at Race Equality [Foundation], I would have walked a long time ago...*

21 *This is not just research—it’s our lives.”*

22 The lived experience co-investigator was a consistent presence over the duration of the study,
23 which became particularly critical amidst multiple changes in the research team over the five
24 years. This turnover and transitional periods between new research staff had some impact on

1 continuity and relationships, especially with the PAGs, where trust and familiarity were central
2 to sustained engagement. For PAG members, new research staff brought different levels of
3 experience and varying commitment to PPIE. This required PAG members to rebuild trust with
4 the research team and adapt to new relationships, approaches and sometimes extended gaps
5 between meetings. The lived experience co-investigator became a stable and consistent
6 anchor who understood the PAG's perspectives and progress made with their involvement in
7 the study and was able to advocate and offered reassurance. Her contributions left a lasting
8 imprint on the study's values, approach, and credibility, and she ultimately reflected:

9 *"I think now looking at five years and my contribution ... and seeing the end picture it's like wow*
10 *was I really a part of this? Did I actually make changes? And yeah I have, and it's not just for me,*
11 *I've done it for all parents."*

12 2) Public representatives as research partners: the role of Parent 13 Advisory Groups

14 Active and sustained involvement of diverse parents as genuine research partners was a vital
15 component of the TOGETHER study. While advisory groups are now a common feature in health
16 research and trials, we looked to go beyond consultation and towards more embedded and
17 ongoing partnership. The PAGs played a central role in shaping how the research was designed,
18 delivered, and experienced by participants – often challenging assumptions and surfacing
19 overlooked perspectives. We reflect on how the PAGs were initially established, how they
20 helped shape and positively disrupt the study, and the ripple effects of personal growth and
21 community impact.

22 *Removing barriers to joining the advisory groups*

23 From the outset, we sought to build advisory groups that reflected the diversity of the parents
24 and communities we aimed to reach. PPIE groups can consist of individuals who are more
25 socioeconomically privileged or already familiar with research, which limits their ability to

1 speak to the experiences of families facing structural disadvantage, racism, or exclusion. To
2 address this, we worked through trusted networks, particularly SFSC facilitators, Local
3 Authorities, and community organisations, to invite parents who had completed the SFSC
4 programme and reflected the social and ethnic backgrounds of our target participant
5 population. To enable participation, we minimised common barriers by selecting accessible
6 community venues and providing childcare, travel expenses, meals, vouchers, and
7 interpretation support as standard practice. One parent noted:

8 *I've really enjoyed it. I've always tried to make time for these meetings and to participate*
9 *as and when I can and the team have been very accommodating to me throughout the*
10 *years in terms of childcare and transport and also bringing the newborn baby [to*
11 *meetings].*

12 A dedicated Research Assistant based at the Race Equality Foundation also played a
13 crucial role in building trust and maintaining relationships with PAG members. Having a key
14 contact point provided a relational focus for the parents. In total, around 40 socially and
15 ethnically diverse parents joined three PAGs (two in London, one in the North of England). They
16 came from a range of ethnic and sociodemographic groups with notable representation of
17 Black, Asian, and minority ethnic parents, single and partnered carers, and a range of family
18 types. Over five years, a core group of around 24 consistently met around 25 times (14 in
19 person, 11 online), with regular contact maintained via WhatsApp. This wraparound model
20 fostered community, trust, and continuity.

21 *Shaping the study through positive 'disruption'*

22 The PAGs influenced several key elements of the study's design and conduct at an early stage
23 of the study. During the pilot phase, for example, they raised concerns about the suitability of
24 an outcome measure (parenting practices) selected by the researchers, noting that it focused
25 too heavily on negative practices, offered little attention to positive ones, and was lengthy and

1 difficult to complete. Their feedback prompted the research team to review alternatives with
2 the PAG's and replace the measure with one that struck a better balance between positive and
3 negative practices and was more acceptable to complete.

4 PAG members also offered critical insight on randomisation and the use of a waitlist
5 control—a concern raised by the research team and partner services. Contrary to assumptions,
6 PAG members and the lived experience co-investigator accepted randomisation, noting that
7 parents were accustomed to waiting for services and that randomisation introduced fairness
8 and transparency in a process that usually felt opaque or arbitrary. They also accepted the
9 rationale of randomisation in a robust evaluation and felt that other parents would too, if clearly
10 explained. These discussions prompted the research team to shift how the study was
11 presented: not solely as a route to receive an intervention, but as an opportunity for parents—
12 particularly from underrepresented communities—to contribute to a research study.

13 These early discussions helped shape the trial's internal pilot, where we were able to
14 promptly enlist research sites, test our processes and establish if progressing to a full trial was
15 feasible. We met 95% of our recruitment target and retained 89% of participants during the pilot
16 phase which gave confidence to progress to a full trial [27]. In the lead up to a full trial, services
17 still held some reservations around randomisation and the waitlist condition, so the research
18 team also introduced quarterly study newsletters and delivered webinars as a way to discuss
19 the research and encourage services to learn from each other's experiences and hear from PAG
20 members directly. The direct voices from the PAG continued to be a source of assurance and
21 influence throughout the study in this way.

22 The research team had also planned to translate materials and run SFSC programmes
23 in a range of community languages (as standard and advocated by the Race Equality
24 Foundation). The PAGs supported and influenced this process by pushing for the inclusion of
25 community researchers and champions. One PAG member shared how she took on a research

1 'champion' role in her area which helped address parents' concerns about trust with the
2 research. She reflects:

3 *I work in the community in a Nursery so we have lots of people coming and I have very*
4 *good relationship with parents and when I asked them to be involved in this research*
5 *some of them like said 'yes' and after said 'no we don't want to be part'. I said 'why?'*
6 *and they said 'maybe the information will go here and there'. I said 'no the information*
7 *will be only in the study no one will share your information' and because they trust me*
8 *they accept it and [agree] to be part of the research.*

9 Drawing on community members helped build trust in the research which likely boosted
10 engagement and enhanced the quality and integrity of the data collected.

