

<b>Institution:</b> University of Northumbria at Newcastle		
<b>Unit of Assessment:</b> 3 (Allied Health Professions, Dentistry, Nursing and Pharmacy)		
<b>Title of case study:</b> Using lived experience research, co-produced film and theatre to help communities get ready for ageing		
<b>Period when the underpinning research was undertaken:</b> 2011 – 2020		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Cathy Bailey	Associate Professor	01/07/2010 – present
Catherine Gibb	Senior Lecturer	12/04/2011 – 31/08/2013
Natalie Forster	Research Fellow	01/09/2008 – present
Sue Tiplady	Senior Lecturer	03/05/2011 – present
Joanna Reynolds	Senior Lecturer	01/08/2007 – present
<b>Period when the claimed impact occurred:</b> September 2013 – 2020		
<b>Is this case study continued from a case study submitted in 2014? N</b>		
<b>1. Summary of the impact</b> (indicative maximum 100 words)		
<p>There is a lack of research focussing on the lived experiences of people with dementia, their friends and their families. By exploring this through research, and subsequently through iteratively co-produced theatre and film productions based on the findings, researchers from Northumbria University have exposed the need to become 'ready for ageing' and highlighted challenges to, and opportunities for, this within local communities. Public and professional audience members provided a knowledge exchange of their experiences of dementia and subsequently of later life housing needs. This informed and enriched future theatre and film iterations and improved public and professional understanding. The work has led to 1) improved health promotion strategies of public health bodies and local authorities; 2) the adoption of new engagement initiatives and policies by housing providers; and 3) the creation of a network of 34 dementia-friendly organisations.</p>		
<b>2. Underpinning research</b> (indicative maximum 500 words)		
<p>Dementia is a degenerative disease, characterised by a decline in memory and cognitive skills, affecting around 850,000 people in the UK. Alzheimer's Research UK predicts that the number of people living with dementia in the North East will rise to 40,000 in 2021. Building on prior research into older people's perceptions of everyday risks and taken-for-granted activities that shape their interaction with community life (Bailey et al. 2011, <i>Ageing &amp; Society</i>), Northumbria researchers identified an absence of lived experience studies of people with dementia and their support networks [R1]. Bailey and colleagues (including PI Prof Charlotte Clarke, who left Northumbria in 2011 but remained a collaborator on the project) undertook NHS-funded research [G1] to uncover the experiences of people with dementia and communicate these to public and professional audiences. A critical review of the research literature and policy documents underpinned an in-depth qualitative study investigating the changed perceptions of risk and resilience for people living with dementia and their support networks [R1, R2]. Northumbria's approach expanded how lived experience was defined by considering how people living with dementia includes not just the individual with the disease, but their support network, and how this has implications for the community around them [R1, R2]. This new approach then informed research into diverse lived experiences of home and community in later life [R3, R4].</p> <p>Between 2011 and 2013, Bailey and colleagues' research demonstrated that although there was a will among researchers and policy makers to develop positive responses to dementia, the absence of accessible channels for people living with dementia to give voice to their experiences limited these responses to narratives of vulnerability and protection, rather than empowerment and enablement [R2]. In addition, Bailey and colleagues determined that top-down policy</p>		

responses alone do not have the nuance and flexibility to meet the complex and diverse needs of people living with dementia. Meaningful change requires disrupting the perception of managing dementia as being down to individual capability or family responsibility [R1, R2]. If people with dementia and their families are to be independent from ties of caring obligation and involved in social life, then their communities must become 'ready for ageing' in ways that see dementia-friendly and enabling practices as a community responsibility, supported by well-funded, local initiatives [R2]. An understanding of local context, and the physical and infrastructural challenges and opportunities within local communities, is offered by having the lived experiences of people with dementia, and their families and friends, communicated in powerful and effecting ways [R1, R2].

As a result of this new understanding, and to tackle these challenges, Bailey and colleagues, worked with Skimstone Arts (a company that creates collaborative theatre to reflect challenges in society) to develop a creative participatory approach to give voice to the experiences of people living with dementia through theatre and film productions. The findings of the original 2011-2013 NHS-funded research [R2] were used to create a fictionalised theatre production informed by the words and experiences of the study participants, called 'Jack and Jill and the Red Post-box' (hereafter *Jack & Jill*; <https://www.skimstone.org.uk/jack-jill-and-the>). This method formed the basis of a subsequent project led by Bailey with Skimstone Arts and new partners – the Elders Council Newcastle (ECoN) and Care and Repair England (CRE) – exploring diverse lived experiences of home and community in later life and how the physical environment can improve physical safety and enhance socialisation and wellbeing [R3]. This research led to the creation of a new theatre production and film entitled *Doorbells of Delight* (hereafter *Doorbells*) [R4].

