**Why you should read this article:**

- To recognise the challenges in transferring knowledge to people from ethnic minority and disadvantaged groups
- To learn more about using storytelling to share research knowledge
- To understand how to create composite digital stories from qualitative research findings

# Cocreating composite digital stories to share research findings with minority ethnic and disadvantaged communities: a reflective guide

**Louise Condon, Prue Thimbleby, Denise Barry et al**

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## Abstract

**Background** Researchers have an ethical responsibility to share their findings with their studies' participants and those who can influence policy and practice. Storytelling is an arts-based approach increasingly used in nursing research to share findings, but little has been written about how to use the approach in participatory research involving people from minority ethnic and socioeconomically disadvantaged communities.

**Aim** To present a guide to cocreating digital stories to share research findings with minority ethnic and socioeconomically disadvantaged communities.

**Discussion** The authors and peer researchers from minority communities used a rigorous method to cocreate composite digital stories from their qualitative research's findings. The authors describe and reflect on the stages of the creative process, focusing on the actions required before, at and after the collaborative workshop.

**Conclusion** A rigorous process is required to create composite, naturalistic digital stories that authentically reflect research findings and are accessible to listeners.

**Implications for practice** Digital stories are an engaging, feasible and equitable way to share research findings with minority ethnic and disadvantaged communities.

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## Keywords

dissemination, knowledge transfer, methodology, narrative, qualitative research, research, research methods, storytelling, study participation, substance misuse

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## Introduction

Healthcare researchers have an ethical responsibility to share their findings with their studies' participants and those who can influence policy and practice to inform their actions (Jull et al 2017). Increasingly, researchers are using creative and innovative methods to do this in an engaging and accessible way (Boydell et al 2012).

Storytelling is a powerful arts-based way to disseminate research, as it conveys people's experiences naturalistically and engages the listener's emotions (Rieger et al 2018, Park et al 2021). Digital stories often consist of still images combined with a narrated soundtrack (Kajder et al 2005); these are then made available on a website or other digital platform, and accessed using smartphones or other internet-capable devices.

Digital stories are individual or composite verbal narratives based on people's firsthand experiences. In an individual story, one person narrates the story of their own experience (Archibald et al 2018). Composite stories integrate several sources into a single story that reflects the participants' experiences while protecting their anonymity (Archibald et al 2018); the aim is to convey generic truths in a way that communicates quickly and effectively to any audience (McCall et al 2019).

Qualitative research data can inform or be part of a digital story, but the literature does not describe very well the processes necessary for cocreating such stories (Archibald et al 2021).

In this article we will therefore describe a method for cocreating composite digital stories to disseminate research findings to non-academic audiences.

## Background

'Telling our own stories: a qualitative study of alcohol use and harm among Travellers, Roma and Gypsies' (TaSTe) was a participatory research study we conducted into UK minority ethnic and cultural minority communities' experiences of alcohol use and harm (Condon et al 2024). TaSTe considered the potentially sensitive subject of 'how people like us drink', exploring the social norms regarding drinking among men and women in these communities who are at least 16 years old. The four communities involved were Liveaboard Boaters, Irish Travellers, Roma and Gypsies, who share a nomadic background, have high healthcare needs, and experience barriers to using healthcare services (Greenfields and Lowe 2013, House of Commons Women and Equalities Committee 2019).

Involving people from groups who are traditionally excluded from research helps to shift power dynamics, facilitating relationship-building between institutions and communities (Gillibrand et al 2023). The sharing of research findings with participants is also compatible with the ethos of participatory research, as both aim for democracy in generating knowledge (Jull et al 2017).

We therefore asked members of these communities to work as peer researchers within the TaSTe research team in equal partnership with the university researchers. The peer researchers were involved at all stages of the study from design to dissemination. The peer researchers helped the study, as they could establish trust with participants and then extend this to the wider research team (Condon et al 2022).

We decided to use creative methods to share TaSTe's findings with the communities, as this would increase its participatory nature and optimise its transferability. It was also culturally relevant to use stories to disseminate the findings as Gypsies, Roma, Irish Travellers and Liveaboard Boaters are all highly sociable and some have traditions of storytelling (Dumitrescu 2010); it was also preferable to disseminate the findings orally, as many Gypsies and Travellers have low levels of literacy (House of Commons Women and Equalities Committee 2019).

We developed a composite digital story for each of the four ethnic/cultural groups who participated in our study. We based the stories on TaSTe's main findings, with the most prominent themes from each community forming the basis of the corresponding narrative (McCall et al 2019). Each story lasted three to five minutes and was accompanied by still images.

We present below a reflective guide to creating digital stories for multidisciplinary research teams.