11 During the COVID-19 pandemic, the PAGs also played a vital role in helping the study
12 rapidly adapt during a time of great uncertainty and concern. Many participants in the study at
13 that point came from groups who were disproportionately affected by the pandemic and the
14 PAGs urged the team to take an active role in supporting participants. They suggested that we
15 could be a trusted source of information and support in our position as public health
16 researchers with an existing link. The team co-developed a newsletter co-developed with the
17 PAG which included clear, accessible public health messaging with practical tips on home-
18 schooling etc. In total, 14 newsletters were shared with participants during 2020 as well as
19 being shared more widely through other networks.

20 The PAG went on to advocate for a return to in-person formats for programme delivery,
21 group meetings, and data collection—citing digital exclusion and the emotional toll of
22 lockdowns on families as important considerations to maintain study recruitment and
23 retention. For many research studies, progress stalled or paused and PPIE efforts with
24 marginalised groups reduced with the transition to online methods [33]. In the TOGETHER
25 study, this was a live and ongoing discussion and the PAG were clear in advocating for a return

1 to in-person modes. This required negotiation with the research team who had adapted to
2 remote methods and saw the value in offering a flexible mode of engaging whilst arguably
3 protecting personal and public health with ongoing risks of COVID-19. A consensus was
4 eventually reached with the return to in-person PAG meetings and SFSC programme delivery,
5 but with online methods still maintained for data collection. These discussions and actions
6 most likely helped maintain high levels of engagement with the PAG and maintain participant
7 retention in study.

8 At times, PAG members also felt the impact of differing views within the research team
9 about how PPIE should be enacted. While some researchers actively embraced the PAG's input
10 and emphasised PPIE, other researchers prioritised their involvement less. When combined
11 with staff turnover, there were fluctuations where PAG meetings were regular with active
12 involvement and other periods saw less frequent meetings which were largely consultative and
13 focused on providing updates only. This inconsistency could be unsettling for parents who had
14 invested in long-term relationships with the study. There were some missed opportunities for
15 PAG members to contribute more consistently which impacted the quality of engagement.

16 Despite the strengths of the PAG model, certain limitations remained—particularly
17 around the involvement of men and fathers. Just three fathers were active PAG members. While
18 their contributions were thoughtful and consistent, the small number of male voices likely
19 constrained the extent to which the study reflected fathers' needs and experiences. This was
20 reflected in the trial where only 5% of trial participants were male, despite SFSC's usual reach
21 of around 20% male participation [34]. As one father in the PAG reflected:

22 *I find sometimes researchers can be quite rigid with their task... we kind of create a bit of*
23 *friction there and then that rejigs their thought process... I think it's crucial that all research is*
24 *done with lived experience parents."*

1 This concern was shared by the Race Equality Foundation, who regularly championed
2 the need for a specific strategy to engage fathers (e.g. through dedicated fathers-only groups). It
3 took time for specific action around the low uptake of fathers, and by the time several fathers-
4 only groups were attempted the impact on overall father participation was limited. In hindsight,
5 part of the challenge may have been shaped by the intense pressures of running a complex trial,
6 with constant demands to meet recruitment and retention milestones. Within this context, the
7 fact that all researchers on the ground were women may also have contributed to a blind spot
8 around recognising the specific barriers fathers face. More broadly, however, the research was
9 embedded within systems and services that are not father inclusive. Many of the community
10 organisations we partnered with were staffed predominantly by women and were accustomed
11 to working directly with mothers, who are often prioritised as the primary carers. Statutory
12 agencies involved also had low levels of engagement with fathers, and the programmes
13 allocated for the research were mainly scheduled during the day, making them less accessible
14 to working men. These structural and systemic factors together constrained the representation
15 of fathers in the study. Nonetheless, the PAGs reflected on their role on their involvement as
16 concluded that: “*without this group there would be no study*”.

17 *Ripple effects of personal growth and community impact*

18 While the primary focus of the PAGs was to shape the study, members increasingly reflected on
19 their own personal growth, skills, and confidence they gained through their involvement. These
20 ripple effects—both individual and collective—highlight the wider value of inclusive research
21 beyond study outcomes. From the outset, members were invited to share what they hoped to
22 gain from their involvement and how they wanted to develop. Many set personal goals around
23 confidence, public speaking, community leadership, and contributing to change. Over time,
24 these aspirations were realised in a variety of ways.

25 Several PAG members reported taking on new community or professional roles directly
26 inspired by their experience. One member reflected on how the PAG motivated her to become a

1 Trustee of a local children’s centre, working with directors to improve facilities and activities for
2 parents. A parent reflects:

3 *“It’s encouraged me to continue being part of my community in many different ways and I’ve*
4 *gone on to become a Trustee of the Children’s Centre, and work with the directors to improve*
5 *the facilities and the activities that we have for the parents and in the community, and I do relate*
6 *that back to this, you know being on this parent advisory group as well because it is very similar*
7 *what we discuss and the format of the meetings.”*

8 Another described how her first exposure to research through TOGETHER gave her the
9 confidence to join a new NHS role as a patient safety partner and even consider studying
10 research formally. She states:

11 *“I never done any research [before] but to be part of this research was a very big thing for me*
12 *and it give me like push to be part of different research, like I recently involved in a job with the*
13 *NHS as a patient safety partner and I was using some experience from this research to do my*
14 *other things.... I think like maybe I can go and study to do some research, yeah I find it very very*
15 *helpful, great.”*

16 In some cases, references were provided by the research team to support PAG members gain
17 these opportunities. Other examples included members writing newsletter articles, speaking at
18 webinars, contributing to national policy discussions, and representing the group in external
19 forums. One participant went on to train to deliver the parenting programme in her area (outside
20 of the research), while another established a parent-and-baby drop-in space in her community.

21 These reflections show that advisory group involvement can be mutually beneficial
22 through enhancing the quality, relevance, and legitimacy of research, while also supporting
23 confidence, voice, and leadership within communities. In this way, inclusive research practice
24 does not only shape knowledge but can actively build social capital and capacity in those who

1 participate. Further reflections and insights directly from PAG members can also be found here:
2 <https://www.youtube.com/watch?v=x4cb71K9mUU>

3 3) Roots into the community: Building deep, relational partnerships with 4 local community organisations

5 Our third enabler centres on the importance of intentional recruitment strategies and relational
6 partnerships to ensure inclusive participation, particularly among ethnically and socially
7 diverse families.

