

Arts engagement for people with dementia

Independent evaluation of
the Art Access Program
Art Gallery of New South Wales

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Dr Gail Kenning for the
Art Gallery of New South Wales



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Contents

List of Artworks	2
Glossary of terms	2
Foreword	3
Introduction	3
Background	4
This study	6
Methodology	7
Findings	10
Conclusions	14
Findings from ethnography	15
Findings from the survey questionnaire	32
References	37
Author biography	38
Appendix – Details of the Art and dementia program	39

List of Artworks



John Brack. *The new house* 1953
oil on canvas on hardboard, 142.5 x 71.2 cm
Art Gallery of New South Wales. Purchased with funds provided by the Gleeson O'Keefe Foundation 2013. © Helen Brack



Herbert Badham. *Breakfast piece* 1936
oil on hardboard, 59 x 71 cm.
Art Gallery of New South Wales. Purchased 1936. © Estate of Herbert Badham



George W Lambert. *Important people* (1914-21)
oil on canvas, 134.7 x 171 cm
Art Gallery of New South Wales. Purchased 1930



Russell Drysdale. *Sofala* (1947)
oil on canvas on hardboard, 71.7 x 93.1 cm
Art Gallery of New South Wales. Purchased by the Gallery Trustees from Macquarie Galleries, Sydney 19/12/1952. © Russell Drysdale Estate



Elioth Gruner. *Spring frost* 1919
oil on canvas, 131 x 178.7 cm
Art Gallery of New South Wales. Gift of F G White 1939



Fred Williams. *My garden* (1965-67)
oil on canvas, 152.6 x 183.3 cm
Art Gallery of New South Wales. Purchased with funds provided by the Art Gallery Society of New South Wales 1999. © Estate of Fred Williams

Glossary of terms

Artwork	The work selected for the attendees to view
Attendees	People with dementia enrolled on the Art Access Program
Care staff	Staff employed or people doing volunteer work with the care organisations attending the Gallery
Facilitators	Art Gallery of New South Wales volunteer guides trained to facilitate visits for people with dementia in the Art Access Program
Family members	Family of people living with dementia participating in the Art Gallery of New South Wales Art Access Program
Primary carer	Carer of people living with dementia and attending the Art Gallery of New South Wales Art Access Program
RACF	Residential aged care facility, also known as nursing homes in The United States and United Kingdom
Researchers	Researchers from University of Technology Sydney undertaking an evaluation study of the Art Gallery of New South Wales Art Access Program
Volunteers	Carers accompanying attendees not in the employment of the care organisation

Foreword

The Art Gallery of New South Wales's Arts Access programming is a wonderful example of a social support available to people living with dementia and their carers.

Art Access programs at the Art Gallery of NSW are world-class, providing a pleasurable, and often joyful, experience for people with dementia and their carers and families.

At Alzheimer's Australia NSW we promote community activities for people with dementia that can bring meaning to their lives, reduce social isolation and enable them to live well.

The Art Access program for people living with dementia meets this brief beautifully. The flexible nature of the program and the 'in the moment' approach ensures a rewarding experience for all participants.

This evaluation provides solid evidence for the continuation of the Art Access program for people with dementia as it provides a much-needed respite from the day-to-day realities of living with dementia and caring with someone who has dementia - with obvious ongoing benefits for everyone taking part.

The Honourable John Watkins AM

Alzheimer's Australia NSW CEO,

Introduction

The **Art Gallery of New South Wales** (AGNSW) has permanent collections of international and Australian art; hosts national and international touring exhibitions; runs outreach programs; and engages in research. **Over 1.3 million people visit the Gallery annually.** In addition to its exhibitions, the Gallery hosts lectures and symposia, film screenings, music recitals, and performances, and offers a range of access and education programs that engage with diverse audiences and people with differing needs.

The Gallery is funded by the NSW government, through corporate sponsorship and from donations from private benefactors. It is currently undergoing a period of change. As part of 'The Sydney Modern Project' the Gallery is transforming the way that it engages with the public and the experiences on offer to audiences. An important element of the transformation is ensuring that the Gallery continues to evolve opportunities for diverse audiences to engage with its permanent collection and temporary exhibitions (Art Gallery of New South Wales, 2015a). Through education and access programs, the Gallery aims to break down social barriers and promote inclusion for people with different physical, sensory, and intellectual needs and enable disadvantaged community groups to actively engage and connect with art (Art Gallery of New South Wales, 2015a).

The Gallery has been running Art Access Programs for people living with dementia, carers, family members, and health care professionals since 2010. It began with a six-month pilot program, which informed the current program developed by the Access Program Producer. Further training of gallery staff and voluntary guides was undertaken in 2013 facilitated by funding from a private donor. In 2015, with the support of its sponsor **State Street**, the Gallery was able to engage with more people than ever before (998).