## Method

We designed TaSTe's cocreation process to provide authentic, realistic, digital stories based on qualitative research data. It was important to follow a methodologically rigorous process to ensure our composite stories were validly based on TaSTe's findings. We based ours on that of the Royal College of Physicians (RCP) (2017), which has the advantage of preserving participants' confidentiality when synthesising findings from multiple interviews to provide comprehensive insight – breaking confidentiality is a risk in small communities where members are closely interrelated in families and extended social networks. We also developed the RCP's (2017) method further for use with minority ethnic and socioeconomically disadvantaged communities.

The TaSTe process involved:

- 26 semi-structured interviews with Roma, Gypsies, Irish Travellers and Liveaboard Boaters to gather the data.
- The Framework method (Ritchie et al 2014) to analyse them.
- The cocreation of four composite digital stories based on the main findings from each community. This involved four workshops led by one of the authors (PT), who is a professional story facilitator with a master's degree in community arts practice.

Table 1 provides an overview of the process, showing the actions we took before, at and after each workshop.

### Before the workshops

Before each workshop we shared with the storyteller the themes that had emerged from the analysis of the semi-structured interviews (Condon et al 2024) (Figure 1). We also selected quotes that exemplified the themes we selected and sent them to the story facilitator, so she could see what stood out and what might make a good story.

Several Liveaboard Boaters talked about issues concerning alcohol and safety. For example, one young woman described difficulties in boarding her boat when returning home drunk after a night out:

*'I had a gangplank at the time. I was on the Thames. And I was quite far away from the bank. And I had to take two or three attempts to get up this gangplank. I was like: "Look, abort, abort, get back, get back." And I remember the next morning thinking: "Yes, you can't do that again. That was really daft and you could have got yourself in trouble there."'*

## Key points

- This article presents a reflective guide to the process of creating composite digital stories from qualitative research findings
- The authors aim to give a voice to communities by cocreating research outputs
- A rigorous process is needed to reliably share knowledge from research with minority ethnic and disadvantaged communities

**Table 1. Overview of TaSTe's cocreation process**

| Before a workshop | At a workshop | After a workshop |
|---|---|---|
| » The research team conducts thematic analysis of the qualitative research data to identify the main themes to present in the digital stories<br>» The research team prepares a summary of the main themes with illustrative quotations and shares these with story facilitator<br>» The story facilitator familiarises herself with the research findings, and notes possible stories in the illustrative quotations<br>» The story facilitator prepares materials to bring to the workshop, including recording equipment and pens or paper for group work | » The story facilitator and the research team cocreate a persona and life story for each ethnic/cultural group<br>» The story facilitator and the research team agree the points to highlight in each composite story. They do this based on the study's findings and the themes identified for each community<br>» The story facilitator works with the research team to shape the story – for example, whether it should be chronological or use linked events<br>» The story facilitator coaches each peer researcher to 'become' the persona. The researcher is recorded as they tell the story for their community | » The story facilitator shapes the story into something that flows well by editing the recording, cutting out any unnecessary material and reordering the narrative where necessary<br>» The research team listens to the recording and provides feedback to the story facilitator. Small changes can be made to the story, such as deleting an incorrect word<br>» The peer researchers check whether the story is culturally acceptable to their communities<br>» An artist is commissioned by the research lead to illustrate the stories |

It was therefore apparent that this was a vivid, evidence-based point to bring out in the final story.

To assist in imaginatively creating a persona to tell the story, the facilitator compiled a small selection of publicly available photographs of community members that the research team could view and focus on at the workshop.

## At the workshops

At each workshop the research team developed the composite stories that the peer researcher from the relevant community would tell. The peer researcher, the project lead (LC), the story facilitator (PT) and at least two other members of the research team attended each workshop, which lasted around three hours. PT led each workshop. Those who could meet in person did so; the others attended virtually using the Zoom online meeting platform. Three of the peer researchers used Zoom; the fourth came in person.

Each workshop started with PT sharing the images she had compiled. The aim was for the workshop to choose the most useful and realistic image, which would be the focus in developing the composite persona. This was not always straightforward: some images had to be discarded, as the peer researcher knew the individuals depicted or felt they were stereotypical or inaccurate portrayals of their communities; if necessary, the team members at the workshop searched for a new image.

Once an image was selected, the members of the workshop were all encouraged to create a character based on it, who the peer researcher would name. They then developed a timeline, setting out the character's major life events from birth up to the present, typically arranging them as a story arc with a disruptive event, followed by crisis and resolution (Reagan et al 2016). They also considered how to include alcohol use or harm on the timeline.

For example, the Roma story featured migration to the UK followed by difficulties in adjusting to a new lifestyle. It ended with the character successfully seeking help for problematic drinking.