8 *Working within and beyond statutory agencies*

9 In the TOGETHER study, we sought to reflect the open-access ethos of the SFSC parenting
10 programme, which is grounded in prevention and universal access, not crisis-driven or a
11 narrowly targeted intervention. We deliberately kept recruitment pathways broad and
12 accessible, accepting both self-referring parents and those referred through a variety of
13 services. Participants entered the study through Local Authorities, community organisations,
14 family support services, schools, social work and criminal justice professionals, and
15 community-based outreach activities like coffee mornings. Parents could also self-refer based
16 on local promotion or word of mouth. This approach aligned with SFSC's ethos that parenting
17 support should be proactive and preventative, not restricted to families already in crisis.

18 Adopting this approach required careful negotiation with delivery partners. Statutory
19 services, often operating under constrained budgets, tend to prioritise families with the most
20 acute or immediate needs. While understandable, this form of gatekeeping can inadvertently
21 reinforce inequality—limiting access for families who do not meet narrow thresholds, but who
22 would still benefit from support. Similar concerns are often raised in research, where open-
23 access recruitment is sometimes seen as a risk to methodological integrity, fearing it may
24 'dilute' the sample by attracting more resourced or 'worried well' parents.

25 We were keen to consider the balance between universal access, inclusion and equity.
26 We adopted a version of 'proportionate universalism' where our strategy was universal but

1 targeted proportionate to the level of disadvantage and actively addressing the greater barriers
2 faced by some [1]. We focused efforts on areas with high levels of deprivation and ethnic and
3 social diversity but recognised the barriers in accessing statutory agencies. We therefore
4 partnered with 16 agencies and delivered 34 SFSC programmes: 19 led by Local Authorities
5 (56%) and 15 led by community organisations (44%) (see Table 1). Together, they contributed to
6 reaching, recruiting, and retaining an ethnically and socially diverse sample. Community
7 organisations recruited 45% of participants and Local Authority led sites recruited 55%. Self-
8 referral was higher in community organisation sites, as expected given their community-based
9 nature.

10 Each pathway brought different strengths and, in combination, helped ensure inclusivity
11 (see Table 2). Examining demographic characteristics collected from baseline interviews, we
12 found some variation in the participants recruited through Local Authority or Community
13 Organisation sites. Local Authority sites had more participants reflecting single parents or
14 those not in a relationship, those who are unemployed, and with a split between White British
15 and racially minoritised groups. In contrast, community organisation sites brought a greater
16 proportion of racially minoritised ethnic groups and participants who spoke multiple languages
17 or from migrant backgrounds. Furthermore, there was a greater proportion of participants living
18 in council housing and on low incomes and being housewives/husbands rather than
19 unemployed or employed. Although the overall proportion of fathers and men was low in the
20 study, those that were in the study largely came through statutory referral routes.

21 Importantly, baseline needs such as mental wellbeing, child wellbeing, parent-child
22 relationships, parenting practices, self-efficacy, and neighbourhood and community cohesion
23 did not differ by community organisations or Local Authorities sites (see Table 3). Therefore,
24 dispelling concerns regarding ‘diluting’ need when recruiting outside formal statutory services.

1 This highlights the strength of a mixed recruitment model—ensuring inclusion without
2 compromising comparability.

3 *Embedding cultural and language inclusivity*

4 The TOGETHER sample included 65% of participants identifying as Black, Asian, mixed, or other
5 minoritised ethnicities; almost half reporting a first language other than English; and more than
6 half living in households with incomes under £20,000. Community organisations were
7 particularly effective in engaging families who may be reluctant to access statutory services.
8 The community organisations brought agility, cultural competence, and deep community trust.
9 Many had longstanding relationships with the Race Equality Foundation, and recruitment
10 efforts built on these existing links. Organisations such as Westway Trust, Minik Kardes, and the
11 Somali Youth Development Resource Centre played vital roles in reaching Arabic, Turkish, and
12 Somali speaking families. Their involvement enabled the study to run targeted, community
13 responsive SFSC programmes—for example, a Somali speaking group for Somali women in
14 Camden, and a mixed Arabic/English group at a youth arts centre in North Westminster.

15 One notable example was the partnership with the London-based Muslim Community
16 Association (MCA) in Tower Hamlets (<https://mcasite.org/>). The study originally aimed to
17 partner with the Local Authority, but despite a long-standing relationship with several staff and
18 multiple conversations, staffing shortages and challenges with the parenting service in the
19 borough made this unfeasible. The Race Equality Foundation were clear that the Bangla-
20 speaking community in East London were an important ethnic group with high take up of SFSC
21 and should not be missed from the study. As a result, they facilitated a collaboration with MCA
22 and a local SFSC facilitator, resulting in the successful delivery of three Bangla-speaking SFSC
23 programmes (plus three more for waitlist participants after the study).

24 Crucial to the success of this collaboration was both the local SFSC facilitator, who had
25 delivered the programme for more than a decade in the borough and her reputation as

1 someone imbued with expertise and trust, but also the support provided by MCA. Several key
2 people within MCA and East London Mosque had trained as SFSC facilitators and the
3 programme had been previously delivered to mothers and fathers through the organisation.
4 This meant both the Race Equality Foundation and the programme were trusted entities. This
5 existing relationship was key in allowing for rapid mobilisation and the roll out of the research.

6 Sessions were hosted in known venues such as a Muslim Women's Centre and a
7 nursery at The London Muslim Centre attached to East London Mosque, with local and trusted
8 Bangla-speaking facilitators and childcare providers. Participants were recruited through
9 mosque announcements and other staff and volunteer communications, word-of-mouth, drop
10 ins and peer networks. Facilitators worked closely with the research team to ensure ethical
11 consent, clear communication, and culturally appropriate data collection.

12 Translation was another area where thoughtful planning, adequate budget, and
13 infrastructure support were critical. In areas with a high proportion of families from ethnic
14 minority groups, Local Authorities and community organisations often run SFSC groups in
15 languages other than English (most commonly Turkish, Somali, Bengali, and Arabic). To enable
16 families who required language support to fully participate in the study, all core materials,
17 including consent forms, participant information sheets, adverts, and letters, were translated
18 into key community languages.

