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HOME/CARE 2021 – Reporting *with not on* people

A project between Contemporary Narratives Lab, Bureau Local
and Coney, funded by City, University of London

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Foreword

This report looks at a 2021 project which was funded by Research England's Higher Education Innovation Fund (HEIF) at City, University of London.

Through the network of Contemporary Narratives Lab (contemporarynarratives.org), we brought together the health inequality team of Bureau Local, part of the Bureau of Investigative Journalism and the internationally recognised interactive theatre makers Coney in order to work with the public and report with, rather than on, people.

We aimed to reimagine reporting by actively bringing community representatives, artists, journalists and researchers together to collaborate on innovative ways to investigate and produce new stories to amplify marginalised voices. This culminated in an online event HOME/CARE in July 2021.

Unlike traditional newsmaking, the integration of journalists, the public and practitioners from the outset of this project put people whose voices would normally be marginalised at the centre of the story as it is developed and created an interactive experience in which the public could not only hear about but play the role of those directly affected by the issues uncovered by the investigation.

The issue

During the Covid-19 pandemic, journalists reported widely on the devastating amount of deaths in care homes and in hospitals.

What received less publicity was home care or domiciliary care in which people receive care in their own homes. These people are some of the most vulnerable people in the country – the elderly, those with physical and learning disabilities and mental health conditions – yet the pandemic's impact on the service and its clients' health was largely overlooked. This was a story that the Bureau Local Health Inequality team started to investigate in early 2021.

<https://www.thebureauinvestigates.com/stories/2021-05-10/revealed-thousands-of-pandemic-deaths-in-home-care>

The Bureau Local's reporter Vicky Gayle was tasked to send Freedom of Information requests to the CQC, England's care regulator, and its equivalent in Scotland, the Care Inspectorate, and compared this to 2019 data published by the ONS. The result of this journalism was the discovery that more than 25,000 people died in the first 12 months of the pandemic, while receiving home care in England, and almost 3,000 died over that period in Scotland. The figures Gayle uncovered suggested that reported deaths increased in England by nearly 50% and in Scotland by 70% between April 2020 and March 2021. This compared with 22% in the general population. Yet while a lack of PPE and slow vaccine take-up amongst care workers may have contributed, deaths from Covid-19 itself were relatively rare – only 8.7% – suggesting that one of the reasons for the rise may have been cuts in care funding and provision.



Background to the project

The Contemporary Narratives Lab began in June 2018 with a small pilot project. It commissioned five groups of artists and journalists working together to create pieces that emerged from their meetings and the notes journalists made during their reporting and the finished articles.

This pilot was a partnership between the Financial Times, People's Palace Projects, Queen Mary University of London and the Battersea Arts Centre. It was funded by a research grant from QMU's Humanities and Social Science collaboration fund.

The works were rapid ones: artists and journalists were given four days of development and rehearsal. The artists then presented their works-in-progress to a [live audience of 40 people at Battersea Arts Centre](#). It went on to inspire similar projects such as the Open Society Foundation's #CreativeStorytellingSA in South Africa and the De Balie Arts Centre's Live Journalism events in Amsterdam

With HOME/CARE however we wanted to do something different and see what would emerge if artist and journalist collaborated over the course of a long-term investigation, from the beginning of the journalist researching the story,

to the culmination of publication and beyond. The other element that was key to this was to involve the public as part of the process. We wanted to provide a knowledge-exchange environment where community stakeholders, journalists, creative practitioners and researchers could come together to test innovative investigation and storytelling practice that would be radically collaborative, rooted in the community, relevant on local and national levels and promote a more empathetic engagement to help the audience process the information both cognitively and emotionally.

With funding from City, University of London and its knowledge exchange HEIF (Higher Education Innovation Fund) award, the original plan for the project was for this to be a face-to-face event in the Battersea Arts Centre. Because of the emergence of the Covid-19 pandemic, we had to adapt to this. Instead we moved to work with Coney, the interactive theatremakers, to produce an online event. Given the subject matter and our desire to interact with the public and service users, this actually proved more useful in terms of this particular investigation.

The project: preparation

We started talking to Bureau Local in early 2020 to conceptualise the idea. Key to it was working with them over a long period of time, and ensuring that journalist, artist and public could work together. There was a long consultation period, first to make sure that the Bureau had a suitable long-term investigation that we could work together on, and second to secure funding from City, University of London.

It was also very important that we understood where each other was coming from. Of course, theatre inspired by real-life events is not new – the ‘living newspaper’ movement in Soviet Russia and the American Federal Theatre Project date back as far as the early 20th century, and there was the rise in verbatim theatre from the 1980s onwards. But reporters often shy away from the word “creativity”, seeing it as alien to their norms of objectivity and truth telling.