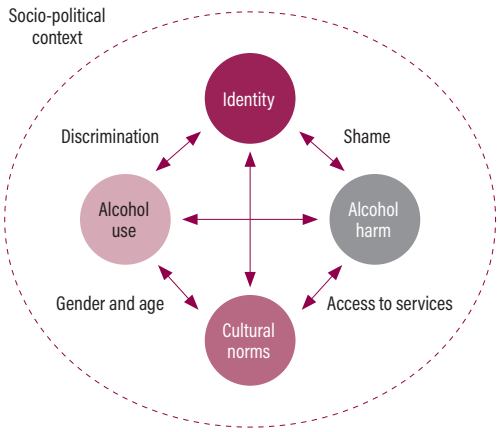
The group then discussed each character's timeline, to ensure it was realistic and congruent with the TaSTe study's findings. Input from the peer researcher was vital here, as the life events that the academic researchers imagined could differ greatly from the peer researchers' real-world experiences – for example, one researcher imagined that the Roma character would have one sibling when it was more realistic to think they had a larger family.

PT then suggested a potential story based on these discussions that was fictional but realistic for each community. The story did not have to be chronological. The Gypsy story, for example, used an approach that evolved organically from the discussions and the themes selected for inclusion and featured three life events based on the themes from the TaSTe study:

1. 'Discrimination': being turned away from a restaurant.
2. 'Cultural norms' of drinking responsibly: putting partner and family first.
3. 'Shame': childhood feelings about parental alcohol use and harm.

Once the workshop had agreed the structure of each persona's story, a graph for the character was constructed to act as an aide memoire for the narrator, as

**Figure 1. Main themes identified for use in composite digital stories**



they would improvise the story and not use a script. The graph was annotated with the story's main events and traced its ups and downs.

PT then encouraged the peer researcher to tell the story naturalistically. When they felt ready, they told the story in the first person from the perspective of its character. PT audio-recorded the story.

Table 2 presents brief biographies for the personae created and the themes covered in their stories.

### After the workshops

After each workshop, PT listened to the audio recording of the story then edited it to make the story flow well and last between two and four minutes. The peer researcher then checked the edited version and PT made any changes necessary to ensure it was culturally acceptable and authentically reflected the study's findings. For example, the peer researcher felt references in the Traveller story to exact amounts of money limited representativity so were removed; an inaccurate reference to social services in the Boater story was also cut. The whole team listened to the final versions to agree their suitability.

To enhance the digital stories for listeners, they were then sent to an artist to illustrate them with line drawings. It was agreed that animating the script would distract from the audio and was unnecessary for telling the story (Kajder et al 2005), so we asked the artist to create a few still images that portrayed only significant events in each story.

Each peer researcher watched the illustrated, digital story. If they considered an image to be too negative or stereotypical, it was removed or replaced. We repeated this until they deemed the story to be culturally realistic and acceptable.

## Discussion

There is often a gap in knowledge between Gypsies, Roma, Liveaboard Boaters and Irish Travellers and the people who provide them with health services. Adopting an arts-based approach in qualitative research provides an opportunity for enhanced engagement and makes research accessible beyond academia (Boydell et al 2012). Digital stories are a way of bridging this gap that fosters empathy between audiences and people who are frequently seen negatively as 'other' and different from the general population (Crew 2024) – the stories are glimpses into their lives, within their specific socio-emotional and socio-cultural contexts (Quah et al 2023).

Participatory research and knowledge transfer share the aim of disrupting the division between those who conduct research and those they research (Jull et al 2017). If research teams include peer researchers who are members of the communities being studied, that changes the power dynamic and aids in the transfer of knowledge; it also gives academic researchers opportunities to examine and question their own tacit knowledge and understanding of cultural practices.

**Table 2. Biographies of the story personae and the themes**

| Group | Persona | Biography of persona | Themes covered |
|---|---|---|---|
| Gypsy | Susan | A woman whose father was dependent on alcohol but whose husband drinks responsibly | » Cultural norms of drinking<br>» Impact of parents' drinking on children<br>» Shame about drinking<br>» Discrimination |
| Roma | Kveta | A woman who had migrated to the UK with her family, then had some problems with alcohol as a teenager | » Cultural norms of drinking<br>» Impact of migration on drinking<br>» Shame about drinking<br>» Seeking help for problematic drinking |
| Irish Traveller | John | A man whose daughter is getting married, who had experienced alcohol harm among family and friends | » Cultural norms of drinking<br>» Impact of parents' drinking on children<br>» Discrimination<br>» Seeking help for problematic drinking |
| Liveaboard Boater | Ivy | A woman who moved to the Boater community and, following bereavement, accessed health services for dependent drinking | » Mental health<br>» Injury<br>» Bereavement<br>» Seeking help for problematic drinking |

In TaSTE, we engaged in self-confrontation and reflection, questioning our knowledge of the communities and how they contextualised alcohol use and harm. This continued throughout the research and informed the cocreation of our digital stories.