19 The study followed a rigorous, WHO-informed translation process to ensure materials
20 were not only accurate but also culturally and contextually appropriate [35]. Translations were
21 reviewed by bilingual community members, some of whom were Parent Advisory Group
22 members, alongside researchers to ensure clarity, resonance, and relevance. Back-
23 translations were used to check conceptual alignment with the original text, and final versions
24 were tested with target community members. This collaborative approach took time, care, and

1 financial investment which ensured that translated materials were meaningful, accessible, and
2 respectful to the families involved.

3 This approach reflected a wider ethos: inclusion cannot be ‘bought in’ through
4 transactional services. It must be embedded through relational, context-sensitive practice
5 underpinned by trust, understanding, and a deep commitment to removing barriers to
6 participation. Community organisations played a central role, not just in reaching families, but
7 in co-shaping how the study was delivered in different local contexts.

8 *Building partnerships – not extracting resources*

9 Crucially, local community organisations were not treated as simply delivery channels. They
10 co-produced engagement strategies and ensured sessions were delivered in known venues,
11 supported by multilingual staff, and aligned with participants’ ethnic, linguistic and cultural
12 needs. The research team co-hosted a range of events to reach and recruit parents including,
13 coffee mornings, sharing information via mosque newsletters and Friday announcements,
14 organising online Q&A sessions and in-person info events, and mobilising SFSC-trained
15 community facilitators to spread the word through everyday interactions.

16 Another example of this approach was our partnership with the Westway Trust
17 (<https://www.westway.org/>), a London-based organisation in North Kensington’s diverse local
18 community. Westway’s team both reflected and represented the community and had long-
19 standing connections through a network of over 60 member organisations ranging from
20 residents’ associations and supplementary schools to sports clubs and local charities. We
21 approached them during the early pilot phase knowing that we were still in the learning phase of
22 recruitment and needing partners willing to learn with us. Early discussions covered the
23 research need with openness around the partnership for mutual learning (rather than
24 immediate requests or expectations). We started conversations with discussions around what
25 programmes they wished to run, what strategies might work to engage the community, any

1 training and resource needs, and what they might gain from the partnership. Westway staff
2 were enthusiastic, seeing the research as an opportunity for local parents to attend the
3 programme and for the organisation to further support community wellbeing.

4 The Westway Trust brought invaluable insights into how best to engage parents and
5 connecting the researchers to their existing networks and communities. Researchers joined
6 Westway staff at various events, many in the evenings and weekends to visit supplementary
7 schools, meet families, and hand out materials. During particularly intensive periods of the
8 study, the research team became more embedded with the Trust with dedicated space for
9 working and collaborating together. These efforts that not only boosted recruitment but also
10 built trust and legitimacy for the research with the visible collaboration with a trusted
11 organisation. They also brought ideas on where to run the SFSC parenting programmes and
12 provision of appropriate food and childcare facilitates (i.e. some programmes were run in a
13 private room in a soft play centre which had a large window for parents to see their child under
14 the supervision of quality childcare). Lessons learned from Westway helped shape our study
15 processes across all our sites and the collaboration continued beyond the pilot phase where
16 they continued to run programmes and recruit parents as well as support translate of research
17 materials. Westway went on to be one of our most successful research sites, delivering five of
18 the 34 SFSC parenting programmes in the trial and bringing in the second-highest number of
19 participants. This close working relationship was both productive and personally rewarding for
20 the research team.

21 What made these partnerships work was mutual respect and reciprocity. Local
22 community organisations are sometimes seen as mere 'referral providers' and some
23 organisations express frustration where they are contacted by with requests to 'pass on'
24 ethnically and socially diverse communities they have spent time and resources to cultivate.
25 These requests can feel extractive with little discussion, interest or long-term investment in

1 their work. In contrast, our approach sought to build relationships that were mutually beneficial
2 with discussions around any training needs, cost and resources needs and how we could
3 support and promote their work (e.g. through branding and public recognition of shared
4 successes). This helped shift the dynamic from extraction to partnership.

5 While statutory services played a vital role, particularly in reaching families with high or
6 complex needs, the involvement of local community partners ensured greater diversity,
7 stronger trust, and more culturally appropriate delivery.

8 4) Speaking the same language: Community researchers supporting 9 culturally and linguistically inclusive data collection.

10 Building on these community partnerships, our fourth enabler focused on the role of
11 community-embedded researchers, who were critical for recruiting and collecting data from
12 culturally and linguistically diverse groups. While community organisations opened the door to
13 participation, it was the community researchers, who sustained participant engagement
14 throughout the study. Using the translated materials developed in collaboration with
15 community organisations, they conducted recruitment interviews as well as follow-up data
16 collection interviews in participants' first languages, to provide clear understanding, build trust,
17 and cultural resonance.

18 Seven community researchers were trained and supported over the course of the study.
19 They reflected the linguistic and cultural diversity of participating families, collectively speaking
20 Arabic (n=3), Somali (n=1), Turkish (n=2), and Bengali (n=1). Two community researchers had a
21 background in psychology, one held a PhD, one was a dental public health student, and three
22 had no formal research experience. Training covered the research protocol, randomisation
23 procedures, ethical and consent processes, and data collection methods. For many, this was
24 their first formal role in research, and the research team invested significant time and care to
25 train, support and build confidence whilst ensuring fidelity to study procedures. Ongoing
26 supervision, regular check-ins, and peer support were crucial to sustaining engagement,

1 particularly as community researchers were often balancing caring responsibilities,
2 employment, study, and community commitments alongside the research role.

3 The community researchers understanding and closeness within their communities
4 was both a strength and a challenge. On one hand, it enhanced trust, facilitated informed
5 consent, and allowed nuanced communication about a complex trial. Community researchers
6 could explain randomisation in culturally and linguistically appropriate ways, using metaphors
7 and everyday examples that resonated with participants. On the other hand, their closeness to
8 participants occasionally blurred professional boundaries, creating emotional and ethical
9 tensions that required careful support. For example, researchers were intended to remain
10 'blind' to participants' allocation, but this was sometimes compromised, given how embedded
11 the community researchers were within their local networks.