The program provides opportunities for people living with dementia to engage meaningfully with artworks in the Gallery's collection under the expert guidance of Gallery staff and volunteer guides who serve as program facilitators. These program facilitators are trained by the Access Programs Producer and, in addition, **36 volunteer guides have been given dementia-specific training by Alzheimer's Australia NSW**, and **20 volunteers were provided with additional training by Adriane Boag, the Program Coordinator of the Learning and Access Programs at the National Gallery of Australia.**

The program supports the Gallery philosophy of lifelong learning, enrichment, and inclusivity through engaging with art, and through this approach aims to

contribute to reducing the stigma associated with dementia. The program is flexible and adaptable and takes place in the public Gallery during normal opening hours. It caters for a wide range of people with different physical and cognitive capabilities and is inclusive of people with early-onset dementia, in early stages of dementia, and those in more advanced stages. Attendees of the program come from residential aged care facilities (RACF), community groups, and people living in their own homes alone, with family members, or with carers.



Figure 1. Art Gallery of New South Wales access program for people with dementia and carers. Image courtesy Art Gallery of New South Wales, 2015.

Facilitators introduce program participants to 3-4 artworks per visit. They provide a context for the artwork and opportunities for discussion. The artworks are pre-selected by trained staff to provide visual and intellectual stimulation and to promote self-expression. Program attendees and accompanying family members, primary carers, or professional care staff are all encouraged to share their views, experience, knowledge, or associations arising from the artworks and interact with the facilitator and their peers.

Evaluation of the impact of arts engagement for people living with dementia is still very much in an early stage of development. While clinical, medical and health care professionals are able to draw on an array of scales and measures to evaluate physical and intellectual abilities, assessing the impact of social and cultural engagement on health and wellbeing is complex. For example, we might ask how important is the choice of the artwork to the experience? How does the way that it is introduced or contextualised impact those viewing the work? Is it important that the person viewing the artwork retains any information about the artwork or remembers the experience the next day?

This evaluation study, commissioned by the Art Gallery of New South Wales, used a mixed methodology approach involving qualitative and quantitative research to gain an understanding of the impact of the Art Gallery of New South Wales Art Access Program for people living with dementia. This report provides:

- A brief overview of academic and professional access programs;
- A description of the methodology used for evaluation;
- Key findings including examples and illustrations of participants' and stakeholders' responses.

Background

Ageing and dementia

As a result of scientific and medical breakthroughs and improved standards of living, more people than ever before will live well beyond 65. By 2050 it is predicted that the percentage of the world's population over 65 will double to 16% and the number of people living beyond 80 will have quadrupled. An unprecedented number of people will live to be 100 years of age (AIHW, 2013; National Institute on Aging, 2015; World Health Organisation, 2014).

While many people continue to live healthy active lives and remain independent long into old age, the **incidence of age-related conditions such as dementia will increase as people live longer** (World Health Organisation, 2012). By 2050 it has been estimated that more than 135 million people worldwide will be living with dementia, many of who may be undiagnosed (World Health Organisation, 2015). Dementia is a condition that impacts cognitive function and can affect memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. However, consciousness is not affected (World Health Organisation, 2015).

Scientific and medical research continues to search for a cure. However, meanwhile, many people are currently living with dementia at home, with family, in the community, and in RACFs where they need help and support to carry out everyday activities that they once did unaided. People with dementia often have fewer opportunities to pursue employment or hobbies, to engage socially, have new experiences, or meet new people. Research has shown that keeping physically and mentally alert and active is important in the management of the condition and can combat depression, which so often is an integral part of dementia. Social and cultural activities can provide opportunities for social interaction, physical and mental stimulation, enjoyment and pleasure (Zeisel, 2011). Engagement with creativity and art has been shown to have a beneficial impact on individuals, including those with dementia.

Art for people with dementia

Because dementia impacts cognitive functioning, memory and judgement are often impaired. This means that an individual who has been a regular attendee at galleries and cultural events may no longer remember details about artists and artworks. However, consciousness and emotional memory persist. This means that even in the later stages of dementia, people can experience pleasure and all of the benefits that come from 'feeling good' (Cohen, 1988; Cohen-Mansfield et al., 2012; Guzmán-Vélez, Feinstein, & Tranel, 2014; Sabat, 2006; Zeisel, 2009). While some research has suggested that emotional stimuli such as looking at pictures can impact working memory and can have long-term effects (Satler & Tomaz, 2011), Art Access Programs primarily focus on the 'here and now'. They provide opportunities for individuals to experience 'in the moment pleasure' and the benefits and enjoyment of engaging with cultural artefacts and in social and cultural activities and events that are often taken for granted by the broader population.

