

Participate Grant Research Project Report



Written by:

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Overview

In 2024, the University of Bath awarded £50,000 in grants to community organisations and charities to work in collaboration with the university on a small research project. The aim of the grant was to involve ordinary people in academic research so they could understand and enjoy the process, with a useful result for the organisation.

We made an application via the two-stage process and were awarded £7100 to research our impact on the people who have taken part in our work. We were partnered with Dr Megan Robb, a qualitative research specialist and lecturer in the Department of Social and Policy Sciences.

This report is a review of this work and our outcomes.



About Us

Invisible Army was founded as a community project in 2019 and became a CIC in 2023. It was launched by writer Carina Andrews, a young carer who supported her disabled parents throughout her childhood, and Tina Gue, a photographer with an interest in unpaid care. Jai Breitnauer, a parent carer to two autistic children, joined in 2023 to support fundraising and impact, becoming the third director in 2026. Together

they want to draw attention to, and raise awareness of, unpaid and invisible care work by recording the stories of carers through documentary photography and carers' own words, captured during a visit to their home or chosen safe places. These stories are then displayed in carefully curated exhibitions with key partners.

“We want to shine a light on unpaid carers. A carer is someone who provides support to family or friends who cannot manage without this help. This can be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems all while not receiving a living wage. We want to make the challenges and joys carers cope with every day visible. We want to raise awareness about unpaid care in the UK, using art as a tool to achieve social change, waking people up to the realities of caring.” – **Carina Andrews.**

There are 10.58 million unpaid carers in the UK: that's one in every five adults (according to Carers UK). In Bristol alone, there are 40,000 carers. Yet most people probably don't know or understand what a carer is. Additionally, in England alone, it's estimated there are 600,000 hidden young carers not receiving any support (Action for Children). Carers, young and old, are invisible. Three in every five people will become carers in their lifetime, many having to give up work in order to provide care, yet Carers Allowance is just £86.45 a week for 35 hours of care work – that's £2.47 an hour. Carers are often so deeply entrenched in their role, they are unable to seek support or community, get their voices heard in political, medical or community settings, and many do not even self-identify as carers.

At the time of receiving the grant, Invisible Army had collected 38 carer stories and shared them through two exhibitions, viewed by the general public, professionals, local politicians and carers themselves. They had just received a grant of £22,000 from the National Lottery to collect a further 20 stories and put on two more exhibitions in Bristol. The hope was to use the Participate Grant to create a small piece of carer-led research to help Invisible Army understand the impact they had on the carers they documented, learning what worked well and what needed to change.

“I am a lecturer in social work at the University of Bath. I am also a registered social worker and (through working with Invisible Army) recognise I am a parent carer. I was drawn to working with Invisible Army on this project, firstly, because of my significant practice and research interest in any project that serves to develop and support social care, and, secondly, because I am deeply committed to working in a co-produced way with people who have been historically excluded from research or have been the subject of research without meaningful input.” – **Megan Robb**

This project offered an exciting opportunity to develop and deepen my understanding of carers' experiences while also supporting a group of co-researchers to develop their own research and analysis skills. As a researcher, my aim is always to strengthen understanding of social issues and innovate new ways of researching in truly collaborative ways; this research project offers the opportunity to do both.

Invisible Army's proposal

In our original proposal, we stated that we wanted to better understand the impact, or potential impact, of our work. We noted that we had already surveyed a small cohort of carers we had worked with and discovered carers found it very validating to be seen.

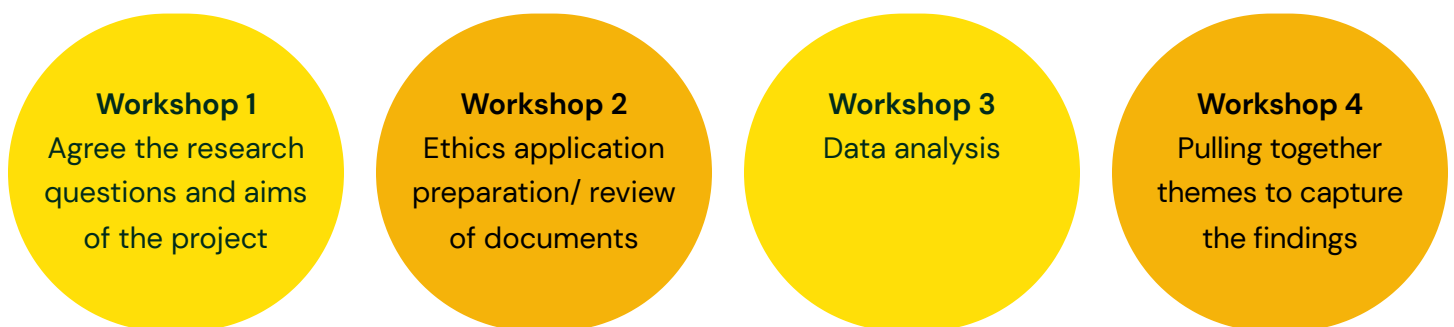
- 16.7% of carers we engaged with in Bristol did not identify as carers before speaking with us
- 55.6% had never talked about being a carer, or only told family and close friends, before speaking with us
- None of the carers we worked with felt well understood. 55.6% said they were not understood at all
- 94.4% of the carers said they felt 'truly heard' by Invisible Army
- 100% felt that sharing their story would help others understand carers more
- 44.4% said they felt less isolated after sharing their story, either definitely or somewhat
- 77.8% said they felt more proud of their role as a carer after speaking with us, either definitely or somewhat

