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Social Distancing while Blind: A Co-Designed COVID-19 Rapid Response Comic

COMIC

ERNESTO PRIEGO 



ABSTRACT

According to the Royal National Institute for the Blind (RNIB), more than two million people have sight loss and about 350,000 people are registered blind or partially sighted in the UK (RNIB 2019). Information about social distancing measures in the UK has been mainly visual and therefore poses specific challenges for visually impaired persons. We present a COVID-19 rapid response two-page comic created employing co-design methods adapting an interview with a visually impaired person and their experience of the communication of social distancing measures during the early stages of the first COVID-19 pandemic UK lockdown between March and April 2020.

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KEYWORDS:

COVID-19; codesign; accessibility; participatory design; sight loss; comics studies; graphic medicine

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CONTEXT

It is not an overstatement that COVID-19 is ‘a new illness on a scale not seen in living memory’ (Rayner, Lokugamage and Molokhia, 2020). The Royal National Institute for the Blind (RNIB) has campaigned since the first 2020 lockdown began in the UK for accessible COVID-19 information, ‘so blind and partially sighted people have access to the same information at the same time as everyone else. Unfortunately, this hasn’t always been the case, with notable examples like the letter sent to those judged to be ‘extremely vulnerable’ to coronavirus not available in accessible formats’ (RNIB 2020).

Indeed, research by the RNIB published in May 2020 found that ‘social distancing is near-impossible for many blind and partially sighted people’, with 74% of respondents reporting they were either ‘very or quite concerned about getting access to food’ while 21% of people reported ‘they had had to ration food’ (RNIB 2020).

At the time of writing this, as the UK eases the 2021 lockdown, social distancing measures have remained in place, and are likely to have enhanced or added new challenges to visually impaired and blind people. (Similarly, any changes to the government guidance is likely to be challenging too). There is still a need for further research and coverage of the experience of the COVID-19 pandemic, lockdown and/or social distancing measures for blind or visually impaired people, both in research and different media, including comics.

Graphic medicine has been considered a valid medical information tool beyond comics scholarship circles to include medical journals (for example, Gray & Back 2020). Graphic medicine proponents argue that, comics can provide ‘new insights into the personal experience of illness’ (Green & Myers 2010), and previous work has looked into the role of graphic medicine linking graphic narratives to medical education, narrative medicine and/or the medical humanities (Farthing & Priego 2016; Priego & Farthing 2020). In the context of the COVID-19 pandemic, there are precedents of comics created as ‘communication aids [...] to promote rapid sharing of communication skills with clinicians across diverse disciplines’ (Gray & Back 2020).

The development of the comic presented here was motivated by the creative brief from the United Nations, particularly addressing the ‘Key Message’ of ‘kindness contagion’, which was to have the ‘tone: common humanity, mental health, caring, solidarity, empowerment, destigmatisation, inclusive, joy’ (United Nations 2020) as well as the RNIB’s #InfoForAll campaign (RNIB 2020). The two-page comic we present below (*Figures 1* and *2*) sought to make a rapid original contribution within the domain of graphic medicine to the medical and public debates

around COVID-19 containment measures and how patients experience them in the early stages of the first UK lockdown in the spring of 2020.

METHODS

The comic was created following user-centred, interactive narrative design methods involving co-design techniques. The study, development and use of comics in the field of Interaction Design is well documented and takes a variety of forms. These include, but are not limited to, communicating personas and scenarios, as a component of participatory design, in lab-based studies, as a means to make ‘research results a more engaging and enticing experience quickly and efficiently’ (Haughney 2008) and as ‘a powerful and valuable medium for representing research through design’ (Dykes et al. 2016).

With an increasingly aging population, care, health and wellness have also been, needless to say, the focus of much research and development by the Interaction Design community (Chen et al. 2013). ‘In the context of disability’, Wilson et al. remind us, ‘codesign is consistent with the changes in attitudes that have occurred in the last 30 years, particularly the uptake of the social model of disability (Oliver 1996). This model views disability as arising not from the medical impairment, but from disabling barriers and attitudes within society.’ Because ‘codesign techniques encourage designers and end-users to work together in the creation of design solutions’, this technique can contribute to ‘blurring the boundaries between traditional stakeholder roles in user-centred design,’ and therefore can place people with disabilities should be the heart of the design process (Wilson et al. 2015).

The development of the comic followed an iterative process composed of the following sequential steps.

1. Informed Consent in accessible format
2. Audio-recorded semi-structured interviews
3. Qualitative data analysis
4. Co-design workshop sessions – script
5. Co-design workshop sessions – art, layout, breakdowns
6. Draft testing with participant via accessible, descriptive means
7. Qualitative data analysis
8. Co-design workshop sessions
9. Final drafting with participant via accessible, descriptive means for final approval.

Due to the emergency situation in the first months of the COVID-19 pandemic, the comic was meant to be produced and released rapidly. However, further work needs to be done to continue testing the comic with different stakeholders.