Art Access Programs

Access programs for people living with dementia have been established worldwide. The **Museum of Modern Art (MOMA) in New York** was one of the first to set up a dedicated program for people living with dementia, and the *Meet Me At MOMA* program established in 2006 has informed the development of similar programs internationally (Basting, 2009, p.118). Building on the growing understanding of the beneficial impact for people with dementia of engaging with artworks (Zeisel, 2009), Australia has been at the forefront of providing opportunities for high quality engagement and interaction with artworks in both Sydney and Canberra. The Art Gallery of New South Wales established a pilot Art Access Program soon after the successful program at MOMA in New York. The project was in keeping with the Art Gallery of New South Wales' aim to be a Gallery for the 21st century and to provide

opportunities to "open people's eyes and minds to the wonder, richness and sheer pleasure of art" (Art Gallery of New South Wales, 2015b). In consultation with MOMA and the National Gallery of Australia and with funding from a private benefactor, the program was expanded and adapted to suit local conditions, the work available in the Gallery collection or in touring exhibitions, and local expertise of Gallery staff and volunteer guides.

The Art Gallery of NSW Art Access Program for People with Dementia, sponsored by State Street from January through to December 2015, is one of number of programs aiming to make artworks available and accessible to a wider community. However, when facilitating arts engagement for people with different cognitive and physical abilities, and in introducing new audiences to art and the Gallery, there are special requirements that need to be met. Simply getting people living with dementia in the same space as the artwork in order to experience it first hand, takes organisation and dedication on the part of many people.

All volunteer guides who facilitate on the program undergo specialised training and are encouraged to gain a broad understanding of communities with differing abilities. The works selected for viewing by Danielle Gullotta, the Access Program Producer and her team, are amongst the most highly valued and respected artworks in the world. They include iconic Australian and works from high quality national and international touring exhibitions such as *The Greats: Masterpieces from the National Galleries of Scotland*, and *Matisse and the Moderns*, and winners and finalists in national art prizes such as the Archibald, Wynne, and Sulman. The selected works include well-known pieces and Gallery 'audience favourites'. They also include works that may be considered challenging to both an art-going public and those less familiar with the arts. Danielle Gullotta explains: "We aim to talk to the person first, dementia is just a condition they have. It is important that people are given the opportunity to see things they love, but we also want them to have opportunities for new experiences" (personal communication, July 4, 2015).

Evaluation of the Art Access Program

Evaluation of the impact of people living with dementia engaging with art has often focused on the long-term benefits and the extent to which art experiences, treated as 'interventions', alleviate stress or manage so-called behavioural problems and psychological symptoms. Understanding long-term benefits and/or the impact of an activity on physical and mental good health are important aspects of caring for people with dementia. However, such approaches only partially address the social and cultural aspect of how arts engagement impacts on health and wellbeing.

Long-term improvement is an unrealistic outcome for people living with a degenerative condition such as dementia. Kitwood (1997) argues for a change in the way we understand dementia and calls for a focus on wellbeing. He suggests that rather than thinking in terms of deficits or perceived problem behaviours, we should address the person as a whole recognising the impact of their social context, their personality, social relationships, physical health, life experience, and neurological impairment. Sabat suggests that positive emotional experiences can have an ongoing impact on people with dementia. He argues that a “person may not be able to recollect consciously some previous experience, but his or her actions will reflect a memory of that previous experience nonetheless” (2006, p.11). Therefore, positive emotional experiences can contribute to wellbeing (Cohen et al., 2006; Cohen-Mansfield et al., 2012). However, this is complex to evaluate. But, addressing the person as a whole and providing pleasurable experiences has been shown to reduce depression, stress and tension (frequently associated with symptoms of dementia). Therefore, in evaluating the impact of Art Access Programs we need to understand the extent to which arts engagement can prompt the type of ‘In the moment’ pleasure and ephemeral joy and give rise to the intense emotional experiences that Sabat suggests have ongoing impact, how individuals experience ‘in the moment’ pleasure and the context in which it exists.

This study

Researchers at the University of Technology Sydney undertook an evaluation of the Art Access Program for people with dementia to gain insights into the benefits of the program for people living with dementia. The study explored whether engaging with artworks and discussion about artworks facilitates and promotes ‘in the moment’ pleasure and thereby contributes to positive wellbeing. In doing so, it sought to gain an understanding of the environment and context in which people experience the artworks, and take into account the views of stakeholders in the care and wellbeing of people living with dementia – that is professional care staff, family, primary carers, and facilitators at the Gallery.