We said we would like to build on the data already collected through surveys by conducting in-depth interviews about the project with people who have worked with Invisible Army. We aimed to conduct 10 interviews in total to help us better understand our impact.

We said this information would inform our practices as we move forward with our work, help us secure additional funding, and could also help other organisations that work with carers through sharing the results. We would also like to share the way we have worked as a potential model for other organisations moving forward.

As well as working with 10 carers we had already worked with to gather good-quality qualitative information about their experience of collaborating with us, we said we would support five of our volunteers to help co-produce this piece of research and analyse the results.

After a meeting with Megan Robb from the University of Bath, we decided the best approach would be to organise 4 workshops as follows:



We said the benefits would include:

- Carers understanding the project better
- Developing new connections via consolidating the relationship with existing volunteers, offering them the opportunity to become co-researchers
- Co-researchers understanding our work better
- Volunteers understanding the research process and outcomes and gaining research skills
- Invisible Army understanding their impact better

- Other organisations, including funders, better understanding the role of the arts in carer self-identification, support and lobbying

We also spoke with Megan about the possibility of publishing something about our experience of working with the University of Bath in this participatory way, and/or about our research itself.

We said we would measure success, with Megan's support, by our ability to consistently monitor involvement and impact through the open, co-productive nature of the research. We will have regular check-ins with the co-researchers through the qualitative interview process and workshop process. We said we would engage the University of Bath's ethics committee to make sure we are running the project effectively and appropriately. There will be anonymous and quantitative feedback opportunities at every stage for all participants and co-researchers.

What does success look like for us? It looks like:

Stronger connections with our co-researchers and carer community

Usable data for funding applications

If possible, a published piece of research

Having developed useful skills in research and analysis that will strengthen our organisation as we move forward

We estimated this piece of research would take six months.



Project results

Changes and Successes

We stayed very close to the original proposal, with some minor changes as follows:

- We did not engage the ethics committee and decided the publication of the findings would be informal. This is because of the ethical complexities involved in the project, short timeframe and budget limitations
- The project actually took around 18 months due to the challenges related to engaging carers with lived experience
- Workshop 2 focussed on refining the questions we would ask the 10 carers, as this was a part of the process we wanted to get right

We successfully recruited a team of five carers with lived experience to work as co-researchers, and Jai Breitnauer also took part as project manager. One of the five was only able to attend two of the four workshops due to their caring responsibilities, but everyone else was able to attend all four workshops and complete the homework. We held our first workshop in October 2024, workshop 2 in February 2025, and workshops 3 and 4 in April and May 2026.

The interview period for the 10 carers was estimated to take six weeks, but it actually took 8 months. This was because of the challenges carers face around free time, and was in itself an important part of the learning process. We approached 28 carers, and secured 10 who were both interested in speaking to us and available.

The budget

The proposed budget was as follows:

Each workshop would include five experts by experience (people with lived experience of caring). Costs of the workshops would be:

- Room hire £100
- Refreshments £75
- Transport costs £50
- Payment for experts by experience time £25 per hour x 4*

Per workshop costs £725 x 4= £2900

Paid research assistant who is also an expert by experience to arrange the interviews, gather the data, etc. 120 hours @ £25 per hour = £3000, plus travel costs of £100.

Transcription of 60 mins interviews x 10 x £1.50 per minute transcription=£900

Paid incentives- £20 voucher per research participant = £200

This would come out at £7100 total.



The fee of £25 per hour was chosen because it links to the amount the National Institute for Health and Social Care Research (NIHR) funds for patient and public engagement.

We were pleased to have come in on budget, with a slightly higher spend on room hire costs, refreshments and travel costs, plus some additional unbudgeted project management hours and additional contribution hours from the parent-carer team. We had an underspend in transcription costs which balanced out the difference.