12 The team addressed these challenges through flexible supervision, reflective
13 discussions, and ongoing support. The community researchers were invited to our weekly data
14 collection meetings. These meetings were for researchers involved in data collection and
15 created a space to reflect on their week and openly discuss any challenges encountered. These
16 meetings were used to reinforce principles such as maintaining confidentiality, avoiding
17 conflicts of interest, and managing expectations about the research, which was particularly
18 important since community researchers sometimes held personal connections with potential
19 participants which required ongoing training and discussions with the wider team. These
20 experiences suggests that research teams working with community researchers should
21 anticipate that boundary challenges may arise particularly when researchers are recruited
22 because of their strong community connections. Regular reflective supervision, opportunities
23 to discuss dilemmas collectively, and clear guidance to support genuine embedded
24 community-based research.

1 Variations in community researchers' confidence, availability, and research experience
2 also created unpredictability and could be demanding for the research team at times. Practical
3 issues, such as delays in reimbursements for the community researchers or complications
4 relating to benefits and carer allowances, added additional strain. Dependence on individual
5 researchers also posed challenges. For instance, for some SFSC language groups there was
6 only one community researcher available for follow-up interviews, so the study relied heavily on
7 them. Identifying and training new community researchers was time consuming for the
8 research team with data collection windows being just four weeks. Balancing relationships,
9 supervision, training, and management of the community researchers required careful
10 coordination and flexibility from the research team.

11 Yet despite these challenges, the community researchers were indispensable, particularly
12 for follow-up data collection, where their local knowledge and persistence helped achieve the
13 high retention rates. Their contributions went beyond operational delivery; they acted as
14 cultural interpreters and advocates, helping the team navigate community norms, sensitivities,
15 and expectations. By involving community members as researchers, the TOGETHER study
16 exemplified inclusion not only in who participated but also in who conducted the research. At
17 the same time, it exposed the limitations of traditional research infrastructures which are often
18 ill-equipped to support community-based employment, flexible payment, or training pathways
19 within the required timelines.

20 **5) Connecting the dots: The third sector as powering inclusion**

21 Our fifth enabler centres on the pivotal role of the third sector, specifically, the Race Equality
22 Foundation, in 'connecting the dots' between lived experience, community engagement, and
23 academic research. They played a central role in ensuring that the TOGETHER study was
24 inclusive, prioritised lived experience, and meaningfully connected to the communities it
25 sought to engage.

1 From the outset, the overall research leadership was intentional about having a lived
2 experience co-investigator and creating an open, accessible space where all forms of expertise
3 could be shared and valued equally. This clarity of vision set the tone for collaboration. The
4 academic lead brought deep experience of RCT's, methodological rigour, and academic
5 credibility; the Race Equality Foundation contributed its expertise in the SFSC programme and
6 community engagement; and the lived experience co-investigator brought first-hand knowledge
7 of the realities facing parents. Recognising and valuing these distinct contributions early
8 established mutual respect, trust, and a shared sense of purpose and enabled the Race
9 Equality Foundation to fully engage and offer expertise. This commitment was backed by
10 dedicated research resources and funding.

11 As co-investigators and members of the core research team (see Figure 1), the Race
12 Equality Foundation brought a unique combination of content expertise in the SFSC
13 programme, longstanding relationships with delivery partners, and extensive understanding of
14 anti-racist practice. Their role was not peripheral or symbolic—they 'powered inclusion' by
15 acting as advocates, translators, connectors, and critical friends throughout the study's
16 lifecycle. For community organisations and delivery partners, the Foundation advocated for the
17 time, training, and resources required to implement SFSC in the context of a complex research
18 trial.

19 For the lived experience co-investigator, the Race Equality Foundation created a space
20 of psychological safety and support, holding regular pre-meetings ahead of formal governance
21 structures to explain terms, clarify expectations, and process concerns. This consistent
22 scaffolding enabled her full and confident participation in decision-making and helped maintain
23 her engagement across a demanding study. For PAGs, the Foundation provided critical
24 infrastructure by coordinating meetings, handling expenses, maintaining regular contact, and
25 ensuring their input remained visible and valued even during periods of heightened pressure

1 around recruitment or data collection. In many ways, the Race Equality Foundation acted as
2 the study's 'connective tissue' in being able to identify barriers to inclusion and guiding the
3 process so that community voice, lived experience, and structural equity were embedded at
4 the heart of its design and delivery, not treated as add-ons. For instance, when community
5 organisations were invited to deliver programmes and support recruitment, the Race Equality
6 Foundation helped guide these partnerships to be meaningful and not extractive through
7 ensuring costs were covered and providing ideas for outreach activities, refreshments and
8 childcare provision, community-language facilitators from their past experience working within
9 communities. More broadly, the Race Equality Foundation also helped sustain a relational
10 approach to involvement across the study during intensive phases of the research where
11 engagement with the PAG reduced with the demands of delivering other aspects of the study.
12 Here, the Race Equality Foundation encouraged sessions which engaged the PAG's in reviewing
13 emerging findings and supporting sense making (particularly relating to the process evaluation).

14 Working across academic, community, and lived-experience domains brought richness
15 but also complexity, requiring ongoing translation, negotiation, and trust-building. In this way,
16 the third sector did more than enable participation, it powered inclusion. It helped to reframe
17 whose knowledge counts, how research relationships are formed, and what it means to centre
18 equity in a large-scale trial.

19 **6) Investing in inclusion: Budgets, resources, and leadership**

20 While inclusion is often talked about in terms of values and intent, delivering inclusive research
21 required concrete investments of time, money, infrastructure, and leadership. The success of
22 the TOGETHER study was not only the result of community partnerships or public involvement,
23 but also of the structural conditions that supported them. This final enabler underpinned and
24 enabled all the others.

1 Dedicated budgets for involvement and delivery were essential. From the outset, the study
2 team recognised the importance of fairly resourcing those involved, including public
3 contributors and third sector partners. The PPIE lead role was properly resourced with
4 payment, travel and subsistence costs covered making sustained involvement possible over
5 the five-year study. The Race Equality Foundation managed logistics and payments for PAG
6 members, allowing reimbursements to be made promptly and with less bureaucracy than
7 university systems typically allow. Resources were also allocated to ensure inclusive PAG
8 meetings, with childcare, meals, interpreters, travel arrangements, and digital support made
9 available to reduce barriers to participation.