High levels of shame about dependent drinking in Gypsy, Roma and Traveller communities (Figure 1) means it is unlikely any member of these communities would tell their own story, which is why we created composite stories. It was also important because of this stigma to put participants' cultural and social world views at the centre of each story (Parsons et al 2017).

We began from a position of 'how people like us drink' and explored this in terms of cultural identity, gender and age. This helped the peer researchers to talk to participants about issues rarely discussed in their communities, such as women's drinking, the impact on children of parental drinking and links with mental health.

A finding we had not anticipated was the unlawful discrimination encountered by Gypsies and Travellers at pubs and restaurants, including being refused service. Subtleties emerged, such as Roma encountering prejudice when drinking outside the home in their countries of origin but not in the UK, where they are rarely identified as a stigmatised ethnicity (Grill 2018). These contentious themes were narrated by the peer researchers in the digital stories.

Boydell et al (2012) raise three issues to consider when engaging in arts-based dissemination of knowledge:

1. How to judge the quality of a project.
2. The need for critical discussions about its impact.
3. The ethical challenges involved in this work.

Ethical concerns were at the forefront of TaSTe, because of the studied populations' vulnerability in terms of health equity, education and employment, as well as the exceptional levels of hate crime that Gypsies and Irish Travellers experience (James 2015, Traveller Movement 2017). A paradox of alcohol harm is that when people of different socioeconomic status consume similar amounts of alcohol, the least advantaged are most adversely affected (Bellis et al 2016).

We took care when devising the stories not to further stigmatise the communities we were studying. This meant checking that the narratives and accompanying images did not contribute to stereotypes, with peer researchers taking the lead in judging acceptability.

Peer researchers perform a difficult role in bridging the communication gap between their communities and university researchers, and in making judgements as representatives of their own cultural or ethnic group (Condon et al 2022). This complex responsibility was compounded in TaSTe as the peer researchers were also the narrators of the digital stories.

If members of a community share research findings, this may reduce the community's latent resistance to public health messages (McCall et al 2019). Our digital stories included such messages, including that people dependent on alcohol should seek help and that parental drinking has adverse impacts on children. The stories are available on the Alcohol Change UK website (Alcohol Change UK 2023).

Funders increasingly emphasise the impact of research, rightly demanding that the public benefits from their investments (Reed et al 2021). Greater focus on the evaluation of interventions aimed at translating knowledge to healthcare providers, managers and policymakers results in less focus on service users, especially those from minority ethnic and socioeconomically disadvantaged groups (Chapman et al 2020). We were fortunate that our funders not only recognised the opportunities of an arts-based approach to knowledge translation, they also understood the associated additional costs.

It is important in cross-cultural research to show that participants receive something

in return for taking part (Liamputtong 2010). This could be the translation of knowledge to those who have the authority and power to change polices and practice or change locally.

Too often, researchers are accused of involving people in their studies but that when their research is over 'nothing has changed' for the participants; this is particularly relevant for Gypsies and Travellers, who experience persistent disadvantage and discrimination (House of Commons Women and Equalities Committee 2019).

More knowledge is needed about the effectiveness of dissemination strategies aimed at healthcare users and their caregivers in arts-based research (Boydell et al 2012, McCall et al 2019). Many research teams aim to do this, but the reality is that this is challenging at the end of a project, as some staff may have moved to other projects and the funding deadline is near.

## Conclusion

We aimed to give voice to communities by creating collaborative, accessible research outputs. Knowledge translation needs to be easily accessible and culturally acceptable when conducting research with people from minority ethnic and disadvantaged communities.

Digital stories can be customised to convey research findings accurately, acceptably and accessibly to members of minority ethnic and marginalised communities. We developed digital stories to convey the findings of our research in an accessible and acceptable way to participating communities, practitioners and policymakers. We have discussed in this article how we developed stories derived from our findings, and identified the practical and ethical challenges we encountered.

It is important that you use a rigorous process that authentically and accurately reflects your research's main themes when creating composite digital stories to convey your findings. We have demonstrated that the process we used was rigorous and ensured the digital stories we produced were linked to the themes we identified in our study. Amalgamating multiple participants' experiences into a composite narrative also protected their confidentiality, while remaining true to the qualitative findings.

Our completed digital stories have been presented at a science festival and other public events, as well as at feedback events for communities, local authorities, Alcohol Change UK and other relevant stakeholders. We anticipate they will be used in education, healthcare and policy development, and will increase people's understanding of alcohol use and harm in minority ethnic and disadvantaged communities.

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