In fact, journalism and theatre creatives are closer than they think. Both use narrative forms and language to create representations of reality. Story telling is hugely important in both forms. And many journalists and artists have similar kinds of precarious work conditions and express similar motivations for why they do the work that they do.

Nevertheless, a vital part of the process was creating a common manifesto which acted as a stepping stone for a **practice sharing workshop**. The manifesto, which was developed via a shared Google doc, established common ground around values aims and objectives.. The practice sharing workshop, in which each side presented for 20 minutes, before a 20 minute conversation, built on that foundation to understand each other’s approaches, concerns and priorities.

Bureau Local said that their initial priorities for the project were to:

- See how participatory/co-production could result in affected communities being better served by investigative journalism
- See how fusion of journalism and art can lead to affected communities being better served by investigative journalism
- See how fusion of journalism and art can lead to deeper and more empathetic engagement with the stories and their findings (by all audiences)
- See how fusion of journalism and art can strengthen the potential for top-down impact and critical “agenda-setting” conversation
- By sharing knowledge and ideas and coming together for participatory production, community, artists and journalists learn from each other in ways which strengthen their own respective work

For Coney, the interactive theatre makers their priorities were:

- How can we design something about ‘live’ death and trauma that feels engaging, but respectful and ethical?
- The game / creation should provoke more questions/follow up than answers
- We should start from the perspective of the audience / reader / participant. How is this different from written journalism, but hits the same beats?
- It is important that all team members spend time really understanding the data, the journey, the purpose of the investigation, and the ethical / legal issues involved
- How can this tool empower people who are living through these issues of care at home, as well as those who know very little about the issue?

The project itself

The two core parts that we wanted to explore were 1) journalist and artist working together over a long period, from the investigation phase of the story, and 2) involvement of the public as part of this process and the final events created.

We had regular meetings between Contemporary Narrative Labs, Coney and BL staff, and the artist Rhianna Ilube spoke regularly to Vicky Gayle and Rachel Hamada of the Bureau. Our original idea that the artist would physically be in a newsroom one day a week for ten weeks was not possible because staff were working remotely. However Ilube and Gayle in particular corresponded regularly via Zoom and email as the investigation advanced.

We had also originally planned to hold face-to-face Story Circles to engage the public. Story Circles are a method used by different groups in which you convene small numbers of people who are affected by different dimensions of an issue and create a welcoming space to share first-hand stories. The Bureau had used Story Circles fruitfully in the past. That was not possible with this project because of Covid-19 restrictions but in many ways it turned out to increase access and participation.

Many of the public who were consulted for the story had disabilities and care needs, and came from different parts of the UK. Online discussions meant that they could access the events from their own homes and their voice was heard on more occasions and by a larger number of people.

Coney also worked by incorporating creative experiences into BL outreach activities. On 15 April 2021 the Bureau held an Open Newsroom – a crowdfund chaired by Victoria Macdonald, health and social care editor of Channel 4 News and including panel members such as Dr Zubaida Haque of the Equality Trust, Ellen Clifford, author of *The War on Disabled People* and care worker Carol Thompson to which 108 people signed up. This was followed immediately by Coney’s conceptual ‘Afterparty’, described as ‘a series of short and sparky conversations in the “Coney Zoom Bar”, where you’ll be able to share your own thoughts, experience and wisdom and help us collectively understand some of the inequality issues at play in the health and social care system’

The aim of the afterparty was to get people from different backgrounds and experiences talking through the medium of games and discussion. So for example the personal networking game devised by Coney looked at how to build connections and the subsequent two discussions branded as ‘first’ and ‘second round of drinks’ looked at what people’s reactions to the panels were and what their first experiences were. Coney sought to build a relaxed atmosphere, prefacing the discussion with notes such as:

“Grab yourself a drink from the zoom bar, hot or cold, still or sparkling, caffeinated or not :) and join others in your snug booth (aka the break-out room).

You can choose to chat about whatever you like (or you can choose to turn off your screen and chill if you’d rather).”