Workshop review

Workshop 1

We met as a group for the first time. We did introductions, talked about the intention and the process, and began identifying broad themes that interested us.

Workshop 2

We refined those broad themes into 10 specific questions with guidance from Megan Robb that would allow us to gather useful qualitative data. We discussed ethical approaches to gathering data and ensuring informed consent.

Workshop 3

Megan showed us how to review the transcripts of the interviews and how to “code” them (a core process of qualitative data analysis) so we could identify themes. We talked about micro-themes within each transcript and also macro-themes across all 10 transcripts.

Workshop 4

We went through the transcripts to see what themes had been identified. We used post-it notes to record the themes. We grouped similar themes together. Then Megan talked us through how we could draw useful conclusions from this data by categorising these groups under four clear umbrella themes.

Workshop 3 Homework: We each took between four and six transcripts home, including Megan, and used our new data-gathering skills to highlight the essential areas independently.

Here are the questions we co-created:

Q: Why did you share your story with Invisible Army?

Q: What were your expectations from connecting with Invisible Army? (Support, signposting or connection with services? Or were you just happy to tell your story?)

Q: How did you feel about Invisible Army coming to take pictures/meet you in your home?

Q: What was your experience of seeing your own story?

Q: How does knowing your story might be shared in the media/online/galleries etc make you feel?

Q: What impact did Invisible Army have on your view of yourself as a carer?

Q: What impact do you hope your story will have and on who?

Q: Invisible Army want to co-create stories with people in a collaborative way. Do you feel this was achieved?

Q: Did engaging with Invisible Army have an impact on your relationship with the person you care for?

Q: Did you feel able to be honest about your caring role with Invisible Army while still protecting the relative privacy of your loved one?

Q: Is there anything you wanted to add that we haven't asked you?



Conclusions from the research

We were able to classify every theme under the following four umbrella themes:

What carers wanted from working with Invisible Army

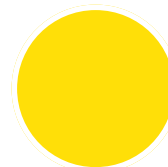
Carers' experience of the process of working with Invisible Army

The outcomes carers experienced as a result of working with Invisible Army

Odds (the themes that didn't fit the three main umbrellas)

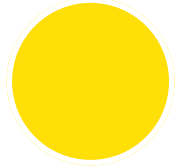
Here are the sub-themes, as expressed by our 10 carers through their interviews, that recurred frequently across the entire qualitative data set:

What carers wanted from working with Invisible Army



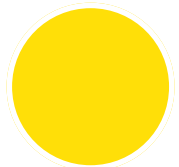
- Greater awareness of the caring role among general public
- Greater awareness of the caring role among family and friends
- Greater awareness of the caring role among politicians and law makers
- Greater awareness of – and respect for – the caring role among medical staff
- Societal change regarding the caring role and how it is viewed/supported
- Greater preparation for caring among people who aren't caring at the moment
- Visibility/being seen
- To express pride in their role
- To feel validated in their role
- To feel understood in their role
- Greater systemic support and recognition for unpaid carers, including policy change at national government level
- To have the lack of choice, sense of isolation, and the 'life subsumed by caring' acknowledged
- To express gratitude to Invisible Army and request an expansion of their work

Carers' experience of the process of working with Invisible Army



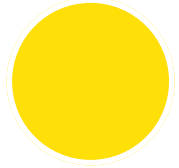
- Felt they had control/ownership of their own story
- Trusted Invisible Army with this work
- Felt centred in the process
- Felt accepted, respected and not judged
- The reality of carer lives was seen
- Carers felt safe and reassured
- Felt visible in their own home (where they often feel least visible)
- Felt there was true collaboration/co-creation and the power to say no
- Felt a sense of community/connection to other carers; belonging
- No additional support was provided but it was not needed: sharing story was enough

The outcomes carers experienced as a result of working with Invisible Army



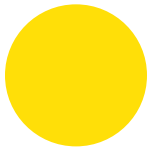
- Carers felt empowered, special and important
- They were pleased with the honest and non-sensationalised narrative
- They realised caring was a real job, and realised how much they do
- They recognised that they provide far more care and support than many people realise, including other family members, professionals and policy makers. The caring role means they go above and beyond the social expectations of parents/partners/children.
- They felt they had a better relationship with the person they care for after speaking with Invisible Army
- Carers felt less guilt and more pride in their role
- They felt emotional when they saw their story
- They felt community, connection and belonging
- They felt hopeful their stories could raise awareness and effect change
- They felt pleased they were able to have some tricky conversations with people, especially the person they care for
- They experienced increased self-confidence
- They experienced increased satisfaction through caring
- They had some treasured family photos that would have been difficult to capture otherwise.