10 Infrastructure support was important, but this was not always consistent. The Clinical
11 Research Network (CRN) (now called Research Delivery Network [RDN] since the research
12 concluded) provided important infrastructure support to the trial. In some CRN localities,
13 individuals within these systems played a critical role in championing inclusive approaches by
14 offering staff, budgets and support whilst removing barriers for the research team to access this
15 support. For example, three CRN researchers supported the data collection team with
16 conducting interviews which was invaluable during busy times and allowed us to comfortably
17 reach participant targets in those areas. However, this was not universal; some CRNs were far
18 more engaged and helpful than others. Furthermore, there were limits to how much CRN
19 researchers could support aspects of the study such as building partnerships with community
20 organisations and the PAGs. CRN staff were often working across several projects rather than
21 providing dedicated, sustained time to the study, which made it difficult to develop the kinds of
22 relationships that were essential for inclusive research. This inconsistency highlights the
23 importance of not just having infrastructure in place, but ensuring the right people are in key
24 roles, people who value inclusion and are willing to put in the work to make it happen.

1 The study benefited from leadership that was not only open and values-driven but also
2 practically engaged. The Chief Investigator was visible, approachable, and responsive, playing a
3 key role in creating a culture of respect, inclusion, and mutual learning. The academic team
4 remained open to challenge from the PPIE lead, Race Equality Foundation and community
5 partners, even when this was uncomfortable or required rethinking previously agreed plans.
6 Inclusion was not a side activity it was woven into the study’s core, supported by people,
7 processes, and infrastructure.

8 Yet the reliance on individual staff members to champion inclusion also created
9 vulnerability. When those individuals moved on, the emphasis on inclusive practice sometimes
10 waned until others took up the mantle. This highlighted how inclusion can hinge on personal
11 commitment rather than being embedded as a non-negotiable aspect of research
12 infrastructure. These vulnerabilities underline a wider truth: without the time, funding, care, and
13 leadership to support this work, even well-intentioned inclusion efforts can quickly become
14 tokenistic or unsustainable. At the same time, the TOGETHER study showed that when these
15 conditions were in place, even within a challenging academic environment, meaningful
16 inclusion could be achieved at scale, leaving a legacy that influenced both the research team
17 and participating communities.

18 Discussion

19 The TOGETHER study set out to evaluate the effectiveness of the SFSC parenting programme
20 for ethnically and socially diverse families in England. While the primary trial findings will be
21 reported elsewhere, this paper has focused on the underlying strategies that supported
22 inclusive research practice—particularly the partnerships and processes that enabled
23 recruitment, engagement, and retention of a diverse sample. Six key enablers were identified:
24 (1) lived experience leadership through a co-investigator; (2) public involvement via local Parent
25 Advisory Groups; (3) relational partnerships with community organisations; (4) community

1 researchers (5) strategic support from a third sector organisation, the Race Equality
2 Foundation, and (6) investing in inclusion through dedicated budgets, resources, and visible,
3 supportive leadership.

4 These findings add depth to current agendas around inclusive research and PPIE by
5 providing practical insight into how inclusion can be embedded into complex trials. These
6 findings resonate with critiques of tokenistic or performative approaches to PPIE, where public
7 involvement is reduced to procedural compliance rather than meaningful influence [22,23,25].
8 In contrast, our case illustrates how relational infrastructure and sustained partnership can
9 shift PPIE from symbolic inclusion toward something more transformative which supports the
10 representation of ethnically and socially diverse groups in research. Health research has long
11 failed to adequately represent ethnically and socially diverse communities [9,10]—raising both
12 ethical and scientific concerns [7,8,36]. Our findings highlight that inclusive and equitable
13 research is fundamentally relational, built on trust, cultural understanding, and shared
14 ownership with communities. These relationships cannot be engineered solely through policy
15 agendas, tools and checklists alone; they must be cultivated through sustained engagement
16 and a willingness to confront power imbalances. Our approach to public involvement
17 developed gradually - rooted in transparency, humility, and a readiness to listen, learn and
18 adapt. This process was not always smooth. It required navigating disagreement, discomfort,
19 and the constraints of a research system often ill-suited to relational practice. Yet it was
20 precisely this openness to challenge that strengthened the study's integrity and relevance.
21 Importantly, the work of the PAGs extended beyond shaping study procedures. During the
22 COVID-19 pandemic, PAG members encouraged the research team to recognise its position as
23 a trusted actor within participants' lives, prompting the co-development of accessible public
24 health newsletters and practical support. Similarly, the study created opportunities for PAG
25 members' own leadership and development beyond the confines of the trial. These experiences
26 highlight that inclusive research does not occur outside the social world of participants; rather,

1 it situates researchers within that world, implicating them not only as observers but as
2 relational actors with responsibilities that extend beyond data collection. The study offers a
3 compelling example of how PPIE and EDI, when properly aligned, can move beyond tokenism to
4 drive genuine transformative change.

5 A core insight from this study is that inclusion cannot be achieved through goodwill
6 alone. It takes investment of time, money, and people. Inclusive research demands space to
7 build relationships, flexibility to adapt to community needs, and leadership that values process
8 as much as outcomes. Dedicated capacity such as embedded roles within the Race Equality
9 Foundation and funding for PAGs was not a nice-to-have, but essential. Without this, inclusive
10 intentions risk becoming empty rhetoric. Leadership also mattered. Inclusion was supported
11 because the Chief Investigator, key members of the research team and partners actively
12 prioritised it not just in principle, but in the decisions that shaped staffing, governance, and
13 resourcing.

14 The findings also have implications for how research proposals and interventions are
15 assessed for 'value for money'. Inclusive research requires dedicated staffing, community
16 partnerships, supervision structures, and sustained engagement — all of which carry real
17 costs. If funding boards and commissioners fail to recognise and resource these elements
18 explicitly, inclusion risks being deprioritised in favour of cheaper, faster, but less equitable
19 approaches. In the TOGETHER study, our inclusive approach was vital to producing robust and
20 reliable research. Value for money assessments must therefore account not only for
21 intervention delivery costs, but for the relational and infrastructural work required to ensure
22 equitable participation and impact.