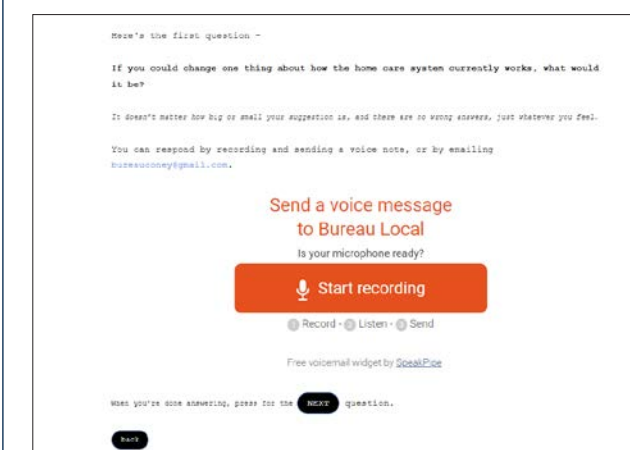
Issues raised in the afterparty informed Coney’s creative input as well as the Bureau’s reporting. In a meeting after the Afterparty, one of the Coney team said:

“After the Afterparty, what I was struck by was that the whole system is broken at every level, how could we communicate that? What if we created some kind of game, in which you play different people from the ground up - you have decisions to make because the system is so awful...and ideally use real people’s stories.”

Care givers and care users were then encouraged to use a specially created online Speakpipe tool (<https://www.speakpipe.com/>) to report their experience of the care system by recording voice notes through a browser. The artist and journalist also shared interviews with those involved in the project as case studies.

<https://twitter.com/bureaulocal/status/1391654362796150784?s=20&t=j-AGm86NghlBjzuGskYnw>

The Speakpipe test created by Coney

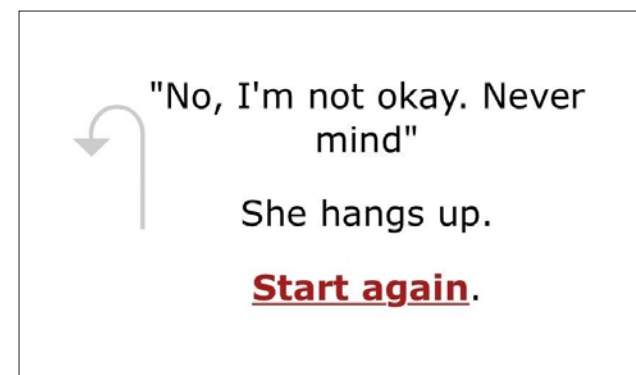


A playtest event and a scratch event were held in which a creative storytelling interactive experience gave the public and policymakers the opportunity to learn through playing. This helped attendees put themselves in the shoes of those affected by the issues investigated by the Bureau by making decisions in safe, creative scenario-based online games.

The first game 'Home-mapping' was designed to highlight people's lack of understanding of what it's like providing care inside other people's homes. Participants were put into breakout rooms in pairs and given a series of tasks where they had to draw a detailed plan of the other's home as described, first drawing without being given any direction using sound, using only physical gestures or the Zoom 'reaction' buttons; second, drawing only with the other person giving yes/no responses, and finally being able to communicate freely before coming back to the main room to explore the difficulties faced.

The second experience was an online game made using Twine (an open-source tool for telling nonlinear, interactive stories) that attendees played individually. In the game, the participant either played the role of a family member trying to sort out care or a carer themselves facing difficult issues. The interactive game provided choices, based on journalistic facts and figures. Using audio recording and yes/no answers, it mimicked the difficult and often circular process that carers and families often go through while trying to ensure that appropriate and affordable care was given.

Image from Twine game recreating the care user/family experience



The third experience SICKNESS OR MISTAKE put participants in pairs in a breakout room where they chose whether to discuss the question 'What happens if you get sick at work?' or 'What happens if you make a mistake at work?', sharing their personal experiences. After the discussion, they were invited to listen to a piece of audio based on journalistic interviews of a care worker answering that question, and to then reflect on the audio.

Image from SICKNESS/MISTAKE experience

Activity 3: SICKNESS or MISTAKE?

You'll be paired up again and put into a breakout room.

Between the two of you, choose between the themes: **SICKNESS or MISTAKE.**

1. If you choose 'SICKNESS', discuss the question:

What happens when you get sick at work / in your studies / life? (Answer based on your real life situation, as far as you're comfortable to do so).

Once you've discussed this question, mute yourselves and [listen to this extract](#) separately.

Then return to your partner to reflect what you've heard.

2. If you choose 'MISTAKE', discuss the question:

When was a time you made a mistake at work / in your studies? (Answer based on your real life situation, as far as you're comfortable to do so)

Once you've discussed this question, mute yourselves and [listen to this extract](#) separately.

Then return to reflect what you've heard.

Finally, participants returned to the main room to reflect on the three different experiences and discuss what had impacted them the most.

What did these teach us?

The project resulted in the online experiences mentioned above, liaison with disability activists and events allowing public and policy makers to learn more about the problems of care within the home during the pandemic. Around 30 people took part in each meeting.

