READ ME!

King's is home to many participatory research projects that have been developed and delivered with experts by experience. This booklet contains case studies of 5 projects, which received a Participatory Research Seed Fund from the Impact and Engagement Services team at King's.

(RESTAR) project

The Regulating Emotions-Strengthening Adolescent Resilience

CORE PROJECT TEAM:

Dorian Poulton,
Luke Harvey-Nguyen,
Amber Johnson,
Issy Jackson, Jordan Altimimi,
Tiegan Boyens, Maciej Matejko,
Steve Lukito,
Myrofora Kakoulidou,
Eloise Funnell,
Susie Chandler, Sylvan Baker,
Lauren Low, Georgia Pavlopoulou,
Edmund Sonuga-Barke.

*Members of the RE-STAR Youth
Researcher Panel

THE PROJECT:

The Regulating Emotions-
Strengthening Adolescent
Resilience (RE-STAR) is an
interdisciplinary research
programme at King's College
London that aims to cut the risk
of depression in adolescents
with autistic and ADHD traits.
Work with neurodivergent young
people co-researchers (members
of our Young Researcher Panel
or Y-RP) has been at the heart
of programme as they shape our
research throughout, from the
co-definition of research aims
to the co-design, co-delivery,
co-analysis and co-dissemination
of findings and outputs.
Quotes/Reflection from the Y-RP
members on why they joined
RE-STAR:

● "What I want to get out of
this: to provide new perspectives
for the research team, giving
something back. Additionally,
as a future clinician who will
be treating others with Autism,
ADHD; to learn from these
sessions from others to make me
a better clinician and provide
better patient care for those who
are neurodiverse".

● "It seems like a possibility
to influence how research on
neurodiversity is carried out.
I wish research treated us
as really fully human and not
deficient - it not always does.
I want to contribute to autism
knowledge and learn how it is
produced. It's also good to meet
other like-minded people and
researchers."

● "To have had my voice heard,
to have made an impact on the
lives of others positively, to
have met others with learning
about their experience and being
able to relate. Also possibly
get skills haven't had before or
improve them. To learn about the
process. To have opportunities.
See something happen and come out
of the work."

THE RE-STAR PROGRAMME CO-PRODUCTION RESEARCH METHODS

The RE-STAR research programme makes use of a range of research methodologies for gathering data and answering our research questions. These include qualitative study interviews, longitudinal surveys, and also a neuroimaging study.
Our discussions with the Y-RP members help to shape our research direction and focus, in a fundamental way, particularly around how closely linked is our emotion to the environment around us. Y-RP members also co-design, co-deliver, and co-analyse data.

### 1.	Photo interviews with autistic and ADHD adolescents

We are running interviews to understand how the school environment impacts the mood of autistic and/or ADHD adolescents who also experience low mood, depression, burnout or struggle to attend secondary school. The Youth Researcher Panel (Y-RP) and academic researchers worked together to co-design and co-deliver an experience-sensitive interview schedule. As part of the interviews, adolescent participants took photos to illustrate their mood and school life.

### 2.	Neuroimaging study tasks development

Both of our neuroimaging tasks are co-designed with the Y-RP members. A study involving one of these tasks is co-produced with the young people from start to finish. Y-RP members formulate the research questions and the hypothesis of the study, plan the research and some also take part in the data collection for the study.

What do the Y-RP members value about working in co-production research with the RESTAR team?

●	"Letting people contribute in whatever mode is more comfortable to them: speaking, chat, e-mail"

●	"Willingness to meet us individually outside of general meetings."

●	"Genuinely incorporating our feedback into the work being done and the way we communicate encourages to continue sharing."

●	"We are always informed of updates, progress and what may be coming up. Invited to meetings to hear progress updates. Even if cant be involved always actively kept informed."

RE-STAR is committed to empower neurodivergent young people through their involvement in different areas of dissemination.

● 	Y-RP members have presented our research findings in key conferences. They have also been part of research panel discussion.

● 	Y-RP members have led several public engagement events such as the Being Human Festival and the "Youth Voice Matters" workshop.

● 	Y-RP members who directly contribute to specific research within RE-STAR are listed as named co-authors for the papers. Y-RP members participate in writing and editing sections and paper contents.

● 	Older Y-RP members (18-25 years at the start of RE-STAR) are mentor to the younger Junior Y-RP (11-16 years).

**Related quotes from the Y-RP about what they value from RE-STAR:**

● 	*"We're being given a platform to give talks, sit on panels and share our perspective."*

● 	*"Educated people on the whole range of the project, From the doing to the outcomes."*

● 	*"How we regularly bring in the personal or us as individuals as well as the collaborative voice. - This is also a collaborative voice with the academics."*

● 	*"How in dissemination with the academics can help make what both say be stronger. We can help bring the real to life."*

Our first end of the year Zoom event

Conferences are opportunities for a get-together

Educating the public through the Being Human Festival

MY EMOTIONS AND ME.

A JOURNEY BEHIND THE MASK
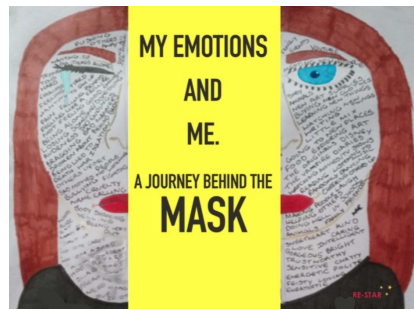
- What if my brain allows me to see and feel things differently to you?
- How could arts and science research help us to better understand our differences?