COMMUNITY MATTERS

PLEASE BE KIND

BASED ON CONVERSATIONS WITH HUGH HUDDY
WRITTEN AND ILLUSTRATED BY FRANCISCO DE LA MORA
PROJECT LEAD & EDITOR ERNESTO PRIEGO

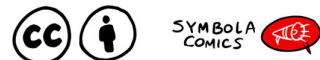
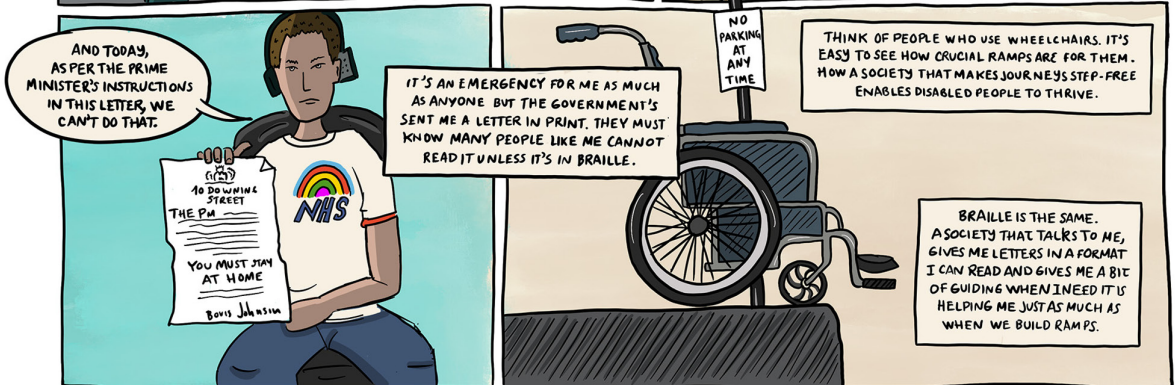
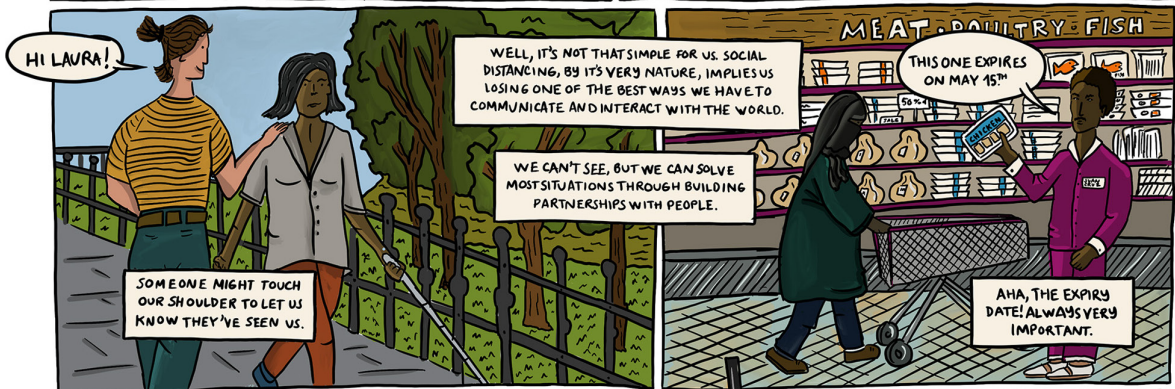


Figure 1 Priego, de la Mora, & Huddy, (2020) Community Matters: Please Be Kind. (A COVID-19 Response Comic), page 1 of 2. CC-BY.