Interactions between journalists and artists – challenges

The Bureau journalists had not worked with artists before, and Coney had not followed a journalistic investigation from the beginning like this, so this was a key part of the preparation for the project in order for it to work successfully. The key issues that were agreed were as follows:

1. Understandings around confidentiality. The artist was given access to transcripts of Bureau Local interviews and to contacts themselves to conduct her own interviews, but it was made clear that nothing could be put in the public domain before the Bureau's investigation was complete and published.

2. Unpredictability of journalistic deadlines. For the artists there was also much to take on board about the way journalists work and how there are often changes in schedule. The Bureau initially planned to publish their investigation in May/June 2021. However, when it became clear, as a result of their requests to the CQC, that the ONS was preparing to release data that would scoop their investigation, the article had to be ready to run much earlier than planned. It also meant that we could not do the event simultaneously with the story publication. The silver lining was that we could reflect on the reaction to the BL's story and for the artist to incorporate it. For journalists, this is a common occurrence, but for the artist that was unexpected.

3. Creativity. The Bureau had not done a project like this before, so there were challenges around how to balance journalistic rigour and objectivity with creative forms of storytelling that still remained true to the investigation. While there was some discomfort in the beginning, the practice sharing workshop and the sustained time period of working together largely overcame these concerns. As one Bureau Local member reflected later: *"Working with individuals whose work is more abstract and creative, does force journalists to think outside of the box for storytelling and also how to present the story after publication when we're trying to boost reach/impact."* [email reflection 2021]

4. Strategising impact. Both sides initially had to work hard to understand what the other was trying to achieve. As one BL member said: *"My takeaway from the project is it has validated why it's so important to consider the impact of an investigation whilst it's in its infancy. This is something Bureau Local focuses on as a core principle of its work anyway, but I think what partly slowed the collaboration down was us, as journalists, not being clear enough on what we wanted the impact of our investigation to be... the outcome has to be considered and clear in my mind at the outset of a project, and that's something I'll now make sure is in the forefront of reporters' minds that I work with, including my own."* [email reflection, 2021]

During the workshop, all partners agreed that the project's biggest impact would be through the engagement of policymakers and working directly with civil society and care workers. From that point on, all partners were well aligned with research impact priorities, focused on either changing people's lives directly (through knowledge, curated experience and critical thinking) or through influencing policy in areas that are in need of radical review.

Creative challenges

While the journalistic investigation itself faced the challenge of being 'scooped' by the Office for National Statistics, for the artists devising the creative events there were various other challenges. First was the understanding around creativity as outlined above.

The artist went through a protracted process, power mapping and carrying out 1-2-1s with Bureau journalists, reading transcripts, interviews and reports and books before devising the workshops, two and solo player game idea, creation and audio script writing.

In creating these experiences, the artist also had to take in mind how to target a wide audience from policy makers to those who did not know the care system, consider aspects of representation and intersectionality. This was often helped by the direct interaction with care givers and care users themselves. Language, particularly the use of the word 'care' also had to be considered, and positionality. Finally, the use of audio in the final games was considered closely as to whether its presentation could result in a manipulation of emotions.

The cumulative events.

Those who took part in the playtest and the scratch events had a positive reaction to them in general. Interviews and chat quotes revealed an increased understanding of home care, the 'privilege' of those who were not caught up in the system and the need for action.

Many were struck by the factual information given in the interactive games – for example the gap between how much care costs versus care workers' pay, their working conditions (particularly those who do overnight care) and the difference in sick pay/leave for the employed versus the self-employed. One participant commented that the audio segments of the interactive games were the most powerful in bringing home these messages.

Participants also commented on the 'mistake' segment of the second game, in which they reflected on mistakes they had made in their own working lives, but which did not have the same 'life or death' quality as outlined for (poorly paid) care workers.

"In our group we all made mistakes, two of us had 'lucky saves' and one did not – but had a good outcome. None related to a life and death situation" [playtest participant]

There was a divide between activists, care workers and those receiving care who were well aware of the personal experience of the system, and those policy makers, academics and journalists who did not. For the first group this was a chance for their voices to be heard in discussion and in the group chat.

“The sad fact is there are those personal assistants [care givers] who want to make it a career choice to make a contribution and don't feel valued.” [playtest participant]

“Even the best carers get overworked because some are nurses and so are working to make ends meet.” [playtest participant]

For the second group, the audio in particular was a powerful tool in making them realise the problems that care workers and those receiving care were often at the mercy of systemic problems across the sector.