Knowledge exchange between researchers and the audiences of *Jack & Jill* and *Doorbells* while exploring and developing the performances demonstrated that these creative productions communicated the nuanced and complex needs of people living with dementia. The process identified those with unmet housing needs in powerful, emotive ways that expanded public and professional awareness and changed perceptions of the potential of community-responsiveness in ways that medical-based information did not [R2-R4]. Facilitated audience feedback informed and helped re-shape future productions, including solo performances. These drew on the facilitated discussion of audience members' reflections on their own experiences, creating a dynamic and iterative research process emphasising the biography of the person living with dementia and giving greater voice to family members and to diverse lived experiences of home and community in later life [R3, R4].

### 3. References to the research (indicative maximum of six references)

**R1. Cathy Bailey**, Clarke, C.\*, **Catherine Gibb**, Haining S.\*, Wilkinson, H.\*, and **Sue Tiplady** (2013) 'Risky and resilient life with dementia: review of and reflections on the literature' *Health, Risk & Society* 15(5): 390-401 DOI: [10.1080/13698575.2013.821460](https://doi.org/10.1080/13698575.2013.821460)

**R2.** Clarke, C.\* and **Cathy Bailey** (2016) 'Narrative citizenship, resilience and inclusion with dementia: On the inside or on the outside of physical and social places' *Dementia* 15(3):434-452. DOI: [10.1177/1471301216639736](https://doi.org/10.1177/1471301216639736)

**R3. Cathy Bailey**, Gilroy, R.\*, **Joanna Reynolds**, Douglas, B.\*, Webster Saaremets, C.\*, Nicholls, M.\*, **Laura Warwick\*\***, and Gollan, M.\* (2018). Ageing in place: Creativity and resilience in neighbourhoods. In *Resilience and Ageing: Creativity, Culture and Community* 157-180 Policy Press. Available on request DOI:[10.1332/policypress/9781447340911.003.0008](https://doi.org/10.1332/policypress/9781447340911.003.0008)

**R4. Cathy Bailey**, **Natalie Forster**, Douglas, B., Webster Saaremets, C., and Salamon, E.\* (2019). Housing Voices: Using theatre and film to engage people in later life housing and health conversations. *Housing, Care and Support*, 22(4): 181-192 DOI:[10.1108/HCS-04-2019-0011](https://doi.org/10.1108/HCS-04-2019-0011)

**Co-produced creative productions:**

**2015** - 'Jack and Jill and the Red Post box' film - Charlotte Clarke, Catherine Gibb, and **Cathy Bailey** with Skimstone Arts (<https://vimeo.com/151884453>).

**2018** - 'Doorbells – Dreaming for the Future' film - Skimstone Arts, **Cathy Bailey** and team from **Northumbria University** and ECoN (<https://vimeo.com/289109651>). Commissioned by Care & Repair England and funded by The Esmée Fairbairn Foundation.

**Research funding**

G1. NHS North of Tyne Primary Care Trust (2011), 'Risk and Resilience in Living Well with Dementia', GBP108,000

G2. Elders Council of Newcastle (2014), 'Growing older in my home and neighbourhood', GBP7,000

G3. Arts Council England (December 2013), GBP33,350 Grant awarded to Skimstone Performance Company Ltd, in partnership with Bailey from Northumbria

\*External collaborators: S. Haining – NHS North of Tyne; C. Clarke and H. Wilkinson – University of Edinburgh; R. Gilroy - Newcastle University; C. Webster Saaramets - Skimstone Arts; B. Douglas, M. Nicholls and E. Salamon - ECoN; M. Gollan - Visual Artist.