… and our Junior young researchers (11-16 years) during our "Be a Researcher's Day"
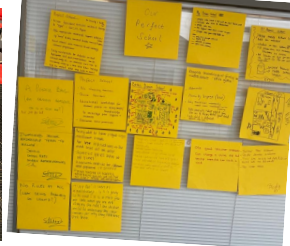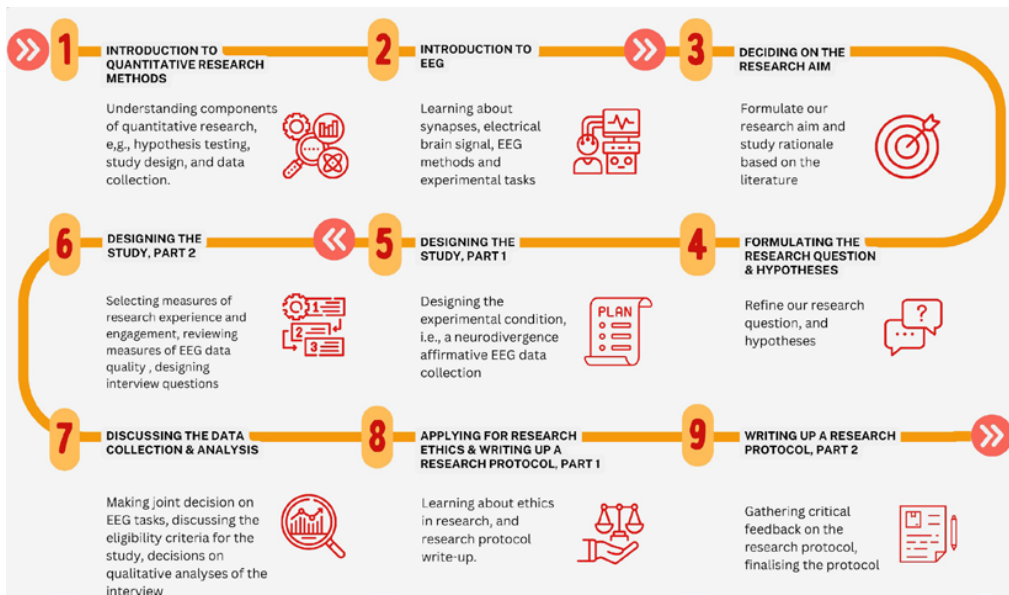

What's your perfect school like?

Formulating a shared aim for our research during a jam-board session

The co-production pathway from an ongoing RE-STAR experimental study

Funnell, Harvey-Nguyen et al. (2023)

Examples of research materials co-designed with the Y-RP members

Interview prompts

At scout camp, I struggle to join conversations during free time. Everyone's quite loud, and I feel like I keep waiting for a gap to start talking when others don't. It is as if I am not there, and no one is paying me attention.

Vignettes co-created and read out by our Y-RP members helped our research participants to discuss life events that trigger difficult emotions.

The use of photo voice as a creative task to help young people answer difficult questions

What is low mood or depression for you?
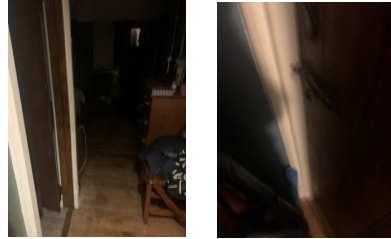
"The first photo shadows symbolise being blinded and not able to see my way out of depression, while the second lock symbolizes being locked in the same state for days without end, not able to open a metaphorical locked door which opens to mental health. The blurriness shows not being able to see what could help me. They relate back to a lack of sight of it, a feeling of being lost and having no clue where to go. I know when I feel depressed I usually feel tired, but on a bad day of depression, I fall asleep in class, stay quiet, and don't like talking about mental health. If I'm having a bad day I typically find a quiet or secluded place to silently cry." Meredith, diagnosis of autism, age 13


Examples of research materials co-designed with the Y-RP members

What does it mean, being autistic, for you?

"This is a bridge cut in different places with lines of different colours. The different colours can represent the difference in my perception of the world and the way being autistic doesn't fit into the perfect picture. Autism is like living in the same world as everyone else but on a different plane of reality, you see all the same things but differently. It makes things harder to process but you see more. Being autistic in school is being misunderstood and discarded and expected to function the same way as everyone else." Mylo, diagnosis of autism, age 15

What things can help you live your best school life and tolerate low mood?
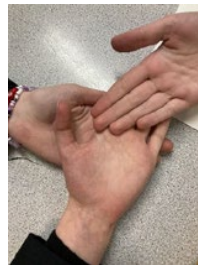
"This is a very rushed photo of 3 of my friends' hands. School is really hard but like even if I've got a bad day, I know I'm gonna see my friends …My friends make it so much better. Like I would literally never go to school at all if I didn't have any friends there…If I'm feeling sad they always try and make me happier. That is really nice…We're just quite a sweet group of people to be honest and we always do little things for each other" Jessica, diagnosis of ADHD, age 15

Examples of research materials co-designed with the Y-RP members

Discussions with Y-RP members helped to shape our research direction, particularly around how closely linked is our emotion to the environment around us.
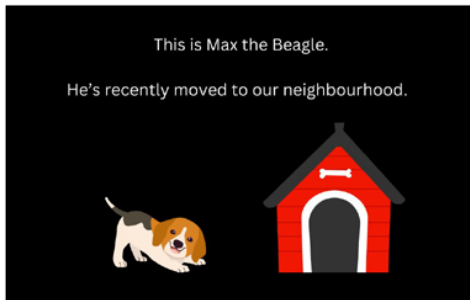
Our neuroimaging task was co-created with the Y-RP members. One of the studies is a Y-RP-steered co-production research from the start to finish.
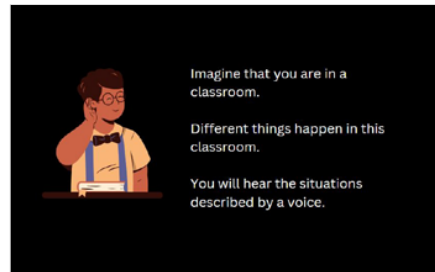
School experience is an important factor in the emotional experience of young people. This is now the focus of one of our neuroimaging tasks.

From co-production to co-delivery of research

Our Y-RP members are involved in the delivery of our research in various way. They were involved in co-delivering interviews with young people, analysing interview data with our research team, and help supporting our EEG data collection.

Tiegan helps piloting the imaging tasks, and they get an in-person training to become EEG data collector with the RE-STAR academic team.

Inspiring Ethics: Case Study

The Project:

Inspiring Ethics is a group of academics, activists and charity staff working to make research in universities and hospitals fairer and more respectful. This is especially for research that involves people from different cultures or have gone through difficult life experience, and research that tries to work with participants as equals and co-researchers. Inspiring Ethics started because its members were unhappy with how complicated and rigid university and NHS rules for doing research ethically were. They found these rules didn't always respect people's rights or understand their needs. By talking together and studying the problem, we want to make these rules better. We believe in making sure everyone involved in research, especially the participants, are treated well and fairly. Our group hopes to change the old ways of doing things by suggesting new, kinder ways to handle research that everyone, including the wider community, can agree on.

THE PROJECT TEAM:

Sohail Jannesari, Hannah Cowan, Sanchika Campell, River Ujhadbor, Tanya Mackay, Bee Damara, Tianne Haggar, Stan Papoulias, Hana Riazuddin.