23 Another central learning from TOGETHER is that inclusive and equitable research
24 requires rethinking not only methods and approaches, but the academic systems that underpin
25 them. Our findings raise fundamental questions about whether the current research

1 environment is equipped or even designed to support the kind of relational, flexible, and
2 community-rooted work that inclusion demands. Over five years, the study experienced
3 multiple changes in core research staff, whilst there was relative stability across the Race
4 Equality Foundation and PAGs. For PAG members, this contrast created a clear tension: while
5 their own commitment to the study spanned several years, they often had to reintroduce
6 themselves, revisit previous contributions, and adapt as new researchers brought different
7 levels of experience and varying priorities around PPIE. These experiences underline how
8 precarious employment structures in academia can undermine continuity in inclusive
9 research, with real consequences for trust and long-term community relationships.

10 These staffing transitions also speak to wider systemic issues. Researchers, especially
11 those early in their careers, operate in a context shaped by intense pressure to publish, secure
12 funding, demonstrate ‘impact’, teach, and deliver high-quality research, all within tight
13 timelines [37–39]. Within this system, PPIE is often valued in principle but undervalued in
14 practice and positioned as peripheral to the outputs that drive academic success. It does not
15 easily fit within traditional indicators of performance, such as publication metrics or grant
16 income, and it is rarely resourced or supported as a core part of research infrastructure. This
17 disconnect can be surprising to those outside academia who may assume that universities
18 offer stable platforms for community partnerships. In reality, many academics experience
19 considerable precarity and must juggle competing demands without institutional incentives for
20 inclusive practice. As a result, inclusive PPIE efforts, no matter how well-intentioned, risk being
21 fragmented or deprioritised. Inclusion becomes aspirational rather than operational. However,
22 several researchers who worked on TOGETHER have since moved into roles that prioritise PPIE
23 or meaningful participation, showing how the study’s influence extended to shaping individual
24 career paths, even if systemic conditions remain fragile.

1 Against this backdrop, the Race Equality Foundation’s involvement became a stabilising
2 force in ensuring continuity, cultural competence, and ethical integrity across all stages of the
3 trial. This highlights the critical but often under-resourced role of third-sector organisations as
4 cultural brokers and custodians of community trust within health research [26]. What made this
5 partnership work was not just the Race Equality Foundation presence, but how the relationship
6 was structured. They were involved from the outset as a co-investigator, not added once the
7 protocol was finalised. Their expertise was treated as integral, not supplementary. However, it
8 is vital not to idealise this model. The Race Equality Foundation itself operates in a precarious
9 funding environment, reliant on external grants and project-based income. In addition, not all
10 third sector or community organisations have the expertise, confidence, capacity, or
11 infrastructure to engage with complex research processes in this way. To build on what
12 TOGETHER achieved, there must be real investment in third sector capacity, not just short-term
13 subcontracting, but long-term partnerships based on mutual respect and shared power.

14 This paper offers reflections and insights on the issues of inclusion in health research,
15 but we recognise that these are inherently partial, shaped by the perspectives of the authors,
16 and may carry blind spots, omissions, or unacknowledged biases. We do not seek to reflect
17 every aspect or experience on the TOGETHER study, nor did we seek to comprehensively
18 scrutinise every enabler, challenge, or structural factor influencing how equity and inclusion
19 played out within the study. Nonetheless, we hope that sharing this reflective and sometimes
20 messy learning helps to open new conversations and invite further dialogue, critique, and
21 exploration of how inclusive research can be better understood, practiced, and supported in
22 real-world contexts. The broader implication is clear: for inclusive research to become
23 standard practice, not the exception, we must shift the structural foundations of how research
24 is funded, governed, and evaluated. To move from ‘tokenism to transformation’, we offer four
25 recommendations for researchers, funders, and institutions:

- 1 • Funding long-term partnerships, not just project-based collaborations.
- 2 • Recognising third sector expertise and organisation as critical research partners.
- 3 • Reconfiguring academic reward systems to value engagement, relationship-building, and
- 4 inclusion—not only outputs.
- 5 • Ensuring equity in power, resources, and voice across all partners, including community
- 6 representatives and those with lived experience.

7 The TOGETHER study demonstrates that inclusive research is possible, but it takes time,
8 budget, resources, and intent and commitment. Without structural change in how research is
9 funded, staffed, and evaluated, such inclusion will remain the exception, not the rule. We
10 cannot simply talk about equity, we must build the conditions that allow it to thrive.

11 Conclusion

12 The TOGETHER study demonstrates that inclusive research within large-scale trials is
13 achievable but requires deliberate choices and sustained work. Recruiting and retaining an
14 ethnically and socially diverse sample required more than translated materials or recruitment
15 targets but also depended on continuity of relationships, practical support for participation and
16 partners who could work across academic and community contexts. Across six interlinked
17 enablers, including lived experience leadership, active PAGs, deep community partnerships,
18 multilingual community researchers, third-sector partnership, and dedicated resourcing and
19 leadership, TOGETHER shows how inclusion can be embedded as a core design feature rather
20 than an add-on. At the same time, our reflections highlight the fragility of these gains within
21 academic and funding systems that often undervalue relational work and rely on short-term
22 staffing and project-based partnerships. If funders, institutions, and commissioners are serious
23 about equity, they must account for the real costs of inclusion and create the structural
24 conditions that allow this work to be sustained. Moving beyond tokenism will require not only
25 better methods, but a shift in how research is funded and valued.

1 **Declarations**

2 **Ethics approval and consent to participate**

3 Ethical approval for the Together trial was granted by the UCL Research Ethics Committee
4 (reference 1538/002). All participants provided informed written consent. No other ethical
5 approvals were required for the analysis and insights presented in this paper.