The study used a range of research methods including observation, interviews, and surveys of those involved in arranging, delivering, and experiencing the program in the Gallery space. It draws on best practice evaluation of music, drama, and the visual arts (Flatt, 2014; Killick, 2001; Mittelman, 2006; Thomson, 2013), as well as social science methods generally. While not specifically focussed on evaluating communication, communication theories and communication evaluation methodologies also informed this evaluation (Bauman & Nutbeam, 2014; Beard, 2012; Cutlip, Center, & Broom, 1985; Flatt, Oakley, Gogan, Varner, & Lingler, 2014; Killick & Allan, 2001; Lindenmann, 1993; Macnamara, 2012; Mittelman & Epstein,

2006; Thomson & Chatterjee, 2013). The evaluation model used in this study will contribute to a growing body of research and evaluation that focuses on the extent to which people living with dementia can have meaningful interactions and engage in activities that impact on subjective wellbeing and enrich their lives (Beard, 2012).

The study investigated the experience of people living with dementia and relevant stakeholders participating in the Art Gallery of New South Wales Art Access Program during 2015. Specifically, it explored:

- The context of the visit – that is when, where, who and how;
- Verbal or non-verbal communication and behaviours;
- Behaviour that suggested joy or ‘in the moment’ satisfaction or pleasure, or negative responses;
- Signs of engagement or connection
 - With facilitators or art Gallery staff;
 - Peer to peer;
 - With the artwork;
 - With the Gallery space;
- Signs of anticipated pleasure prior to the Gallery visit or reflective pleasure after the visit;
- The response of Gallery staff and program facilitators, family, carers and care staff;
- The overall mood of everyone involved in the visit to the Gallery;
- Pre- and post-visit self-assessment of quality of life and self-esteem through participant surveys.

Research questions

The research questions explored in this study were:

- To what extent does the Art Gallery of New South Wales Art Access Program for people with dementia provide pleasure and enjoyment that positively contribute to the wellbeing and quality of life of people with dementia?
- What does ‘in the moment’ pleasure, joy, and mental and emotional stimulation generated in the Art Gallery of New South Wales Art Access Program contribute to the quality of life of people living with dementia?
- What learnings can be gained from the Art Gallery of New South Wales Art Access Program for people with dementia in relation to care, wellbeing, and quality of life for people with differing needs including disabilities?
- What learnings can be gained to inform future evaluation of Art Access Programs for people with different physical and cognitive capabilities including dementia?

Methodology

This evaluation primarily used an interpretivist qualitative approach. The methodology used was informed by findings from the evaluation of the *Meet Me at MOMA* program carried out in 2006 (Mittelman & Epstein, 2006) and contributes to the emerging field of evaluation of programs for people with dementia. Evaluation of arts engagement is in a developmental phase. Models are currently being developed to explore the impact of ‘in the moment pleasure’ (Macpherson, 2009) and how focussing on associations and the ‘reverberation’ of the experience can provide an alternative to focussing on memory of the experience (Muller, Bennett, Froggett, & Bartlett, 2015). Evaluation of arts and leisure activities in relation to people with dementia are increasingly recognising the importance of seeing art experiences as ‘intersections with’ rather than ‘interventions in’ people’s lives – the latter being terminology commonly used in Random Controlled Trials (RCTs) in clinical, medical and psychological studies (Vogelpoel & Gattenhof, 2012).

Evaluation of arts engagement for people with dementia such as *Memories in the Making* and its analysis by Kinney and Rentz (2005) and the *Meet me at MOMA* program and its evaluation by Mittelman and Epstein (2006) employed modified self-reporting surveys to assess individuals’ quality of life. However, as they reported, there are inherent limitations in using self-reporting survey questionnaires among people with dementia because participants may have lost access to memory, language, writing skills and lack confidence and decision making skills. A further limitation of such survey questionnaires is that the number of participants is usually small. Therefore statistically reliable quantitative data are not produced. Nevertheless, with careful consideration of factors such as the length of the survey, the number of questions, and how and when the survey is completed, self-reporting questionnaires can be a useful tool for gaining insights into individuals’ perceptions and reactions, particularly when specialised scales are used as outlined.

The methodology was further informed by social science research methods literature. In particular, interpretivist approaches identify the value of data collected through interviews with participants and relevant experts, and direct observation when this is possible (Neuman, 2012). As language may be partially or entirely compromised for people living with dementia, the nuances of non-verbal communication can also offer valuable insights into the experiences of the individual (Zeisel, 2011).