“When we listened to the audio, we were struck by how nerve-racking it must be [to do the job of care in the home] and how easy it is to make a mistake but also how there is a bigger mistake – that the system put them in that position to start with. And how systemic problems allow mistakes to trickle down.” [playtest participant]

For some as a result, this made them feel that this was an empowering piece of work which could highlight the need for change in the care system, whose flaws and cuts had been exposed by the pandemic:

“I think that we can build on the project to impact policy makers, by developing the interactive activities further and finding ways to share them at policy conferences and incorporating it within campaigns about social care to drive home the message.” [playtest participant]

“I think the events and activities had an impact on the people who attended, and each person learned something new about social care. People expressed emotions of anger, shock, and wanting to make a change.” [playtest participant]

However, some of those who took part felt there needed to be more of an emphasis on action for those participating in it to be able to do following the event:

“We feel there needs to be more of an invitation into the process and to not see it as a ‘game’ to jump into the life of someone...Also it feels like having no positive ending was something that should change. And to have ways we can be shocked and saddened but, in a way, we can participate in systemic change.” [playtest participant]

One other challenge that emerged on the day of the playtest was that not all of those participating could move or draw for the first ‘game’ and therefore moderation had to be made. It meant that organisers had to consider that just because this was an online event which in general was easier for those with disabilities to attend, there could still be issues that had been overlooked.

Both journalists and artists, however, felt that it had been a fruitful collaboration which they were keen to develop beyond the scratch event and that the lessons learned from this primary development could be used further.

“The main impact of this I'd say is it gave people an opportunity to share their experiences and perspective which can't be underestimated, particularly because social care happens in a person's home and it's very easy to feel downtrodden by the system and isolated; not knowing what other families or individuals are thinking or handling similar situations to you.” [journalist, email reflection 2021]

“Before starting this project, I did not know anything about the state of social care in the UK, or the vital work that the Bureau of Investigative Journalism does. Working on the project has been transformational to me. I have had the pleasure to interview many journalists and disabled activists, as well as read unpublished interview transcripts and explore data relating to social care.” [artist, email reflection 2021]

Finally, the engagement with the public as part of an ongoing process was key here: many of those who came to the first Open Newsroom returned to the After Party, Playtest and Scratch or took part in the Speakpipe. This ongoing conversation meant that it was true to the aims of the project to report with, and not on, this particular community. The use of interviews and their data in different ways also helped this feel like communication of equals rather than the traditional journalist-case study relationship in which a journalist interviews and then moulds the responses for one story. As one of the investigative journalists said:

“The audio played in the final activity were transcripts of interviews I'd done as part of the journalism that were then read aloud by an actor. It meant those perspectives were heard by another audience, some of which might not have had any direct experience of domiciliary care and gave another outlet for our research material. The ability for it to be ...used again is impactful because those individuals get to see how valuable their testimony and expertise is. We've not just used their quotes for colour in an article; those opinions have informed follow-on projects.” [journalist, email reflection 2021]

Conclusion

Digital technology has multiplied the sources and channels of dissemination of information produced about the present time. It has allowed different types of storytellers - artists, researchers, journalists or others - access to similar tools to produce their outputs. However, these different groups named above have mostly remained working in their own fields, battling disruptions brought about by the (new) digital information environment.

The HOME/CARE project confirmed that there is a lot that can be learned between storytellers of different sectors through direct collaboration about how to investigate new stories, engage audiences and shape the pathways to impact. One of the most important areas in this is working with relevant communities from the outset. But community engagement practice is in a rapid development stage, as digital technologies also change the way that people communicate within their own communities. This increases the need for curated/facilitated spaces of collaboration where the exchange about storytelling practice is produced fruitfully.

In this project, fruitful connections happened across the media and creative sectors. This is crucial as this fragmented information environment produces social divisions, some of which are purely based on narrative, and explore audience vulnerabilities, such as confirmation bias and lack of diverse knowledge sources. In this short project, a completely new issue about the impact of the pandemic (the structural and pandemic-related shortcomings of the social care system in providing care in homes) has been revealed to an audience beyond the community experiencing the problem. This process has also helped those affected to formulate the problem to an external audience (policy makers and other people in related circumstances) in a way that could be communicated empathetically.

This has been done through multiple media types: online article, online game, online reporting tool and curated online events that provided different opportunities to express and discuss the issues from multiple perspectives. The community has been part of the investigation, construction of the story and had direct engagement with the news/theatre audience. During the final event, those taking part reported deep levels of empathetic engagement in those events, shock at the revelation of the cases, questioning of their own perceptions, behaviours and opinions on current policies, including planned changes to their own lives.

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