\*\*Internal collaborators: Dr Laura Warwick, Northumbria University (submitted to UoA 32)

**4. Details of the impact** (indicative maximum 750 words)

Between August 2013-2017, over twenty-five performances of three iterations of *Jack & Jill* were given across the North East and nationally, including Edinburgh Fringe Festival and the Economic Social Research Council Social Science Festival, to over 1,500 participants including those living with dementia, carers, practitioners, policymakers and service providers [E1, p29-31, p51-56]. A film was also made freely available. Similarly, between 2014 and 2020 three iterations of *Doorbells* toured nationally, the film version premiered in 2018 and a COVID-19 film short was produced in 2020. These performances have: 1) raised public and professional dementia-awareness, leading to changes in health promotion in Scottish Palliative Care and Stockton-on-Tees public health directorate; 2) led housing providers in England and older person advocacy groups to change their engagement strategies with older people, and 3) shaped the action plan and subsequent development of a new community dementia network of 34 local organisations in Newcastle, leading to new dementia-friendly practices and policies to create a more inclusive and enabling community environment for people living with dementia.

**4.1 Increasing public and practitioner understanding of the lived experiences of dementia**

Post-performance discussions and feedback revealed that audience members found *Jack & Jill* to be a powerful, poignant experience that changed their perceptions of dementia in the community [E2, p10-16]. Comments not only highlighted the emotional nature of the work, with some noting they were '*emotionally wrung out*' or '*completely overwhelm[ed]*', but also demonstrated that individuals living with, or caring for, someone with dementia found the performance to be reflective of their experience and thus comforting. One individual noted '*[it was] a relief to see your work and to hear others in the audience. I used to think this was only happening in our house*' [E2, p10].

Persuaded by the power of the performance and its ability to increase public awareness of and response to dementia, public health bodies and local authorities commissioned *Jack & Jill* performances in order to improve their public health outreach and awareness raising strategies regarding dementia. Following one commission by Stockton-on-Tees Borough Council, Peter Kelly, Director of Public Health North East, noted that he would formerly have been '*giving a presentation, probably with PowerPoint slides perhaps even alongside a local carer talking about their personal experience and a local GP or mental health professional giving their perspective and insight. What a mistake that would have been!*' [E3, p1]. Kelly explained how he would pursue ways to use '*the subject matter and also on other opportunities to use this, and other, forms of art in my work*' [E3, p1].

This work included cooperation with Dementia Friendly Stockton, a community organisation working with local people and businesses to raise awareness about dementia. Gayle Tweed, the CEO, working with the local council commissioned a performance of *Jack & Jill* in 2014 to support '*businesses and organisations in each town to take low cost, easily achievable steps*' to become dementia friendly [E4]. Notable successes include securing '*funding to upgrade their large day centre to become more dementia friendly*' and the creation of the LiveWell Dementia Hub, a 'one stop shop' for people living with dementia and their carers to receive dementia advice from trained professionals and memory specialists [E4]. She concluded that the performances had '*contributed to ensuring people have a better appreciation of the disease so the day-to-day challenges faced by families affected by dementia are made that little bit easier*' [E4].

Mark Hazelwood, Chief Executive of Scottish Partnership for Palliative Care, saw the performance in 2014 and spoke of its powerful effect on him, confirming in 2020 that it gave him insights into dementia as a condition as well as showing the value of theatre in terms of public engagement, awareness raising and education: '*Jack & Jill was really outstanding in its ability to convey powerfully something of the personal experience of dementia in a way which policy reports and even documentary films simply cannot*' [E5].

#### 4.2 Improving later life housing policy in the North East and across England

Northumbria's creative co-productions have been effective in guiding dementia-aware policies with housing providers in England. In 2014, North Tyneside Homes convened dementia-friendly sessions with both Skimstone Arts and Northumbria staff. Linda Herman, North Tyneside Living Service Manager, confirms that *Jack & Jill* changed her '*awareness of the implications of dementia*' for both those living with it and the families, and:

*'North Tyneside Living Service has now become an enabling service that is proactive and focused on assisting older people and those living with Dementia... [a]ll Local Authority Sheltered Housing Schemes in North Tyneside have now become Dementia Friendly Communities through the joint work with our University Colleagues [ ...and] support [for] Housing Officers has been introduced providing them with information and skills needed for them to carry out information sessions with tenants, families, friends, local shops and business'* [E6].