Odds (the themes that didn't fit the three main umbrellas)



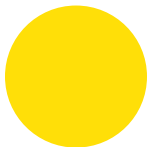
- Not all carers are the same and should be approached as individuals
- There are cultural differences in caring
- Caring experiences are affected by intersectional differences such as gender, ethnicity and sexuality

We consolidated these outcomes into the following statements:



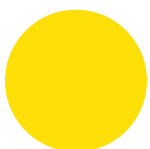
When Carers first work with Invisible Army, they are hoping to raise awareness and increase understanding of unpaid care among the public, their own friends and family, medical professionals and legislators. They would like more financial support; otherwise, they would like to be more visible in society, and they would like more recognition for their role. They enter into a relationship with Invisible Army because they perceive them as trustworthy and understanding.

As evidenced by participant 'Jane', who stated: "I hope that in some small way it makes people in general realise there is a huge issue that is out there and is not really being addressed at all about how society deals with the ageing process."



During the process of working with Invisible Army, carers feel centred and feel they have control. They trust Invisible Army and experience validation and acceptance from them. Carers feel the reality of their lives is seen and not judged by Invisible Army. They begin to feel a connection to other carers and feel part of a community. Although no further support is provided, sharing their story feels 'enough'.

As evidenced by participant 'Ellen' who stated: "Invisible army work with a lot of families who otherwise would not be able to tell their story, they make it easy to share. They were really responsive and engaged with what we were saying, they were respectful of what we did and didn't want to share. We could say, 'oh we don't want to do this photo right now' and they were fine with it. We said some things for background we didn't want shared, they didn't pressure us. We felt we could lead."



After working with Invisible Army, carers feel empowered with improved self confidence and pride in their work. They reported experiencing a realisation of how much they do, and how different the caring role is to parenting, being a spouse or adult child. They reported an increased ability to have difficult conversations with the person they cared for, and ultimately an improvement in their personal relationships. Their sense of loneliness was reduced, and a sense of renewed satisfaction with their caring role came into being. They felt they had done a good thing by raising awareness, and cherished the memories through the photos.

As evidenced by participant 'Anna' who said: "When I saw it written up it was like, wow ... I do, do a lot. It made it real and I felt pleased to be acknowledged. I looked at myself a bit differently, after. I said, yes I am that person, I do all those things and they seem like everyday normal things, you just go along with it, but when you see it on the wall you see this isn't normal, this isn't day to day. It is a thing. It's bigger than normal. When I saw it written like that I thought, no this is above and beyond."

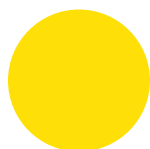


Every case study subject reported feeling Invisible Army's work was truly unique, and they wanted to see their work expand nationwide.



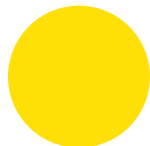
Project outcomes

We can demonstrate clear alignment with project proposal outcomes, as follows:



We said we would like to build on the data already collected through surveys by conducting in-depth interviews with people who have worked with Invisible Army about their experience of the project.

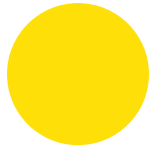
We conducted 10 interviews with carers who had previously taken part, asking questions that built on the quantitative data already collected and helped us further our understanding. The questions were developed from a review of that data and support the conclusions previously drawn: that Invisible Army helps carers self-identify, helps them feel understood by family, friends and wider society, that they felt seen/validated by the experience, and that they value this work and believe it will help others.



We said this information would inform our practices as we move forward with our work, help us secure additional funding, and could also help other organisations that work with carers through sharing of the results.

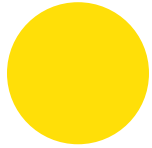
After analysing the data in our group we have more understanding of the impact we have on carers, what works well and areas we can expand on. We were pleasantly surprised that none of the carers interviewed gave negative feedback or suggested improvements other than expanding the work. However, we recognise that a limitation of this research may be that those with more positive experiences of the project were more willing to participate in research being conducted by the organisation. We will continue our practice with a critical eye and ensure we make space for all constructive feedback. The data collected is

already being woven into our case for support to help us secure further funding. We have already connected with other organisations and individuals who may want to find out more about our work and collaborate with us, including Lockleaze Neighbourhood Trust.



We said we would also like to share the way we have worked as a potential model for other organisations moving forward.

With the support of Megan Robb, we intended to review our practices with a view to publishing something and working with other organisations to support truly collaborative/co-creation practices.



As well as working with 10 carers who we had already worked with to gather good-quality qualitative information about their experience of collaborating with us, we said we would support five of our volunteers to help co-produce this piece of research and analyse the results.