Scan the QR to find out more
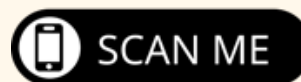
The first Inspiring Ethics meeting was in June 2021. We discussed the research ethics- a process that all research projects must go through to get ethical approval. Ethical approval sets out to minimize harms and risks and maximize benefits of research. However, the process can be long and challenging and it not always accommodating of participatory approaches.

Here is a summary of the discussions that we had about research ethics for participatory research with experts by experience:

UNIVERSITY ETHICAL PROCESSES ARE NOT FIT FOR PURPOSE

We spoke about the bureaucratisation of ethics around the NHS, removing the human element of ethical process. University ethical principles make it difficult to build meaningful long-term relationships with experts by experience, the sort of relationships that might facilitate beneficial and non-exploitative research. This is a particular issue when concerned with participatory research and ethics can quickly become a tickbox exercise. Many participants do not understand the purpose of ethics, and ethics processes can end up doing more harm than good. Relatedly, there is an inherent mistrust around research. This is not only from participants but also ourselves. In migration research, there can be a difference between the principles prioritised in researcher ethics and migrant community values.

A LACK OF TRANSPARENCY IN UNIVERSITY ETHICS COMMITTEES

It is not clear how ethics committees create their rules and recruit their board members. We felt that there is little information on how they set their rules, and power seems to be concentrated in one or two people. People spoke of a rigidity to the ethics process when it comes to researchers and participants, with long turnarounds and a reluctance to provide cash to participants. However, there is an apparent informality and discretion when it comes to deciding on applications. Generally, there is a disconnect between the ethics applications and the procedure demanded by university ethics committees. Yet, there is no space to frankly discuss this as people are afraid that it will harm their careers.

HOW CAN WE MOVE FORWARD?

We proposed a number of
suggestions including: creating
a participatory research
ethics board made up of peer
researchers, hosting a series of
ethics discussions with local
migrant communities, feeding
back issues within ethics
applications, creating community
ethics boards, writing a series
of publications on issues around
ethics (focussing on useful
methodologies), abolishing
ethics committees and starting
again, approaching potentially
favourable senior staff, and
changing the ethical values on
which research is assessed (e.g.
moving away from an ethics of
care towards an ethics of love).

THE FOLLOWING MATERIALS WERE CREATED IN INSPIRING ETHICS WORKSHOPS

They are:

1.
Visual notes from our 'future of
research' community event which
highlights the challenges we
currently face, our values and
our ambitions.

2.
Graffitied funding and ethics
applications from our 'future of
research' community event. We
invited community organisations
to graffiti on these documents
to highlight their limitations and
challenges.

3.
Our values, hopes and actions.

INSPIRING the FUTURE of RESEARCH ETHICS

· 2ND OCTOBER 2023 ·

VISUAL NOTES BY TAMARA-JADE KAZ

ICEBREAKERS
→ "BRAVER" SPACES
MY PRONOUNS: SHE/THEY
MY SHOES

1! AH! 2! 3!
COUNTING + SOUNDS GAME

KER-CHING!
URGHHH! HMMMM...

SOUNDS OF RESEARCH ETHICS
- BUREAUCRATIC
- EXTRACTIVE
- COLONIAL
- RIGID

WHERE DOES THE MONEY COME FROM?

DOESN'T ALIGN WITH PERSONAL VALUES

PARTICIPANTS SHOULD BE PAID

REMINDS ME OF POWER DYNAMICS AT SCHOOL

"MAPPING ETHICAL CHALLENGES"
IN PARTICIPATORY RESEARCH → BROKEN DOWN INTO THEMES

A MAP COLLATED ON MIRO BY INSPIRING ETHICS

CONFRONTING THE SYSTEMS WE WORK WITHIN

"Human Subjects"
POINTS TO MEDICAL RESEARCH ROOTS

"Vulnerability"
WHO QUALIFIES → FOR PERSONHOOD?
WHO IS DEFINED AS VULNERABLE AND WHY? WHO CAN CONSENT?

"Is the researcher competent in the methods?"
AMBIGUOUS QUESTION → HOW IS THIS DETERMINED?
FEELS LIKE THIS IS MORE ABOUT COVERING YOUR BACK MORE THAN AN 'ETHICAL' CONSIDERATION

"...ensure participants remain anonymous..."
IMPLICIT ASSUMPTION THAT ANONYMITY IS ETHICAL WHEN IT CAN MASK PERTINENT INFORMATION ABOUT PARTICIPANT IDENTITY

LIVING STATUES
USING TABLEAUX TO EXPLORE EMOTIONS ABOUT RESEARCH ETHICS

I CONFIRM THAT THIS RESEARCH IS REALLY, REALLY ETHICAL.

CONCEPTIONS
"RESEARCHER"
"HUMAN SUBJECTS"

COMFORTABLE
EMPOWERED?
UNACCOUNTABLE?
UNCOMFORTABLE
DISEMPOWERED?
OBSERVED

BUT, LET'S CONSIDER
HOW MOST RESEARCHERS ARE IN JUNIOR POSITIONS WITH LITTLE GUIDANCE OR SUPPORT - HOW 'EMPOWERED' ARE THEY REALLY?

VISUAL NOTES BY TAMARA-JADE KAZ

SHIFTING POWER DYNAMICS
ANTHROPOLOGICAL
IMPERSONAL
HIERARCHY
COLONIAL DYNAMIC

HAVING ADVOCATE FOR PARTICIPANTS
A CLEAR WAY OUT
GUIDANCE
PAYING FOR PARTICIPATION
HUMAN CONNECTION
RESEARCHER IDENTITY REFLECTING PARTICIPANTS'
TRAVELLING TO PARTICIPANTS
OPTION ON HOW TO PARTICIPATE

LESS HIERARCHY
MORE EQUAL FOOTING

LAYERS OF PRECARITY
· BOSS·
SIX MONTH CONTRACT
JUNIOR RESEARCH ROLE
·RESEARCHED·

CHALLENGES WITHIN the MACHINE of ETHICS

INFLEXIBILITY
TRIES TO COVER LOTS OF RESEARCH TYPES BUT DOES NOT FIT

DISCONNECT
PAPER PROCESS HELPS TO THINK THROUGH PROCESSES BUT DOES NOT GUARANTEE RESEARCH WILL BE ETHICAL IN PRACTICE

WHOSE 'ETHICS'?
WHO DECIDES WHAT IS ETHICAL?

ACCOUNTABILITY?
DOES NOT CONSIDER RESEARCHER POSITIONALITY OR PROTECT PARTICIPANTS SUFFICIENTLY

IMPLICIT PROBLEMATIC FRAMING OF 'POWER' & 'VULNERABILITY'

DATED
FEELS UNPROGRESSIVE
LANGUAGE DOESN'T FIT

IDEAL APPROACHES TO RESEARCH ETHICS

ETHICS MANIFESTO?

