



Essay series

Creating knowledge together

Exploring the power of
community engaged research

britishscienceassociation.org



Contents

Welcome	2	Essay 8: Listening, learning, and leading together: redefining the relationship between communities and scientists	11
About the essay series project	3	Essay 9: Representing the underrepresented: developing a framework for equity in health research and biobanking through public dialogues	12
Essay 1: A lived experience journey in health inequalities research	4	Essay 10: The charter for anti-racist co-production in research: what can it do for you?	13
Essay 2: Black community power: advancing equity through community-led research	5	Essay 11: The future of community engagement with the trans+ community	14
Essay 3: Building community engagement into place-based research agendas: constructing the Co(I)aboratory	6	Essay 12: Voices in data: the power of public involvement in data research	15
Essay 4: Community-based research in 2050: speculative futures on a London estate	7	Essay 13: Working with conflict in community research	16
Essay 5: Creating shared accountability and ambition for community research	8	Discover the full story	17
Essay 6: How to ethically share power with public research partners: AKA keeping blobs blobby	9		
Essay 7: It's not the what, it's the how	10		

Welcome



Hannah Russell
Chief Executive,
BSA

Welcome to the launch of our essay series, **Creating knowledge together: exploring the power of community engaged research.**

This booklet offers a glimpse into the powerful stories, insights, and ideas shared by our incredible contributors who have generously poured their time, expertise, and lived experiences into these pieces. Today's event is the culmination of months of collaboration, born out of a commitment from all involved in this project to amplify voices often left out of traditional research spaces.

We are deeply grateful for the support of our sponsors UK Research and Innovation (UKRI), without whom none of this would have been possible, as

well as the communities and organisations who have partnered with us throughout this project.

Today marks the launch of this series, but we see it as just the beginning of an important journey. By participating in this event, you are joining us in building on the ideas and themes the essays explore. By working together, we can continue to grow this important area of work and champion the value of community-led research.

To read the full essays and find out how to get involved, scan the QR code below or visit rb.gy/a78k1r



Thank you for being part of this journey – we look forward to exploring what we can achieve together.

About the essay series project

This essay series was produced by the British Science Association (BSA) with support from UKRI with the aim of strengthening and sharing the growing evidence base for the impact that community-engaged research can have.

Research has the power to transform lives, but too often, the voices of those most affected by its outcome are missing from the conversation. We created this series of personal accounts, experiences and narratives to highlight the ways in which that is changing.

Each of the 13 essays within this collection are the product of a participatory process – we designed the writing and editing process together with the authors and their communities, to share ideas, and to support people, some of whom had not written about their work in this format before. Contributors from a range of diverse backgrounds have

worked with us to shape not only the content, but the very approach to this work – the result is a series that doesn't just talk about inclusion – it embodies it. Together we've explored what meaningful co-production of research looks like, what this work achieves and what needs to change to support it.

The themes within this series speak directly to the urgent challenges facing our society and the role of community-engaged research in shaping policies and driving change to improve impact. We reflect not just on what community-engaged research is, but what it could be.

By sharing these perspectives, we hope to spark new conversations and to inspire action and investment in this vital area of work, so that research can become more relevant, representative and connected to society.

Essay 1

A lived experience journey in health inequalities research

Contributors:

Kiz Manley and Celeste Ingrams

About the contributors:

Kiz Manley is Lived Experience Producer from the research project Mobilising Community Assets (MCA) to Tackle Health Inequalities, led by University College London's Culture-Nature-Health Research Group. Kiz works with funded projects and Lived Experience Experts (LEXperts) to ensure lived experience and community voices can be better represented in research. Celeste Ingrams is an artist, facilitator, researcher and member of the Lived Experience Advisory Group.

Involving people with lived experience in health inequalities research is vital to ensuring it has real impact. But how do we ensure lived experience experts (LEXperts)

flourish in the traditional research system? Kiz and Celeste explore the challenges in making sure individuals are truly included in research and how to support them when it is often related to their personal trauma. They share practical insights and recommendations for creating a safe research environment that openly addresses power imbalances and is fair and supportive for everyone.



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We want to create a third space – neither ‘community’ nor ‘academic’: a safe culture where everyone’s wellbeing is prioritised over doing the work.