Methods

Accordingly, this evaluation used the following methods with analysis based on triangulation of data collected through:

- **Ethnography** incorporating both personal observation and video ethnography;
- **Interviews** (formal and informal) with carers, facilitators, and Gallery staff involved in the program. This provided a level of expert review; and
- Pre and post-visit **survey questionnaires** distributed to attendees, care staff, facilitators and family members of the Art Gallery of New South Wales Art Access Program.

Sample

The researchers were introduced to a number of organisations in the process of arranging visits for people with dementia to the Art Gallery of NSW. Prior to undertaking the research, the researchers met with representatives of three organisations whose clients were scheduled to attend the Gallery – a government funded community centre, a program for younger onset dementia (YOD) through a public hospital, and a residential aged care facility (RACF). This provided researchers with background information about the organisations and their roles and afforded a broader understanding, on the part of the researchers, of the current program. In this sample selection and preliminary stage of the study researchers also met with professional care staff and volunteer guides who accompany people with dementia on their visits to the Gallery. This provided further ‘immersion’ in the field of study and enabled the completion of consent forms from all participants.

Ethics

Ethics approval for the study was gained through the Human Research Ethics Committee of the University of Technology Sydney (HREC 2015000330). This provided for:

- Permission-based participation for people with dementia involved in the Art Gallery of New South Wales Art Access Program as well carers and other stakeholders;
- De-identification of all participants in the study (pseudonyms only used);
- Facility for participants to withdraw at any time; and
- Careful attention by the researchers to reflexivity and mindfulness in the conduct of the study, noting that people with dementia constitute a ‘vulnerable population’ in terms of research ethics.

Ethnography

The study used ethnographic approaches, which afford the benefit of first-hand observation of an individual or group by a trained observer looking at individuals' experiencing; behaviour; patterns of behaviour; vocalisation; physical positioning; and interactions. This approach provided additional data and context to participants' self-reporting questionnaires, which may be affected by, for example, self-consciousness, shyness, nervousness, and, or cognitive or physical limitations.

Personal observation

Two researchers undertook personal observation in the Gallery space of the same groups of people, who were also video and audio recorded. Researchers became immersed in the group as they were guided through the Gallery; sitting or standing alongside attendees as they viewed the artworks. This afforded an understanding of the various interactions that took place. It also provided access to nuanced responses and a greater field of view not available in audio or video recording alone. One researcher completed an observation schedule recording positive and negative behaviours and verbal, non-verbal, and phatic responses of individual attendees as they viewed the artworks and interacted. The second researcher observed the behaviour of care staff, facilitators and group interaction overall as they engaged with the art works, and made journal notes throughout the visits. In observing what happened in the Gallery space, researchers sought to understand the extent to which attendees experienced a sense of well-being as evidenced by demonstrated interest, sustained attention, signs of a sense of pleasure, and signs of enhanced "self-esteem, and normalcy", (Kinney & Rentz, 2005 p.221), or alternatively to what extent they demonstrated negative effects such as sadness, boredom, or irritation. Researchers observed the facial expressions and body movements of individuals looking at artworks, as well as those of facilitators, care staff and peers, and verbal responses including prompted and proactive engagement and discussion with facilitators or each other. Attention was paid to engagement in a variety of forms including general comments, humour, smiling, laughing, clapping, singing, and dancing, as well as negative reactions such as crying, verbal expressions of sadness or agitation, fidgeting, or distraction.

Video ethnography

The viewings of artworks were video and audio recorded. This allowed for the audio and video to be reviewed and analysed separately. A GoPro™¹ camera was used

¹ A small camera with wide-angle capabilities that can capture activities in a room while remaining at a distance from individuals.

because of its high quality of images, wide-angle capabilities, and its very small size, which made the recording **unobtrusive**. Similarly, a small Phillips digital audio recorder was used because it was unobtrusive while capturing high quality sound.

Interviews

Formal and informal Interviews were conducted with Gallery staff, facilitators, and care staff before, during, and after Gallery visits, as part of the ethnographic research. This allowed for accumulated learnings to be captured and explored, rather than a moment in time response. Over the course of meetings and visits, discussions ranged from 30 minutes to several hours of asking questions of Gallery staff facilitators and care staff.

Analysis

In total, this study involved observation and analysis of four separate Gallery visits on four separate days. Researchers observed and surveyed more than **25 attendees** and **14 professional care staff and volunteers** from **three organisations**. Researchers spoke to more than **10 family members** about the study and provided **questionnaires for completion to more than 20 family members**. The study also observed and surveyed more than **12 trained program facilitators from the Art Gallery of New South Wales**. The attendees observed in the study included people living at home alone, or with family members, and people in care facilities with a diagnosis of dementia. Before, during and after each visit researchers carried out post-hoc reviews and discussions with care staff and facilitators. These provided information as to whether any of the behaviours observed in the Gallery were not typical for any of the attendees and whether there had been any known events prior to the visit that would have an impact and cause "ratty" behaviours — a term used by care staff.