CONVERSATIONS
INSTEAD OF A FORM
↳ LEAVES SPACE FOR DIALOGUE
CONVERSATIONS TO GIVE PARTICIPANTS & PEER RESEARCHERS A SEAT AT THE TABLE

POST-PROJECT PLAN
THAT CONSIDERS THE IMPACT OF THE RESEARCH + HOW PARTICIPANTS MOVE ON + PROJECT LONGEVITY

INDEPENDENT COMMUNITY ETHICS BOARDS

RESOURCES FOR PARTICIPANTS TO SELF-IDENTIFY "VULNERABILITY"

CONSIDERS DATA OWNERSHIP
& THINKS ABOUT RISK + PROTECTION DIFFERENTLY
SHARED OWNERSHIP

COLLABORATION
PROCESSES THAT ENABLE CO-PRODUCTION

LIVED EXPERIENCE
REPRESENTED IN THE PROCESS
LIVED EXPERIENCE PANEL

ETHICS SHAPE THE PROJECT
INSTEAD OF BEING AN AFTERTHOUGHT

CONSENT
NOT A ONE-OFF TICK BOX, BUT AN ONGOING PROCESS

ENGAGING + ACCESSIBLE REPORTING

VALUES
SOLIDARITY
TRANSPARENCY
ACCOUNTABILITY
INCLUSIVITY
COLLABORATION
COMPASSION
EMPOWERMENT
CAPACITY BUILDING

Taylor & Francis Group
an **informa** business

Ethics Declarations

☐ I confirm that all the research meets ethical guidelines and adheres to the legal requirements of the study country.

Superficial

Human Participants

People tA!

Taylor and Francis require authors of research involving human participants to adhere to the ICMJE guidelines on Protection of Research Participants, **The Belmont Report**, or the **Declaration of Helsinki**, as appropriate. Research involving human subjects must have obtained formal, prospective, approval from an independent ethics committee (e.g. an Institutional Review Board or Human Subjects Review Committee). If the requirement for approval was waived by the ethics committee this should be explained in the manuscript.

??

Does your study include human research participants?

○ Yes   ○ No

takes autonomy away – Subjects?

Important and necessary! But also daunting

wellcome

Who has, or will, review the ethics of the project and when? Detail any other regulatory approvals you have obtained, or will seek.
We reserve the right to see relevant approval documents at any point during the grant and after it has ended. This is in accordance with our research involving human participants policy.

Specific yet incredibly vague

Before research begins, you must have in place:
- ethical approval in every country where any part of the research will be carried out
- the relevant regulatory and ethical approvals for every site where research will be carried out
- appropriate governance mechanisms.

too much

You must have ethical approval for any research Wellcome funds that involves:
- human participants
- human biological samples
- personal data.

?? *Seriously?*

Any use of personal data or biological samples, relating to living or dead persons, must comply with all relevant legislation where you are working.

EW

hazardous waste?
pee? poo?
DNA?

Human remains protection?

Sounds like a daunting process!

INSPIRING ETHICS: HOPES AND ACTIONS

Voice and choice

Grass roots projects should have conversations with and guide funding bodies and allies; more accessible forms of information for participants instead of relying solely on forms and long documents; Encouraging research participants to alter interview and research questions

Collaboration

; Schools, universities, colleges and community spaces could be used to engage researchers and funders in discussions about what it means to research ethically; University ethics boards should include laypeople, not just academics; share ownership of data between universities, researchers and communities/participants

Compassion

Longevity: there should be a funded process for continuing connections with people and follow-up work; a support process if ethics application gets rejected; a percentage of funding bids to be ring fenced for researcher and participant wellbeing activities and safeguarding

Accountability

Ask researchers for greater accountability regarding empowering communities; dialogical consent – the process should be more like a two-way contract which holds the researcher to account; set up a research monitoring group to review ethics boards, which includes laypeople; Ethics boards should sit outside of universities and be politically accountable

Impact

Create and prioritise community-based ethics boards by persuading journals and institutions to recognise community-based ethical approval processes; longer funding periods to facilitate more meaningful participatory research

Non-conformity

Challenge funders or look for alternative funding; give students tools to 'push back' on ethics forms to challenge status quo; develop a research participants and co-researchers' union.

Emancipation

Ask funders and institutions to give resources for ethics review and to pay for reviewers both internally and externally; priorities for funding should come from communities;

Reflexivity

Dialogue, not just with each other, but with ethics boards; setting up an 'ethics clinic' for guidance, checking in and reflection for researchers and participants/community/co-researchers; iterative direct democracy in research ethics: participants and researchers determine what is ethical within the context of a particular project

INSPIRING ETHICS VALUES

Voice and choice

Maximalising agency for participants, resourcing the support of people in the way they want to be supported (vs blanket vulnerability identification)

Collaboration

Collaborative, not extractive. Working together from a space of solidarity, learning understood as shared and mutual, questioning the direction of the research 'gaze'

Ethics Euphoria

Less damage-centred, more holistic research,

Accountability and transparency

"Nothing about us without us"

Impact

Fruitful research that's meaningful to communities; it centres reciprocity and brings resources and energy to communities

Challenging power inequities

Decolonising research; rejecting individualism; abolishing hierarchical power dynamics

Liberatory emancipation

Going beyond an individualised understanding of ethics or harm

Reflexivity

reflexive, dynamic, relational ethics practices

Include Us In: Palestine

Include Us In: Palestine

CORE PROJECT TEAM:

Meghan Peterson, Lecturer in the Department of Culture, Media & Creative Industries, King's College London

Nadine Aranki, Exhibitions Officer, Palestinian Museum in Birzeit, Palestine.

THE PROJECT:

This project came out of the need to better understand the context that artists and cultural entrepreneurs cooperate in the West Bank, to provide recommendations and support. There are many barriers and challenges offered by the unique context of the occupation in the West Bank, so it was necessary to experience the place through the people to better understand the opportunities and limitations.

We co-designed the project including the questions and structure, with Nadine using her knowledge and experience of the creative industries in the West bank to recommend people to interview.

We interviewed 10 artists, cultural leaders and cultural entrepreneurs face-to-face. Interviewees were asked to submit 3 photos that summarized their aspirations for the future; current challenges and something they were proud of using the photovoice methodology. Photovoice is a research method that invites researchers to take photographs in response to a prompt or provocation, as a way to share their experiences, stories and emotions.