”

Essay 2

Black community power: advancing equity through community-led research

Contributor: Dr Tamanda Walker

About the contributor:

Dr Tamanda Walker is a dynamic practitioner-researcher and sociologist who bridges the gap between community research, storytelling, and change-making. As Co-Director of AiAi Studios and Roots & Rigour, she empowers Black communities to lead their own research initiatives, gathering and reinterpreting data in areas such as mental health and maternal care to drive impactful advocacy and reform.

When Maternity Ambassadors for Change, a group of Black mothers in Birmingham, wanted to improve the experiences of Black women on their pregnancy, birth and postnatal journeys, they developed a community-led research project.

An approach prioritising the agency and wellness of Black mothers meant acknowledging participants' distrust and traumatic experiences of research and challenging traditional research standards, but led to innovative approaches to group analysis and interpretation of their community-owned data.

This essay shows how by reclaiming the power to define, explore, and address issues affecting Black lives, community-led research becomes more than methodology – it is resistance, liberation, and a force for justice.

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How could a Black women-led community research initiative serve as a transformative tool in an inequitable reproductive health system?

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Essay 3

Building community engagement into place-based research agendas: constructing the co(l)aboratory

About the contributors:

Dr Matthew J Young is the Manager of Co(l)aboratory, working alongside Dr Rachel Handforth, Training and Development Lead, and Dr Rebekah Smith McGloin, Director and Principal Investigator. Julia Cons is a Co(l)aboratory PhD candidate researching direct democracy and engagement of Nottinghamshire citizens with local NHS decision making. Prema Nirgude is Head of Insights and Engagement at the Nottingham Nottinghamshire NHS Integrated Care Board.

Since 2022, Nottingham's universities and civic institutions have collaborated to reimagine PhD research through the Co(l)aboratory Research Hub.

The project works with community groups to co-create research projects and redesign the PhD recruitment process in order to address disparities faced by PhD candidates from under-represented backgrounds as well as championing community supervisors – this essay tells us how The Hub is reinventing community engagement in Nottinghamshire.

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The Co-Lab approach allows individuals to showcase their own contextually relevant strengths. It becomes genuinely possible to offer PhD research opportunities to people from different backgrounds with alternative forms of knowledge and experience.

”

Essay 4

Community-based research in 2050: speculative futures on a London estate

About the contributors:

Sheilla Atuhaire, Tohura Lily Begum, Aiyasha Deterville, Ellie Dunn, Filiz Erkmen, Jude Fransman, Ronald Kambeja, Burcu Keser and Anna Rognaldsen represent Campsbourne Community Collective, a research and action initiative based in Haringey, north London.

It's 2050 in the North London Campsbourne estate and families subscribe to Augmented Reality packages to expand the feel of their small flats and hide the mould.

This dystopian future from the Campsbourne Community Collective is drawn from their community-based research into food, housing and care. They explore what needs to change in community-engaged research to ensure relevant, responsible and sustainable place-based practice, to deliver their utopian vision of an

estate built to sustain the existing community, not to attract future home-owning residents: varied housing, green space and decent family-sized homes at affordable social rents with secure tenancies.



“

Our utopian vision extends to future generations and prompts bigger philosophical questions – should we all be aspiring homeowners? Or should we all be social housing tenants, occupying homes on the basis of need at different stages of our lives?

”

Essay 5

Creating shared accountability and ambition for community research

About the contributors:

Anna Coffey and Grace English are High Trees Co-CEOs. High Trees has been serving the individuals and communities across Lambeth for the past 26 years, working to make life better.

Community research doesn't mean inferior research. Nor does it mean tokenistic approaches with only superficial involvement of communities.

High Trees argues it means high standards of research and rigorous methodologies that are not diluted down in the name of community research. It means research autonomy amongst community groups and accountability from all partners. And perhaps most importantly, it needs trust from funders to allow community organisations to lead the way.



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We also need to collectively agree quality standards for community research in order to give it the rigour and value it needs to be taken seriously, and to ensure that organisations who undertake community research have the skills and understanding required to do this.

”

Essay 6

How to ethically share power with public research partners: AKA keeping blobs blobby

About the contributors:

Amy M. Russell, Gary Bourlet, Samantha Clark and Max Clark are part of the “No Research about us, without us” project team. They represent a group that came together to run a research project challenging the barriers that stop research from including people with a learning disability. The project included academics, self-advocates, people who work for learning disability organisations and specialists in accessible information.