Care staff reported no exceptional or out of character behaviour in the Gallery space and no knowledge of anything that would have caused any changes in attendees' behaviours during any of the visits. Care staff in attendance were also asked to comment on any changes to the Gallery visit, Gallery staff or level of engagement compared to previous visits. No changes were observed or commented on.

Facilitators were asked to comment on the access program delivered for each of the four visits and to advise of any changes or differences they observed from previous visits for these groups of people. The only change noted was that on the study days there was a coffee and form-filling period before the visit. Experienced and regular facilitators confirmed the attendees' level of engagement was similar to that of previous visits.

Researchers independently made comprehensive notes. A meeting was held between researchers after each visit. Researchers compared data and prepared for the next visit, making changes as necessary to accommodate the differing needs of the next groups. The analysis of the data began with researchers examining data in relation to deductive themes, which included the criteria used for the observation schedule (positive and negative behaviours, gesture, movement of body and head); issues relating to logistics (travel, seating and chairs, ambient noise); recurring topics of conversation in relation to the content of the paintings; formal and emotional discussion of the artworks (discussion of colour or form, talking about how it makes you feel); and the role of the facilitators in enabling 'in the moment' pleasurable experiences for the attendees. In the second stage of analysis researchers used an inductive approach to develop a set of themes emerging from their observation and experience in the Gallery space, post-hoc 'expert' reviews, and the researchers' post-visit discussions.

All researchers notes were imported into NVivo V10² where they were analysed in relation to the set of identified themes. The audio and video recordings were examined in relation to the established themes and any new themes emerging, and to identify specific examples of these themes in speech, non-verbal communication, or in relation to an attendee, group of attendees, or stakeholders. The overall themes were broadly categorised in terms of communication (peer to peer, stakeholder to attendee, attendee to stakeholder, between attendees), the role of stakeholders in supporting the experience (attendee, care staff, facilitator), the extent and form of engagement with artworks, logistics of getting people to and from the gallery space, and the overall experience. These themes contributed to the development of the key findings.

Survey questionnaires

Specialised survey questionnaires were developed for the attendees, family members and primary carers, care staff, and facilitators and distributed pre- and post-attendance. Pre-attendance survey questionnaires provided benchmark data for comparison with post-attendance survey questionnaire data.

From the literature, the study identified a number of measurement instruments including family assessment measures (FAM), quality of life measures (QOL), self-esteem scales (Logsdon, Gibbons, McCurry, & Teri, 2005; Ready & Ott, 2003; Rosenberg, 1965; Skinner, Steinhauer, & Santa-Barbara, 1983), and adaptations of these scales used in the evaluation of the *Meet Me at MoMa* program by Mittelman

and Epstein (2006). As a result, the Art Gallery of New South Wales evaluation survey questionnaires used a series of scales further adapted from **quality of life (QOL)** measures, **self-esteem scales**, and pictorial **self-rating mood scales**. Modification of the instruments was confined to shortening some questions, eliminating questions not considered relevant for this study, and adapting language for an Australian audience. Thus, these instruments provided *criterion validity* for the study.³

Gallery staff, facilitators, care staff, attendees, and family members were all included in the sample for survey questionnaire and/or interviews. These 'experts', from a range of experiences, could provide insights in terms of understanding and assessing the mood, demeanour, and responses of the attendees. They also provided a level of *face validity*.⁴

- Attendees, family members and primary carers were invited to complete QOL and self esteem questionnaires in relation to their perception of the attendee and to make additional comments.
- Attendees were asked to complete a pictorial mood survey (see Figure 3) and were invited to make additional comments.
- Facilitators were asked about their experience of the program and completed a pictorial mood survey.
- Professional care staff, in attendance at the Gallery, were asked to complete a survey about the program and a pictorial mood survey.
- Immediately after the Gallery visit all participants (Facilitators, care staff, attendees) completed mood surveys.
- Attendees' families had been given a questionnaire to be completed after the visit with the same questions relating to the quality of life, self-esteem, and mood of the attendee. Each form was returned by mail to a specified post office box address.

Smiley-Face Assessment Scale



Figure 2. Smiley-Face self-rating mood scale

³ Criterion validity is established when an instrument is used that has been tested and shown to be valid (Frey, Botan, & Kreps, 2000 p. 116).

⁴ Face validity is established when the qualifications or experience of the researchers or collaborators means that, 'on the face of it', the research is likely to be valid (Frey et al., 2000; Neuman, 2012).