After the interviews, we met to discuss the topics arising in the interviews to assist with the analysis. Meg also completed a daily written and photography journal to help her to further understand her positionality and document her experience in detail.

In the next stage of this project, we will bridge theory and practice to develop a new course called 'The Technology and Music Innovation Programme delivered in Ramallah, West Bank. The pioneering educational initiative has been meticulously designed to foster a robust Palestinian music industry, catering to both music professionals and individuals passionate about serving the music and entertainment sector from diverse fields.
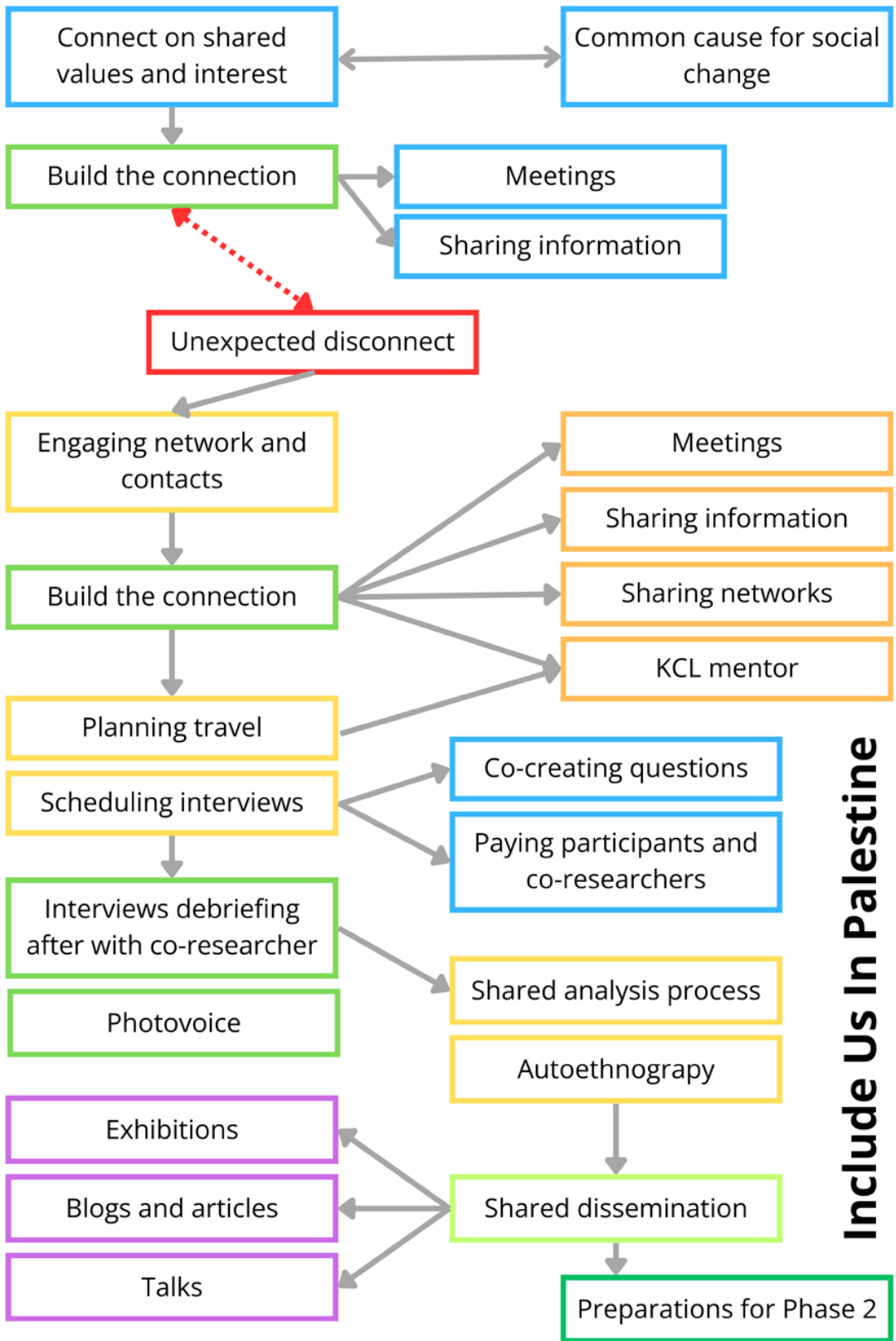
The materials here feature:

An illustration of the stages of
the research project.

Example of the photos taken by
Shayma Hamad, a multidisciplinary
artist, activist and lawyer.

Photos from an exhibition- The
Many Lives of Gaza- co curated by
Meg and Nadine.

Meg's photos from a photo journal
of her trip.

```
Connect on shared          <--->    Common cause for social
values and interest                 change
        |
        v
Build the connection  --->  Meetings
        ¦                --->  Sharing information
        v
Unexpected disconnect
        |
        v
Engaging network and        Meetings
contacts               --->  Sharing information
        |              --->  Sharing networks
        v              --->  KCL mentor
Build the connection
        |
        v
Planning travel  --->
Scheduling interviews  --->  Co-creating questions
        |                --->  Paying participants and
        v                      co-researchers
Interviews debriefing
after with co-researcher  --->  Shared analysis process
                                Autoethnograpy
Photovoice                           |
                                     v
Exhibitions  <---              Shared dissemination
Blogs and articles  <---             |
Talks  <---                          v
                               Preparations for Phase 2
```

Include Us In Palestine

THE MANY LIVES OF GAZA

4 – 6 January 2024
Private View: 4 January 2024, 6-9pm

Curated by Nadine Aranki & Meg Peterson

This watch was inherited by grandma, after grandpa was killed in the Khan Younis massacre.