This work continued with ECoN, an advocacy and policy group funded by Newcastle City Council and Newcastle's Clinical Commissioning Groups to place older persons' issues and views at the heart of local policy. Inspired by attending a *Jack & Jill* performance in 2014, ECoN began using creative arts to deliver public engagement events and develop policy [E7]. As Barbara Douglas, Executive Officer of ECoN, explains, '*our engagement with using the arts (in particular drama) stems from our participation as audience in the inaugural performance of "Jack and Jill and the Red Postbox"*' [E7]. In 2014, ECoN acted on this to '*develop a new project around later life housing decisions... using the engagement with the arts at its core*' [E7]. This new method was '*the missing piece of the jigsaw*' in their engagement and policy development approach and led to them commissioning participatory creative workshops through which older people were able to share their experiences, and to support two artist residencies working with older people's health concerns and communication skills [E7]. This led to ECoN's participation in *Doorbells*, which is already having an impact at a strategic level. Douglas explains, '*this project activity is enabling the Elders Council to use the evidence we are gathering as the basis of discussions with Newcastle City Council and housing providers... to challenge the current housing offer and its appropriateness for an ageing demographic*' [E7].

CRE, an independent charity operating nationally since 1986 to improve housing and related services for older people to live independently, have also directly benefitted from Northumbria's performance-led engagement method [E8]. Sue Adams, Chief Executive Officer of CRE, says that the value of *Doorbells* was that it '*set out to particularly engage with groups of people that may be left out of later life housing and ageing discussions, such as those ageing without children, living alone and/or having primary caring responsibilities, but then, interestingly, the production also attracted intergenerational audiences*' [E8]. As a result, working on *Doorbells* is

*'opening up a conversation with the Local Authority around their policies and thinking about housing for a diverse ageing population. A group of older people who have worked in the creative sector all their lives, hence have low pensions who were more likely to live in private rented sector [PRS] homes are now working with a Housing Association, and they are looking at sites where it might be possible to build an innovative, new later life community of older artists, many ageing without children' [E8].*

#### **4.3 Creating a more dementia-friendly community by forming the Jesmond Dementia Action Alliance**

The research and co-production-driven insights of *Jack & Jill* inspired the Jesmond Dementia Action Alliance (JDAA) and shaped the development of the action plan for a Jesmond Dementia Friendly community and its subsequent expansion into a network of 34 local organisations and businesses committed to raising awareness and creating a dementia-friendly environment [E9]. Felicity Mendelson, Newcastle City Counsellor and Chair of the JDAA, explained, *'seeing this performance and understanding its powerful impact on the audience was a catalyst for the group to formally work towards a Jesmond Dementia Friendly community' [E9, p1].* This new Jesmond-based franchise of a national organisation, the Dementia Action Alliance, used *'audience feedback from the Jack and Jill performance to begin to form and agree [an] action plan' [E9, p1].* Mendelson credits the performance as the basis for their operations by demonstrating *'how we could reach out to individuals, organisations and business in the area to increase understanding of dementia and take positive steps/ action that enables people living with dementia to continue to be active and independent citizens' [E9, p1].* Between 2015 and 2019, the JDAA have been able to support dementia friendly training for approximately 600 Jesmond residents and workforces located in the area, including retail, dental, health, leisure, solicitors, and other local services and businesses.

#### **5. Sources to corroborate the impact (indicative maximum of 10 references)**

<b>Ref.</b>	<b>Source of corroboration</b>	<b>Link to claimed impact</b>
E1	Performance touring details – indicative compilation, see especially: Report - Economic Social Research Council Social Science Festival (held September 2013) Evaluation Report <i>Jack &amp; Jill</i> (pages 28-30)	Details of the various performances of the creative co-productions
E2	Bailey et al. preprint paper describing methodology of knowledge exchange with examples of audience feedback from performances of <i>Jack &amp; Jill</i> and <i>Doorbells of Desire</i> (under review with <i>Dementia</i> )	Increased public and practitioner understanding of holistic experience of living with dementia
E3	Audience participation feedback from Peter Kelly, Public Health Director, Stockton Tees	Change in public health public education practice
E4	Testimonial - Gayle Tweed, CEO, Stockton Dementia Friendly	Inspiring local action and dementia friendly services
E5	Testimonial – Mark Hazelwood, CEO, Scottish Partnership for Palliative Care	Change in public engagement and education practices
E6	Testimonial – Linda Herman, North Tyneside Living Service Manager	Change in housing provider resident-engagement and policy formation
E7	Testimonial – Barbara Douglas, Executive Officer, Elders Council of Newcastle (ECoN)	Change in elder care engagement strategies
E8	Testimonial - Sue Adams, Chief Executive Officer, Care and Repair England	Change in public engagement practice
E9	Testimonial – Felicity Mendelson, Chair of Jesmond Dementia Action Alliance (JDAA)	Creation and development of a new community action group comprising 34 local organisations adopting new dementia friendly practices and policies