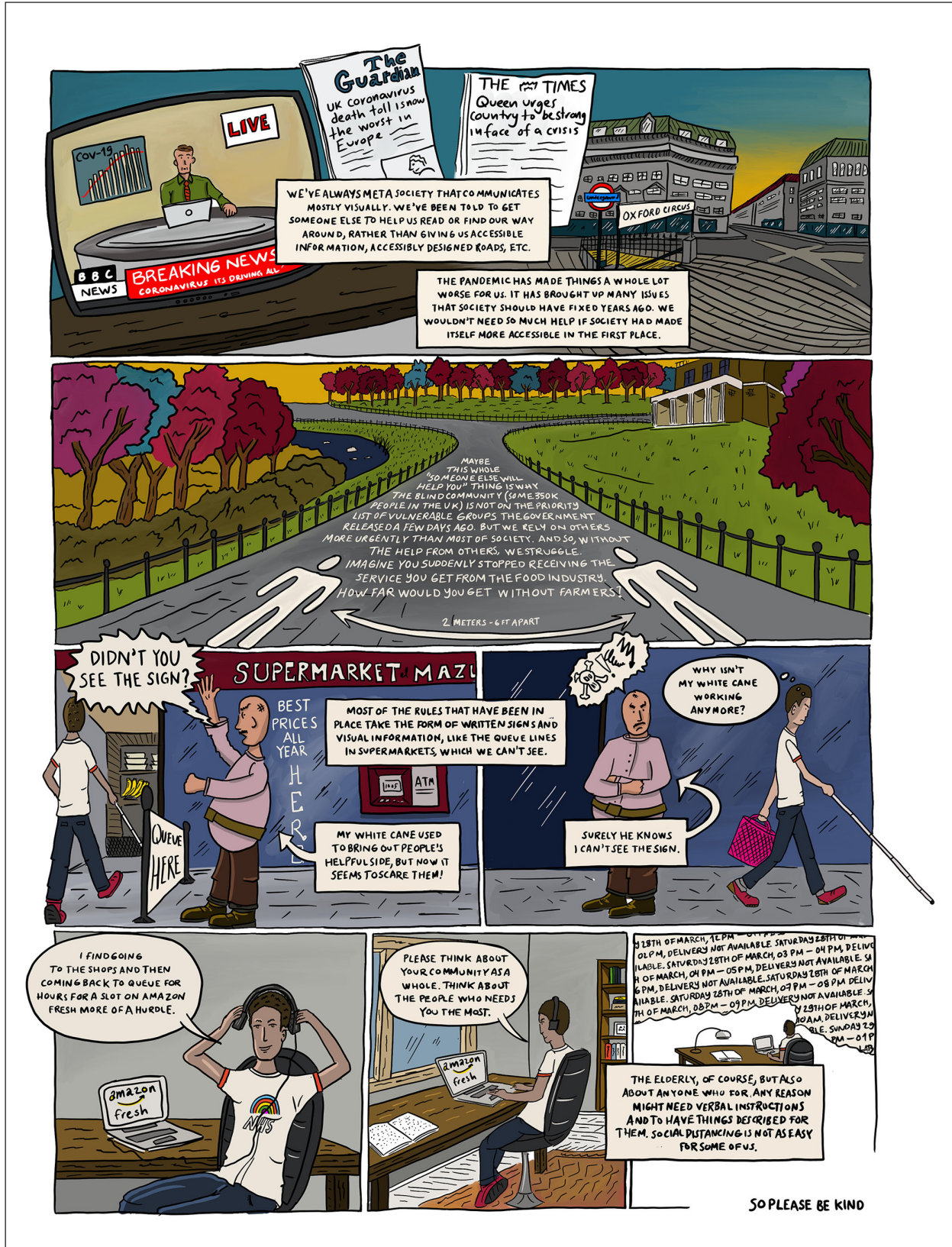


Figure 2 Priego, de la Mora, & Huddy, (2020) Community Matters: Please Be Kind. (A COVID-19 Response Comic), page 2 of 2. CC-BY.

FINAL CONSIDERATIONS

In co-designing this rapid response comic with a visually impaired co-designer and co-author the team recognised it was working ‘with asymmetry’, rather than attempting symmetry (Bennett and Rosner 2019). As a comic, it is idiosyncratic and subjective; it is based on the individual experiences of a blind person, and it does not intend to represent everyone’s experiences nor to make any generalisations (see also Wilkins and Priego 2020). Principles of biographical and documentary comics, and autoethnography and autofiction, were followed (El Refaie 2010; Méndez 2013). Ethical guidelines were followed and written co-design and co-authorship consent was signed by the three co-authors of the comic.

As an evidently visual medium comics present significant accessibility challenges for those with reading and/or visual disabilities or neurodiversity. Accessibility is an essential requirement in design work. A descriptive alt-text of the comic was produced for social media sharing. Future work includes the inclusion of detailed alt-text for the creation of a PDF with machine-readable text so it can be read-aloud (Priego, de la Mora, & Huddy 2020).

We hope the comic makes a contribution to further discussion and foster awareness that blind and/or visually impaired people have experienced the pandemic in specific ways that are distinct. The intention has been to follow the United Nations’ brief of reaching a tone of common humanity, care solidarity, empowerment, destigmatisation and inclusivity, while giving voice to a blind person and co-designing the comic with them. As everyone is different and has different needs, it remains essential that we are aware that social distancing measures and their signalling will be experienced differently, and in many cases may not even be visible at all to others. We propose that user-centred methods and co-design techniques provide a useful framework to place people at the heart of their own graphic medicine stories, and an essential one to at least make our best to represent individual stories more accurately, particularly when those stories are told in a medium they themselves get to access in a different way.

ACKNOWLEDGEMENTS

The author would like to thank Francisco de la Mora and Hugh Huddy for their participation and kind permission for me to present the comic as an academic output in this form.

As credited above, the comic presented here was co-designed as part of research work led by the author, and is based on conversations with Hugh Huddy about his experiences. Francisco de la Mora was the artist and writer

of the comic. The author would also like to thank Angelica Curzi for producing the alt-text for sharing the comic’s images online.

The author would also like to thank Dr Simon Grennan and Dr Peter Wilkins. Our previous work together in the Parables of Care: Creative Responses to Dementia Care project (2017–2020) was an essential step leading to the present work.


ETHICS AND CONSENT

This work was conducted independently and has no official connection with the United Nations nor the RNIB. It was a citizen initiative in response to COVID-19 partly inspired by said campaigns. Consent forms have been submitted to the journal.

COMPETING INTERESTS

The author has no competing interests to declare.

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