What does success mean
to you? What was a
moment that made you
feel proud?
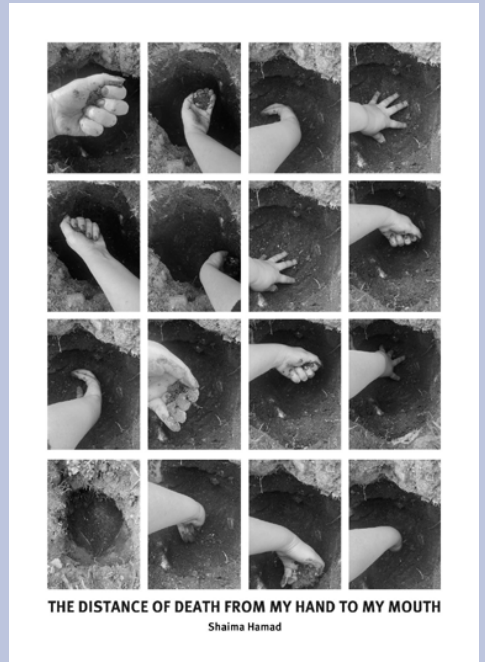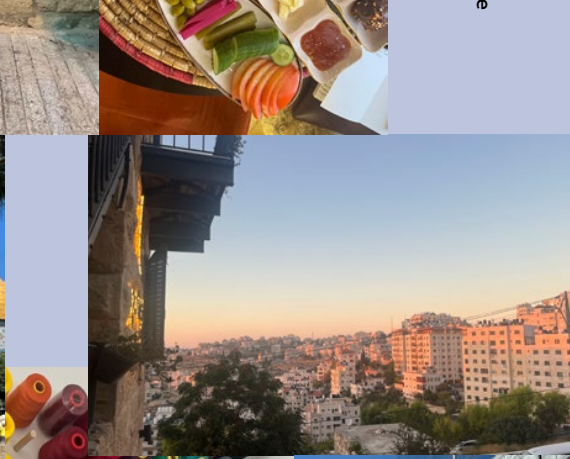
When my art gives me
hope each time

I was trained as a lawyer
but now my tables in my art
are my court. Through my art
I can say, express or show
my beliefs.

Why do you do what you
do? What motivates you?

Where/ when food
becomes a language

THE DISTANCE OF DEATH FROM MY HAND TO MY MOUTH
Shaima Hamad

MAPS

Mapping Approaches to a Programme of Survivor-led research: co-developing our vision, values & principles

THE CORE PROJECT TEAM:

Dr Angie Sweeney
(Academic Lead - Centre for Society and Mental Health & Service User Research Enterprise, KCL)

Laura Fischer
(Arts and Research Lead - Traumascapes & KCL)

Sully Holderbach
(Survivor Artist-Researcher - Traumascapes)

Dr Siofra Peeren
(Ethics Lead - KCL)

Dr Susanna Alyce
(Peer Supporter - Survivors Voices)

All of us identify as survivors of trauma & abuse. This makes our work survivor-controlled.

THE PROJECT:

Our aim was to *map the vision, values and ethical principles* that should underpin a new programme of survivor research in the ESRC Centre for Society and Mental Health and survivor-controlled research more broadly.

We ran *four workshops* with the CEOs of four survivor-led organisations - Little Ro, the Flying Child, Survivors Voices, and We Are Survivors - and a member of the Centre for Society and Mental Health Lived Experience Advisory Board.

traumascapes

Centre for Society and Mental Health

WE ARE SURVIVORS.

THE FLYING CHILD

LittleRo.org
help hope healing

SURVIVORS VOICES

Before the Workshops

PRIORITISING SAFETY AND SUPPORT

We shared an 8-page information pack including details on: the project; who we are; why we are doing this project; what will happen in each workshop; our core ethos; our approach to safety and support; and practical information.

Our approach to safety and support included:

• Individual conversations to understand how to support people to feel safe before, during and after the workshops.

• Following the **Survivors Voices Charter for Engaging Survivors** by aiming to hold workshops that foster safety and empowerment; promote self-care; and are liberating, creative and joyful. Striving to be accountable and transparent throughout, and welcoming feedback and dialogue.

• Offering everyone 2+ sessions with a peer support worker. The peer support worker was also available at each workshop.

• Sharing self-care packs as a symbol of the importance we place on prioritising our wellbeing individually and collectively.

• Listening to concerns and doing our best to address them. Encouraging people to approach us if they felt uncomfortable or upset about something.

• Holding some sensitive and highly contentious discussions one-to-one.

MAPS

MAPPING APPROACHES TO A
PROGRAMME OF
SURVIVOR RESEARCH

After the Workshops

A RELATIONAL APPROACH
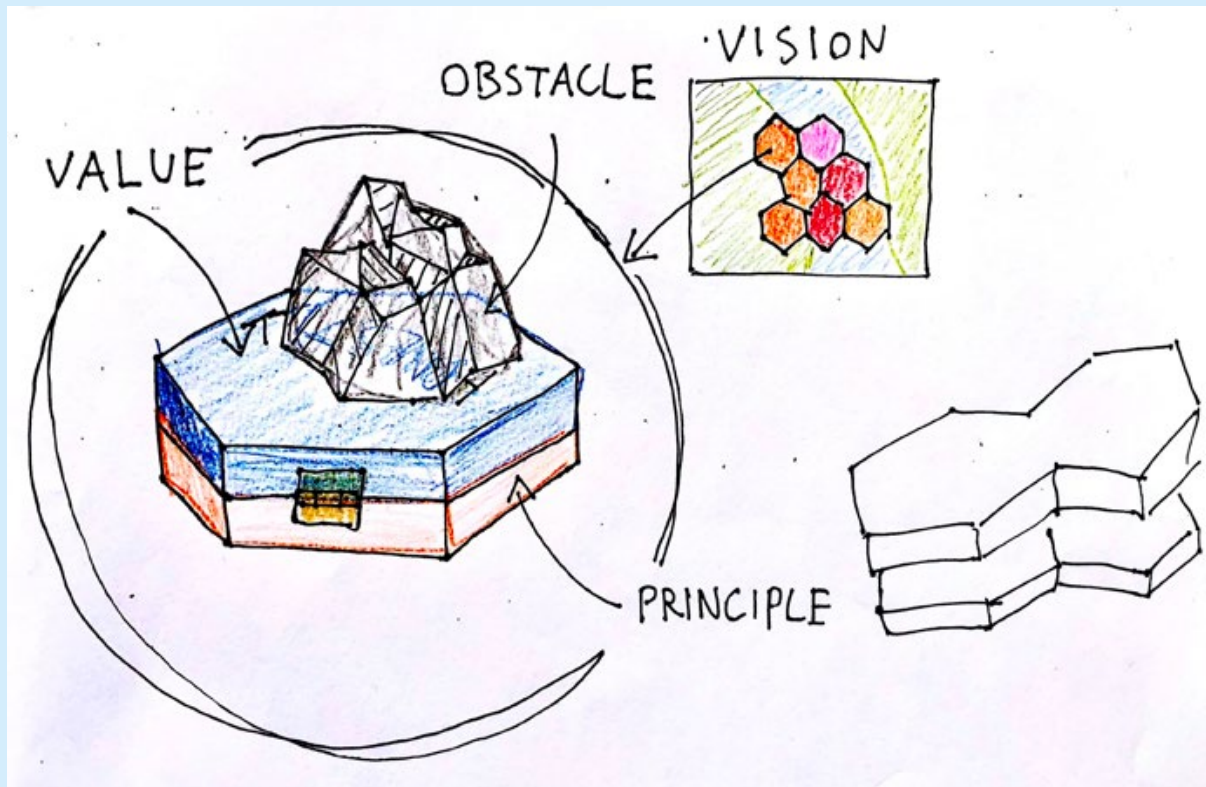
We took a *relational* approach to the research. This meant that we prioritised forming relationships with one another and as a group and used these as the basis for our work.