² QSR International: QSR-NVivo Data Analysis Software for analysis of qualitative and unstructured data.

Findings

Key Findings

While there are methodological challenges in evaluating the cognitive, affective, and conative outcomes that can be achieved by and for people with dementia, this intensive period of study and analysis led to three key findings, as well as further findings that inform operational processes in the Art Access Program for people with dementia, and others in relation to evaluation methodology that can inform future research.

The three key findings relate to:

- Affordance of **normalcy**;
- The importance of **context** surrounding visits to the Gallery, including preparation and logistics such as administrative arrangements, length and method of travel, etc.;
- The need for provision of **social scaffolding**.

Normalcy

The concept of normalcy is based on the rights of every individual to be treated with dignity and respect and accorded the rights and privileges of all citizens regardless of abilities or perceived disabilities (Chenoweth et al., 2009; Killick, 2013; Kitwood, 1997; Treadaway, Kenning, & Coleman, 2014). Kitwood (1997) has been active in promoting the *normalisation* and de-stigmatising of dementia and *normalcy* for those living with dementia. For Kitwood, this is a key element of personhood, which focuses on the potentiality and possibility of all individuals regardless of what stage they are at in their journey through dementia. It should be noted, however, that this does not equate with forms of normalising that promote the concept of a norm or standard approach to be conformed with or a concept of 'normal' to be attained by an individual. Normalcy recognises that individuals are different with different interests, needs, and capacities and seek different experiences. This approach also recognises that dementia is a degenerative condition and has severe impacts on people lives, but does not leave an individual without potentiality and possibility. The Art Gallery of New South Wales Art Access Program for people with dementia adheres to both the theories and practices of providing normalcy for people living with dementia.

Normalcy is achieved by:

- Not offering a 'one size fits all approach', but rather taking into account differences in abilities, neural diversity, and social and cultural backgrounds, providing different experiences for different people;

- Foregrounding the right of everyone to speak, to have an opinion, and to be listened to, regardless of his or her communication abilities;
- Acknowledging that everyone (young, old, neuro-typical⁵ or otherwise, and with different physical abilities) see things differently;
- Focusing on lifelong learning and providing new challenges;
- Focusing on exploring associations, rather than reminiscence or memory;
- Recognising each individual's right to change their mind;
- Recognising that allowing people with dementia to experience normalcy requires supportive social scaffolding that allows the individual to achieve their potential at any stage (see 'Social scaffolding').

Overall, the Art Gallery of New South Wales Art Access Program for people with dementia is flexible and adaptive and therefore can suit a range of conditions and abilities and provide varied experiences to promote 'in the moment pleasure' and contribute to wellbeing. In addition, the study revealed that there were indicators that, for some individuals, the artwork may be used as transitional or transformational objects (Bollas, 1979; Winnicott, 1971) through which individuals could address matters of concern or insecurities (as seemingly exemplified in 'Fiona's' response to *The new house* and *Important people*), or focus attention away from their own condition (as exemplified by 'Richard's' response to *The Important people*).

Different experiences for different people

The conversations in front of the paintings varied significantly depending on the facilitator, the individual attendees, and the group dynamics. The paintings chosen for viewing engaged attendees in a range of ways. Those with retained episodic and semantic memory were happy to be given information about art, artists and to engage with the Australian themes. For others the focus on semantic memory and listing the names of objects in the painting offered a challenge, which many enjoyed. Facilitators were also able to focus away from activities that may tax memory and focus on the materiality of the painting, on visceral responses, and to engage individuals emotionally.

Listing objects depicted in a painting enabled those with cognitive impairments a basis upon which to engage in conversation, and gave individuals confidence to speak up. While explorations of emotional responses allowed for attendees to simply state whether they liked a painting or not (as exemplified by 'Richard') or to engage in more sophisticated responses (as exemplified by 'James')

⁵ A term borrowed from the autistic community to refer to people who are perceived to be without 'impairment'.

recognising that Russell Drysdale's painting *Sofala* is as much about "failure" in relation to the gold rush as it is about the Australian landscape). The conversations that took place often promoted affective responses as shown in discussion of the roles of wife and mother that was emotive for 'Fiona', while in contrast 'Joyce's' background in art, as an artist, and with parents who were artists, meant that she wanted to know more details about the artist and how and when the work was made. On occasions it was not apparent that 'Joyce' had dementia, but on other occasions it came to the fore as the facilitators answered the same question raised by 'Joyce'. These experienced facilitators were able to respond effectively to the particular needs and wants of those in attendance and carefully orchestrated the experience.

