In the picture or behind glass? Describing facilitators, barriers and practices in people with aphasia accessing and participating in Museums and Art Galleries.

Jayne Lindsay, Madeline Cruice and Jane Marshall. Division of Language and Communication Science. City, University of London.

The aim of this Public-Patient Involvement activity was to provide an informed rationale for - and help shape the design of - a large study that will investigate the experience of people with aphasia in accessing and participating in museums and art galleries, and provision for them within this part of the cultural sector.

Successful living with aphasia is linked to inclusion in enjoyable interactions, activities and contexts; however PWA engage in fewer social and leisure activities, and these may be less satisfying [1,2,3]. PWA attend museums and galleries less than their peers do [3], despite the popularity of these spaces with the public and the role of the arts in enhancing life [4,5]. For disabled people, museums and galleries are complicated places, with (e.g.) barriers to physical access, information and events communication encountered [6]. There is a very small literature about activity with and for PWA in museums and galleries, with 2 papers in peer-reviewed journals, and 4 other sources [7-12].

PPI activity was carried out by the first author from March - July 2021. It involved 4 PWA; an SLT and SLTA from aphasia charities; and 2 members of museum and art gallery staff working in access and inclusion. All PWA had been on post-stroke visits alone or with family or friends; one person who had severe aphasia went with stroke and aphasia groups too. The activity mainly comprised one-to-one 1-hour videocalls or phone calls (one to each of the staff, and two to each PWA) about aspects of experience and practice in museum and gallery visits for PWA. Everyone contributed ideas and practical advice about the design of the large study, e.g. on proposed surveys and 'walking interviews'. There was a 1:1 'sense-checking' visit to a museum or gallery for 2 PWA, once Covid-19 guidance allowed. Activity with PWA incorporated communication-friendly resources.

In the calls with the PWA and SLT/SLTA particularly, barriers and facilitators to PWA accessing and participating in these cultural spaces were discussed. The 4 PWA identified 61 barriers and 38 facilitators in post-stroke visits by themselves or with family and friends. Some barriers were encountered pre-visit, e.g. hard-to-read websites. More were on-site, including physical barriers (e.g. noise, affecting concentration); informational (maps with inaccessible graphics and words); communicative (staff unable to communicate with PWA); and those related to knowledge and attitudes (no adjustments for PWA). One PWA, who worked in a major gallery pre-stroke, identified organisational barriers: e.g. 'no re-entry' exhibitions, preventing them leaving the space for restorative breaks. Three PWA reported that they attended museums and galleries less post-stroke, given the difficulties, and were saddened by this. None of the 4 PWA attended tours or talks, seen as inaccessible. The two 'sense-checking' visits included inspection of barriers in-situ, deepening understanding of some already identified. Being on-site revealed additional ones, including those related to how displays are presented.

What was apparent was that PWA wanted to visit museums and galleries more often; for two people, this was intertwined with their identities. SLT staff noted that aphasia group visits were popular. There was overlap between the barriers they and PWA identified, e.g. limited staff understanding of aphasia. They described their work before and during visits to support museum and gallery staff and PWA. The 2 museum and gallery staff members reported that knowledge of aphasia in their sector is likely very limited. It was clear, however, that providing SLT-facilitated experiences and aphasia group visits is not enough overall: PWA want accessible visits and events at other times too. This desire for flexibility was echoed by the museum staff member in explaining their organisation's ongoing work to create an accessible environment. Both museum and gallery staff noted the potential for changes made for people with other communication and/or sensory disabilities to be extended to PWA. The PWA also reported facilitators, including the willingness of museum and gallery staff to try to help them. The sense-checking visits revealed some changes, for Covid-19 management, that benefited PWA: e.g. restricted visitor numbers creating quiet, uncrowded spaces.

The insights and practical advice contributed importantly to a successful application by the first author for a City, University of London, School of Health Sciences Doctoral Studentship, starting October 2021. We thank BAS for the Seed Fund Award that supported this PPI activity.

References

- 1. Brown, K., Worrall, L., Davidson, B. & Howe, T. (2012). Living successfully with aphasia: A qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. *Int. Journal of Speech-Language Pathology*, 14(2), 141-155.
- 2. Cruice, M., Hill, R., Worrall, L. & Hickson, L. (2006). Perspectives of quality of life by people with aphasia and their family: Suggestions for successful living, *Topics in Stroke Rehabilitation*, 13(1), 14-24.
- 3. Cruice, M., Worrall, L. & Hickson, L. (2006). Quantifying aphasic people's social lives in the context of non-aphasic peers. *Aphasiology*, 20(12), 1210-1225.
- 4. Department of Digital, Culture, Media and Sport (2019). *Taking Part 2018/19, Statistical Report.* Available at https://gov.uk/government/statistics/taking-part-201819-statistical-release [Accessed: 23 Nov 2020].
- 5. Dodd, J. A., Sandell, R. & Scott, C. (2014). *Cultural Value: User value of museums and galleries: a critical view of the literature*. Available at: https://hdl.handle.net/2381/37043 [Accessed: 11 Feb. 2021].
- Cock, M., Madge, C. & Sharpe, M. (2020). Museum and Heritage Access 2020 Survey. Available at: https://vocaleyes.co.uk/museum-and-heritage-access-survey-2020/ [Accessed: 26 Jan. 2021].
- 7. Meyer, S., Veneziano-Korzec, A., Larrivee, L. & Stacy, K. (2016). Improving museum docents' communication skills. *Curator*, 59, 55-60.
- 8. Morgan, M. (2020) Making gallery groups at a public art museum accessible to people with aphasia. Unpublished Master of Science thesis. Available at: https://etd.ohiolink.edu/ [Accessed: 7 Oct. 2020].
- 9. Newton, C. & Bruce, C. (2017). Raising awareness of aphasia through art. RCSLT Bulletin, 781.
- Bruce, C., Edmundson, A., Kadri, W., Potter, R., Phillips, L., Bahra, H., & Nolan, C. (2016). Please do touch the exhibits. RCSLT Bulletin, 765, 20–21.
- 11. Duchan, J., Jennings, M., Barrett, R. & Butler, B. (2006). Communication access to the arts. *Topics in Language Disorders*, 26(3), 210-220.
- 12. Jennings, M. & McVicker, S. (2013). Access to the arts for people with communication disability: a guide for arts organisations. London: Connect.