Together, the group decided that everyone would take part in all of the discussions and activities. This removed some of the barriers that separate people, minimising the classic 'us and them' that is seen in standard research approaches by having everyone take on an active role in the project instead of working with 'researchers versus participants'.

As a group, we collectively developed meeting guidelines and identified the values that we wanted to underpin our work together.

There was great power in coming together in these ways and our workshops typically (but not always) felt creative, vibrant, kind, connecting, nourishing and purposeful.
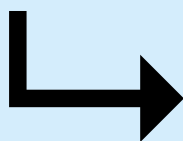
OUR CO-WORKING VALUES

Valuing intersectionality

Being listened to

Using accessible language

Striving for justice

Kindness

Curiosity

Flexibility

Ownership and legacy

Committed to holding the complexity of experiences

Our work as the opposite of abuse

Transparency: as the opposite of opaqueness, which hurts us

Integrity: as the cornerstone of all healing from abuse

Understanding: it's okay to have different/unique experiences. It's okay to not be okay

Responsiveness: being able to respond to changing thoughts, feelings, landscapes & attitudes

Non-judgemental: Judgement can be connected to abuse. It's important not to feel judged by other survivors

Collaborative, not competitive: we are here to combine our unique gifts and talents

THE FINDINGS

We were struck by people's *profoundly negative experiences of academic research.*

People experienced academia as a self-serving, authoritative and oppressive system.

Projects often felt extractive and exploitative.

Ethics committees were experienced as preventing the kinds of research that would benefit people with lived experience and their communities.

OUR MAPS

The physical and virtual maps we created capture the vision, values and principles underpinning ethical, survivor-controlled research; or research led by people with lived experiences of neglect, abuse, violence and/or trauma.

The maps are shaped and reshaped as we find our way in the current landscape and carve out new paths for survivor-controlled research in and outside of academia.

All travellers on this journey are welcome to use and adapt these maps.

www.survivorresearch.org/

OUR SHARED VISION

We envision research led by trauma survivors which constructively disrupts harmful institutional approaches and builds on new approaches based on collective power.

This research should support healing processes and translate into lasting practice, policy and societal changes that serve survivors and prevent further trauma.

OUR VALUES: WE BELIEVE RESEARCH SHOULD BE...

Intersectional & Complex
Activist & Reparatory

Bold & Empowering
Human & Mutual
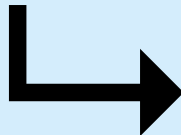
Safe & Supportive
Open & Honest

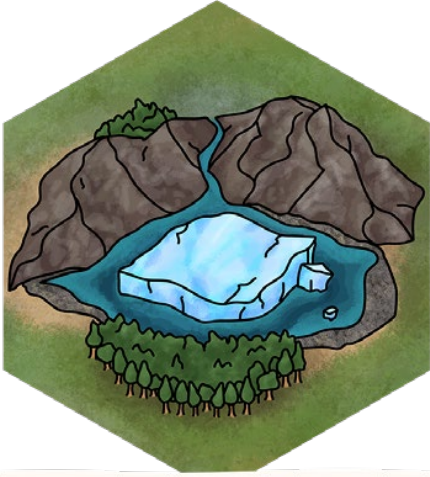**Kind & Gracious**
Hopeful & Joyful

Creative & Playful
Timely & Responsive

Inclusive & Accessible
Truthful & Authentic

Accountable & Non Co-opting

From the
virtual map

Accountable & Non Co-opting

Human & Mutual

Inclusive & Accessible

Safe & Supported

From the
physical map
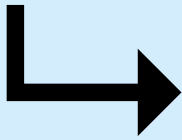
THINGS WE'D DO DIFFERENTLY

Working in partnership between a
university and several community-
based survivor-led organisations
means we are constantly learning
and unlearning.

If we were to do this over we
would:

- Offer the option of having peer
support before the first workshop
for grounding.

- Have consistency of peer
support, but also offer a choice
of different peer supporters.

- Develop accountability
processes to accompany the
meeting & safety guidelines.

- Have more time together to
discuss, share and develop our
ideas.

Maternity Opportunities for Research Engagement (MORE) Project

Quotes

'It was great to meet other mothers and chat through our pregnancy and labour experiences. I really hope our suggestions help improve services for others in the future.'

'A fabulous event. It was so nice to meet other mums, get to share our experiences and to see that we are not alone. It was nice to feel that our ideas and suggestion were listened to and hopefully it will help the system and process to improve for mums in the future.'

'The event was beneficial, but most importantly enjoyable. When an event is organised well, you can see the fruitfulness of the outcome. Great games were used, especially the washing line. I truly enjoyed being in the atmosphere of women who were able to feel comfortable to talk about their faith, culture and their differences. Having food at an event, proper food helps a lot, as we know food brings people together. I would definitely love to see this event quarterly or at least twice a year, as this type of event brings diverse communities together.'

'Thank you for organizing this fantastic event. It was a pleasure to meet everyone and be able to share experiences.'

'The event was really good. It really did feel like you were being listened to. It was nice the mums and researchers all joined together as equals. I wish it was something that all new parents got a chance to do. It was only afterwards that I realised I had never spoken to anyone about some of these questions e.g. the first GP appointment after finding out you're pregnant. It was so nice to hear from another mum who felt exactly like me. The activities like the washing line made it fun and having lunch at the end was so lovely. Not everyone felt the same e.g. the debate over too many scans for some and not enough for others made me think how personal this experience is. Lack of resources and continuity was something that came out again and again which sadly with the funding and staffing crisis isn't going to change anytime soon. The event was great and the researchers friendly and welcoming.'

'I had a great day, the activities were engaging and reflecting. I liked the fact that we were able to talk about our experiences right from the beginning of pregnancy till that very moment, both the good and bad and also show appreciation...'

'During one of the activities I took a step back to take a few photos of the event. As I stood still and focused, what I saw was a group of women working together for a common cause. At that moment it was impossible to distinguish between researchers and participants. Despite the joyful noisiness, there was a trusting and calm atmosphere where everyone was completely at ease. We had succeeded in creating a safe space where people were able to talk about their experiences in an authentic and sincere way, empowered by the knowledge they were truly part of the process.'