How can individuals, communities and partner organisations keep their identities when working with the research system? Can the public partners (or blobs) be valued and included without adapting their shape to the (square) academic system? Learning Disability England and the University of Leeds share honest reflections on their work improving the involvement of people with learning disabilities in health research. They articulate the changes needed in the research and funding systems in order to ensure truly equitable research.

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People with learning disabilities have a right to be part of research that affects them and their lives.

”



Essay 7

It's not the what, it's the how

About the contributors:

Joshua Artus, Hannah Yu-Pearson, and Charlotte Kemp represent Centric Lab, who prototype ways to use health-based scientific evidence to articulate the health injustices felt by many racialised and marginalised communities.

Angela Fonso represents Clean Air for Southall & Hayes (CASH) advocating for a better, cleaner, dignifying built environment in Southall.

In light of the environmental injustice and population illnesses resulting from a gasworks redevelopment in Southall, west London, Centric Lab and CASH detail the story of their partnership in rewriting the Health Impact Assessment 'handbook' through a community centred perspective of the four World Health Organisation

interlinking principles of sustainable development, ethical use of data, equity, and democracy.



© Clean Air for Southall Hayes

“

We asked ourselves: What if the template from which this [health impact] assessment was performed was different? What if it reflected community life more? What would it look like if a community designed it? Could all these problems have been avoided?

”

Essay 8

Listening, learning, and leading together: redefining the relationship between communities and scientists

About the contributors:

Dr Liz Crocker is the Director of AGU Thriving Earth Exchange. Dr Natasha Udu-gama is Director of Community Science Advancement and Sustainability at AGU. Both have fostered public engagement, community-based participatory research and community science in the US and globally for the last couple of decades.

The American Geophysical Union's (AGU) Thriving Earth Exchange program works with scientists and communities to enable them to do science together. Believing that every community science project should begin with community voice, be guided by community knowledge, and end in community impact, the program has enabled the integration of community science throughout the AGU. The authors share a model for how institutions can grow sustained

community networks to address real world issues leading to lasting impacts for researchers and communities alike.

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Community science, it turned out, was more than simply bringing people together. We need to invest – and are still investing – real effort into building a system that would address what both communities and scientists needed before community science could be something that everyone could meaningfully engage in together.

”



Essay 9

Representing the underrepresented: developing a framework for equity in health research and biobanking through public dialogues

About the contributors:

Trupti Patel is the lead of the Equity in Health Research workstream at Genomics England with responsibility towards developing a framework for embedding equity. She worked with community partners as a part of this project including: Circle Steele & Stella Chu (Wai Yin Society), Janpal Basran & Niharika Batra (Southall Community Alliance), Primrose Granville (Bristol Afro-Caribbean Expo), Jose Trueba and Carlos Corredor (Latin American Disability Alliance) and Aman Ali.

Gene technologies and genomic research are a significant part of the future of medicine, but the data they are based on often under represents those of non-European ancestry. Genomics England is exploring how increasing the diversity of datasets is

important, but challenges the idea that being representative of the population automatically means equality in the benefits of research for everyone. Through their public dialogues on genomic research they are exploring how to engage under represented communities to build trust and understand cultural concerns.

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Medical innovation is being encouraged around genomics which aspires to make medicine more personalised. With the timeline of research to deployment being such a fast pace, there's a high risk of decisions being made without sufficient public engagement and involvement in decision making. Trust-building is paramount in this area.

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Essay 10

The charter for anti-racist co-production in research: what can it do for you?

About the contributor(s):

Japheth Monzon Policy & Research Officer, and Chiara Lodi, Senior Researcher are part of Black South West Network (BSWN), a Black-led racial justice organisation based in Bristol. For this essay they also worked with Professor Saffron Karlsen, School of Sociology at University of Bristol.

Engaging with communities and those with lived experience should lead to many questions about how to do it ethically. The Black South West Network have spent years considering these questions and have distilled their knowledge into a Charter on Anti-Racist Co-Production. With clear, actionable principles to address power imbalances and examples of good practice, this essay outlines how the Charter can be – and is being – applied to individual projects and the overall research system.



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Anti-racist equitable co-production involves Black and Minoritised communities recognising and claiming their rightful place within the knowledge-production wider ecosystem, also as researchers themselves, and advocating for ownership of their own knowledge, skills and data.