We appointed five co-researchers, including myself, who took part in the process and learned what it means to be involved in research as lived-experience researchers. We learned valuable skills we can apply to our work as we move forward, and gained a better understanding of academic rigour and what research contributes to wider society.

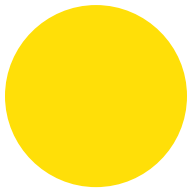


Overall conclusion

This research has shown the value of Invisible Army's approach: the safety felt by participants, the level of trust built, and the validation they experienced. We have shown that, even with no additional support provided, working with Invisible Army makes carers feel seen, improves their confidence and relationships with loved ones, and increases their sense of satisfaction.

Carers reported increased pride and self-worth as a result of Invisible Army's approach, and all 10 case study subjects unanimously requested, without prompt, an expansion of Invisible Army's work.

Every carer said they felt their true reality was not well understood, and their voices were not heard, sometimes even by those closest to them. They felt that by working with Invisible Army, they could improve things for themselves and other carers.



Appendix

Here are some selected quotes from participants that support this report.

“They did amazing, the way they handled it all. I 100% felt in control, and like I had ownership of my story.”

“Invisible Army can help carers have these conversations with the people they care for, and it can create a closer bond.”

“It brought us closer together, to share our journey together.”

“I loved the photos, it was a really good part of it. I loved seeing us all together. It was really sweet. We don’t have many family photos.”

“They made me feel seen and validated ... it helped me self-identify as a carer. It’s made me more confident and assertive in advocating for our needs.”

“It’s my belief if you don’t teach the world what something is, they will not know and they cannot help you.”

“I wanted to share my story to tell people there is different types of caring needs out there. Everyone is different.”

“In my culture, people hide all this. This is a big step I am taking. I’m really proud of myself.”

“They capture the life of the carer as it is. It is so important for professionals, policy makers, and other people to know what the real life is.”

“They captured the moments as they happened ... I was quite impressed when I saw the exhibition. I wanted them to make our story come alive, which they did.”

“To see the other stories together with your story, it was really powerful ... I felt I am not alone. Other people are in this situation. I became part of a family – a bigger family of carers.”

“If what I said in my story helps someone improve their life or feel a bit better that’s a good thing. I can’t change what people go through, but I can say, ‘I go through this too.’”

“Invisible Army are unique in their ability to replicate the real life of a carer.”

“Every carers’ story needs to be told. They’re all different and we can all learn from each other.”

“I hope that in some small way it makes people in general realise there is a huge issue that is out there and is not really being addressed at all about how society deals with the ageing process.”

“We are becoming a society of carers.”

“I was just happy to tell my story ... I didn’t expect any help ... it was mostly just about talking to someone who could understand.”

“It’s felt like it’s just me and my partner against the whole world. But then it was so nice to see the other stories and speak to other carers. I didn’t feel so alone.”

"I've been caring for a little over five years, that time has just flown by and I don't know how to describe it. Seeing the picture made it feel real in a way ... it's really difficult and every day you're just trying to get through it, and you put your head down. This made me feel like I am doing something good ... the exhibition made me feel like I am not totally screwing this all up."

"It was nice to speak to people who understand. I know there are lots of unpaid carers out there, but getting to meet them was so good. I can feel really lonely, and it made me feel less alone to meet other people and talk to them about caring."

"It would be nice if the people I deal with regularly, like medical professionals and social services, if they appreciated that unpaid care is really frigging hard. It's hard to ask for help, and you have to literally beg for it."

"The biggest thing for me was that feeling of validation. I do get into a really dark place a lot of the time. I have the photos as a reminder of the experience and I can look back on it and remember how I felt when Invisible Army were here. It helps me approach caring in a calmer way."

"I've experienced this recalibration of what it means to be a carer."

"I feel proud of myself for sharing that story. It's hard to share. You worry what people will think, or that it isn't the right decision. I also feel hopeful that it will help and support other people who feel isolated and alone. If people can see stories about lives like their own, they will feel less alone and understand they need help."

"Then I saw it written up it was like, wow. I can talk the talk but actually seeing it in writing it makes you realise you do a lot. It made it real. I felt pleased to be acknowledged and I looked at myself a bit differently. I said yes, I am that person I do do all those things."

"When you see your story on the wall you realise this isn't normal, this isn't day to day. It's a thing. It's bigger than normal. It's not a normal thing to do all that you do. It's not normal that you have to give up everything to be that carer. I feel it's not my job, because it's unpaid, but it is my job. It becomes your normal but when I saw it written like that I thought, no, this is above and beyond."