'The activities that were done made me think... It was good learning from others and sharing… So it was a really good event. So well done everyone!'

Project team:

Zenab Barry, Rachael Buabeng, Kaat De Backer, Abigail Easter, Zahra Khan, Vita Moltedo, Mary Newburn, Hannah Rayment-Jones, Jane Sandall, Tania Sutedja and Zoe Vowles.

The project:

The MORE [Maternity Opportunities for Research Engagement] project is a collaboration of researchers, peer researchers and a PPIE (Patient and Public Involvement and Engagement) Lead focused on local capacity building, partnership development, and co-design and implementation of a participatory research project. The project is currently using PhotoVoice to involve an ethnically and socially diverse group of women in South London as partners in the research process to transform public understanding of their lived experiences of pregnancy, birth and the postnatal period.

This will inform future research priorities.

Why?

A project organised with the support of the NIHR ARC South London Maternity and Perinatal Health Theme, as part of a greater effort to confront inequalities in healthcare and healthcare research, and to initiate and maintain a dynamic and constructive dialogue between the healthcare system, academia and service users, by placing them at the centre of research and amplifying their voices.

There is increasing evidence that there are stark inequalities in maternity care and consequent negative and sometimes tragic outcomes for mother and/or baby. Researchers dedicated to maternity care are looking for solutions to reduce and end inequality of care, but in order to do that effectively there needs to be an authentic dialogue and involvement from the service users themselves, the actual protagonists of their stories.

Who?

The project was co-devised and co-produced by a mixed group – consisting of King's College London Researchers whose research focuses on maternity, a Public and Patient Involvement and Engagement Lead and Peer Researchers, people with lived experience of maternity care who are active co-producers throughout the project and in every aspect of it, from the design, to event organising, choice of methods and activities setting, logistics, communication with participants and finally any written outputs (blog, report, etc.).

The events were carried out with the participation of service users from the local area (Lambeth and Southwark) and with the support of community organisations (Mummy's Day Out, LEAP, PACT Southwark, and others).The recruitment of participants was not left to chance. In order to reach as many people and groups as possible but keeping the focus on a specific area in London, we worked together with community groups and organisations, which promoted the event with their members or put us directly in contact with them. In this way there was an immediate and mutual feeling of trust, which enabled a much more authentic and in-depth conversation and exchange of ideas.

This personalised way of recruiting also meant that we achieved one of our goals, which was to have a truly representative group for this part of London, from the point of view of ethnic and social diversity, thus mirroring the community we were hoping to engage with (see charts).
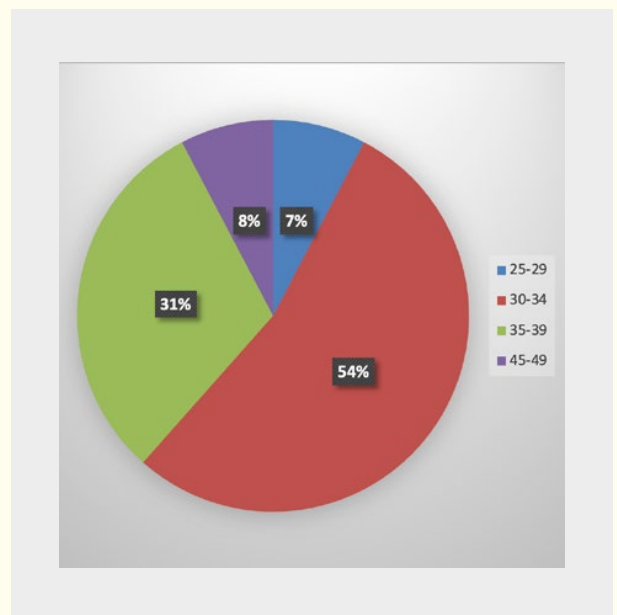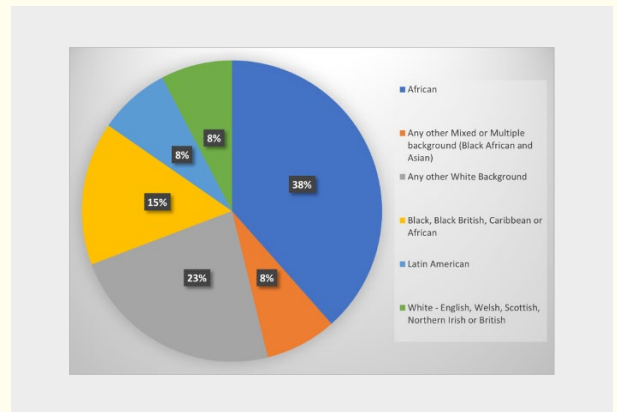
Where?

In terms of accessibility we were mindful of the challenges mothers and carers of babies and toddlers face in their everyday life and especially when they try to access services.

That is why we gave a lot of thought to the space we were going to use for our in-person events - known as *Lambeth Listening Lunches*. We chose a space that was within the local area and close to some of the community children's centres frequented by the participants. The venue was step free, with plenty of space for the prams and pushchairs, and easy to access baby-changing facilities.

We provided a crèche service in the adjacent room with professional crèche workers, as well as offering a selection of toys for the babies and toddlers who preferred to stay with their mothers throughout the event.

Our consideration for the comfort of our participants was very much appreciated and favourably commented on after the events and in successive written exchanges.

How?

Making sure that communication with the participants throughout the process was easy and smooth has been a priority throughout, as well as ensuring that each in-person event was inclusive and accessible to the participants from every aspect.

Before starting, each participant was asked to fill in a consent form for the use of the photos of themselves, their children who attended and any quotes. We made sure this consent was informed, by supporting the participants with any part of the form that was unclear to them or difficult to process.

To thank the participants for their time, we offered a choice of shopping vouchers, and following the more formal part of our meetings, everyone was invited to share a hot meal together. Participants were able to ask for their travel costs to be covered as well.

In preparation, Peer Researchers discussed various ways in which we could facilitate friendly, informal conversations that would nevertheless give the opportunity to attendees to consider and answer some probing questions, so that we could generate ideas to inform future research. We decided to draw on participatory appraisal methods and tools to guide planning of activities, and to help us make good use of the available time.

Participatory Appraisal uses interactive and visual tools, and its basis is that it values people as 'Experts in Their Own Lives' and helps Community Members work together with Researchers to identify issues that affect them, and to find ways to address them. Other advantages to using this way of working are that PA enables anonymity and encourages story-telling. It creates an open and non-judgemental atmosphere, whilst allowing faithful notetaking in real time. Researchers can then analyse these notes and identify key themes as they emerge.