6 **Consent for publication**

7 Not applicable

8

9 **Availability of data and materials**

10 Not applicable

11

12 **Competing interests**

13 The authors declare that they have no competing interests.

14

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20

21 **Authors' contributions**

22 AM, LB and KM developed the initial idea for this paper and led all aspects of drawing on
23 insights and developing findings. JB, RGW, TBP, AL, and DC provided input and support to refine
24 findings. All authors read and approved the final manuscript and accept responsibility for the
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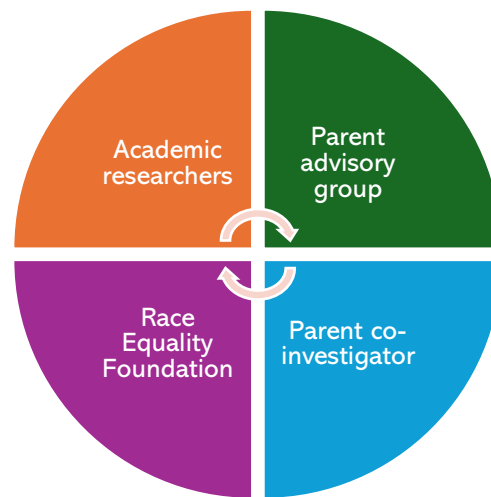
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25

26

1 Figures and tables

2 *Figure 1: TOGETHER team partnerships*



3

Figure 2: Parent Advisory Group visual reflections



Table 1: Recruitment and programmes by referral agency type

	Community organisations		Local Authorities		Total
Number of SFSC programmes	15	44.1%	19	55.9%	34
Number of participants consented/baselined	302	44.8%	372	55.2%	674
Average number of participants per programmes*	20		20		20
Participant self-referred	294	97.4%	305	82%	599
Participant referred	8	2.6%	67	18%	75
Number of participant withdrawals	34	44.2%	43	55.8%	77

* includes SFSC group and waitlist group

Table 2: Participant demographics by referral agency type

	Community organisation	Local Authority
Gender of parent		
Female	11 (3.6%)	22 (5.9%)
Male	291 (96.4%)	350 (94.1%)
Relationship with Child		
Birth mother	286 (94.7%)	339 (91.1%)
Birth father	6 (2%)	20 (5.4%)
Other (incl. adoptive, foster or stepparent)	10 (3.3%)	13 (3.5%)
Parenting structure		
Two-parent family	209 (69.2%)	176 (47.3%)
Single parent	85 (28.1%)	178 (47.8%)
Other (incl. step, foster, grandparent)	8 (2.9%)	18 (4.8%)
Ethnicity of parent		
White British	11 (3.6%)	187 (50.3%)
Black, Asian and minoritised groups	291 (95.4%)	185 (49.4%)
N/A	3 (1%)	1 (0.3%)
Ethnicity of Child		
White British	12 (4%)	184 (49%)
Black, Asian and minoritised groups	290 (95%)	188 (50%)
N/A	3 (1%)	1 (0.3%)
Religion		
Muslim	233 (77.2%)	79 (21.2%)
No religion	23 (7.6%)	150 (40.3%)
Christian	36 (11.9%)	121 (32.5%)
Other (incl. Hindu, Sikh, Buddhist and others)	10 (3.2%)	22 (5.8%)
First Language English		
No	234 (77.5%)	98 (26.3%)
Yes	67 (22.2%)	273 (73.4%)
NA	1 (0.3%)	1 (0.3%)
Born		

Abroad	251 (83.1%)	126 (33.9%)
UK	51 (16.9%)	245 (65.9%)
N/A		1 (0.3%)
Highest Education		
College degree or higher or NVQ Level 4-5	172 (57%)	189 (50.8%)
Secondary school (18 years) or NVQ Level 1-3	78 (25.8%)	116 (31.2%)
Secondary school (16 years)	35 (11.6%)	59 (15.9%)
Primary school or none	17 (5.6%)	7 (1.8%)
NA	0 (0%)	1 (0.3%)
Housing Type		
Owner occupier	21 (7%)	97 (26.1%)
Council rented	133 (44%)	100 (26.9%)
Housing Association	62 (20.5%)	54 (14.5%)
Private rented	70 (23.2%)	91 (24.5%)
Other	16 (5.3%)	27 (8.2%)
NA	0 (0%)	3 (0.8%)
Household Income		
Under £9,999	70 (23.2%)	94 (25.3%)
£10,000 - £19,999	98 (32.5%)	88 (23.7%)
£20,000 - £29,999	36 (11.9%)	33 (8.9%)
£30,000 - £39,999	13 (4.3%)	24 (6.5%)
£40,000 - £49,999	9 (3%)	17 (4.6%)
Over £50,000	13 (4.3%)	37 (9.9%)
NA	63 (20.9%)	79 (21.2%)
Employment Status		
Employed	66 (21.9%)	115 (30.9%)
Student	23 (7.6%)	11 (3%)
Housewife/husband	130 (43%)	81 (21.8%)
Unemployed	67 (22.2%)	132 (35.5%)
Other (incl. retired)	14 (4.6%)	33 (8.9%)
NA	2 (0.7%)	0 (0%)

Table 3: Participant baseline measures by referral agency type

Outcomes (measure)	LA or CO	N	Mean	% Missing
Parental mental wellbeing	LA	364	46.45	2.2
	CO	296	52.21	2
Parental self-efficacy (PMS)	LA	356	19.16	4.3
	CO	293	18.96	3
Child socioemotional well-being (SDQ Total Difficulties Score)	LA	368	17.31	1.1
	CO	302	13.14	0
Child socioemotional well-being (SDQ Impact Score)	LA	370	2.84	0.5
	CO	302	1.43	0
Positive parenting practices (MAPS)	LA	371	4.42	0.3
	CO	300	4.39	0.7
Negative parenting practices (MAPS)	LA	370	1.95	0.5
	CO	300	1.93	0.7
Parent-child relationships - conflict (CPRS)	LA	361	23.63	3
	CO	295	19.87	2.3
Parent-child relationships - closeness (CPRS)	LA	356	30.71	4.3
	CO	298	31.48	1.3
Quality of partner relationships (QMI)	LA	197	35.62	0.8
	CO	209	37.62	0.7
Neighbourhood cohesion –(adapted Buckner Scale)	LA	367	24.57	1.3
	CO	299	26.28	1
Social cohesion –(adapted Buckner Scale)	LA	370	28.18	0.5
	CO	296	29.2	2
	CO	286	73.96	5.3