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Essay 11

The Future of Community Engagement with the Trans+ Community

About the contributor(s):

Trans trUSt are four people involved in trans rights, research and representation – Dr Melissa Stepney, Senior Researcher, The CHIMES Collaborative at the University of Oxford; Dr Clara Barker, Material Scientist, Centre for Applied Superconductivity at the University of Oxford; Dr Samantha Martin, Lecturer in Psychology, Faculty of Social Sciences at Birmingham City University; and Grin, co-founder of UK action network Trans Kids Deserve Better.

This essay reflects on ethical and inclusive research practices with the trans+ community, particularly young people, and the challenges posed by discrimination in doing such research.

The essay centres the importance of trust, lived experience, and the wellbeing of researchers and research partners in creating meaningful community engagement in research.

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Any research about young trans people should always involve them as co-producers and active participants. Trans community-led organisations are also essential to providing oversight and leadership in trans research to ensure ethical practice and build trust in the research process.

”



Essay 12

Voices in data: the power of public involvement in data research

About the contributor(s):

Louise Marryat (University of Dundee), Harriet Baird (Scottish Centre for Administrative Data Research), Shayda Kashef (Administrative Data Research UK Strategic Hub), Elizabeth Nelson (Administrative Data Research Centre Northern Ireland), and Katie Oldfield (Research Data Scotland), are a collective of researchers, funders, and public engagement professionals who are enthusiastic about working with communities on projects involving routinely collected data.

Our data is collected every day – when we’re paying tax, doing an exam or going to the doctor. These data sets are a powerful source of information to researchers, but with such complex analysis techniques, how can communities be effectively involved?

This essay explores the challenges and offers practical advice and examples of involving people in data research in order to ensure it accurately captures and reports the experiences of the people behind the data.



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Discussing emerging findings can reveal insights which only people with lived experience can provide... Enabling these discussions allows for deeper analysis into particular aspects, local contexts and meaning behind the data.

”

Essay 13

Working with conflict in community research

About the contributor(s):

In this essay, Niamh Kavanagh (University of Manchester), Tina Cribbin (poet, community activist and tenant of Hulme), Sanjay Thakrar (Head of Research, Dunhill Medical Trust), Oli Soutar (Grants Manager, Dunhill Medical Trust), Shakira Evans (Community Worker from One Manchester Housing Association) and Mark Hammond (Manchester Metropolitan University) share their experience of working on a project to co-develop an age-friendly initiative in a social housing block in Hulme, Manchester.

Hopton Court, a nine-storey social housing block in Manchester, has a strong community spirit. But with the majority of tenants being over 50, making sure people can age well in place is increasingly important, especially when growing older in a

high-rise brings a series of mental and physical challenges, exacerbated by existing social inequalities. Turning Hopton Court into a Naturally Occurring Retirement Community (NORC) required embracing conflict whilst maintaining hope. In this essay the team reflect openly on the challenges.



“

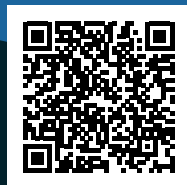
My experience of collaboration has been like a rollercoaster, going through cycles of HOPE, confusion, frustration and anger, HOPE. Repeat

”

– Tina Cribbin, tenant

Discover the full story

You can find longer, in-depth versions of each of the essays featured in this brochure on our website. Scan the QR code to find out more



Acknowledgements

The BSA wishes to thank everyone who has contributed to this essay series.

We are especially grateful to our contributors whose words will shape important conversations that extend beyond these pages. Thank you also to our partners and collaborators for their invaluable support throughout the project and to our reviewers and editorial team for their careful feedback and dedication in ensuring these essays reflect the authors' voices with integrity.

Finally to all those who will engage with this work by reading, sharing and discussing – your participation strengthens dialogue and helps drive meaningful change.

This project was kindly supported by UK Research and Innovation

UK Research and Innovation (UKRI) is the largest public funder of research and innovation in the UK, investing £8 billion annually, spanning all disciplines and all sectors. Within this, UKRI aims to break down barriers between research, innovation and society, by investing in public engagement activity. As outlined in UKRI's Public Engagement Strategy, when wider society is involved, research and innovation become more relevant and useful for everyone. This brings more people into the research and innovation workforce, and eases the path to adoption and diffusion of new ideas and technologies, making it more likely that everyone will benefit from the UK's investments in research and innovation.



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