The right to speak, have an opinion, and to be listened to

A marked difference was observed in the behaviour of attendees during different stages of the visits, such as travelling to the Gallery, in the coffee breaks and form-filling period, and in the Gallery in front of the artworks. When utility and functionality were paramount, it was evident that those who had communication difficulties such as quiet voices, shyness, or who could not articulate their opinions or viewpoints effectively, often underwent periods in which they did not speak or were not spoken to (this is not in any way to suggest neglect). However, in the Gallery these people were central to proceedings and if they needed time to express an idea, or help formulating responses it was available. Any and every response was treated with dignity and respect.

We all see different things

Dementia includes a range of conditions that impact cognitive and physical functioning. In many fields and disciplines, people with a condition such as dementia, who are not neuro-typical are assumed to perceive the world differently to those who are neuro-typical. However, the arts and humanities foreground subjectivity and individualised perception and recognise that not **every** person, neuro-typical or otherwise, see things the same. For example, individuals may see colour differently because of the physical structure of their eyes, or have different responses to colour because of their cultural background. In the Gallery what people see, feel, or how they respond to a painting, is equally validated whether they are living with dementia or not. Differing perceptions are not only acceptable, but are an important contribution to the art experience and are recognised as such.

Lifelong learning and providing new challenges

Interviews with Gallery staff revealed the importance for them of building on the potentiality and possibility of all individuals attending the Art Access Program. This sometimes involved selecting works for discussion that may be challenging and may

cause surprise. This is sometimes of concern to family members or carers. Danielle Gullotta explained that at times, organisations or family members have suggested that viewings should not contain paintings that have, for example, nudity, are abstract, or may have an emotional impact. However such concerns, whilst well-meaning, can limit an individual's right to experience a wide gamut of emotions, a concern raised by health care professionals and advocates of person-centred and individualised care (Chenoweth et al., 2014; Cohen-Mansfield et al., 2012; Killick, 2013; Killick & Allan, 2001; Kitwood, 1997).

Associations, not memory

Family members, carers, friends, and professional care staff of people living with dementia frequently struggle with finding things to do or things to talk about. Often without realising it, conversations centre around memory – e.g., "what did you do yesterday/today/last week?" "Do you remember that place/person/object?" For a person living with dementia, such recall-orientated conversations draw attention to personal deficit or loss. While cognitive functioning and memory may be disadvantaged as a result of dementia, emotions and affective response remain accessible.

Importantly, engagement with an artwork frequently relies on audiences making subjective, objective, cognitive, or emotional *associations*. It does not necessarily rely on past memory for experiences. Enjoyment and stimulation from art can be an 'in the now' experience, which may or may not be remembered later. Intense engagement and feelings can therefore be experienced as a result of associations rather than memory (an example of such engagement is when a facilitator 'Karen' read Henry Lawson's poem *The roaring days* to accompany the viewing of Russell Drysdale's *Sofala*. This created a visibly affective response from all in attendance). Attendees demonstrated use of association and metaphor to voice concerns or reflect on past experiences that may be *felt* if not remembered (e.g., 'Fiona's focus on the couple's relationship and the baby in *The new house* and *Important people*).

The right to change my mind

Observations of people's behaviour in the Gallery and the comments and responses to questionnaires were on occasions highly contradictory. For example 'Harry' was very chatty with one of the researchers during the coffee break and form-filling period. He smiled and laughed when looking at paintings, answered and asked questions, and appeared to be enjoying himself. But in the post-visit questionnaire, he stated that he did not want to go to the Gallery again. While this response may be associated with his form of dementia, it may be that he simply changed his mind and did not feel like going on the next visit. Changing one's mind is common among people regardless of their physical or cognitive functioning and it is an individual's

right, which is to be respected. Similarly, 'James' appeared to enjoy the intellectual stimulation while in the Gallery, but the follow up questionnaire suggested that he was very unhappy after going to the Gallery and that he did not want to go again.

Context

A number of specific findings in relation to the context of visits to the Gallery relate to operational matters and are, therefore, discussed under 'Operational findings'. The overall importance of context is a key finding of this study. Factors such as the length of the journey to the Gallery, the atmosphere on the bus or other transportation used, the seating of the chairs in front of the painting, noise levels in the Gallery, etc. can create discomfort, confusion, or even rejection and withdrawal. Such factors can mean that individuals may not arrive in the Gallery space in a condition to engage with the artwork. For some, this does not mean that they will not have a positive outcome from the visit, but it can potentially be an added difficulty for care staff and facilitators, and impact on group dynamics. Therefore, heightened attention to the operational findings can make a positive contribution to the program.

Social scaffolding

Understanding the importance of social scaffolding has grown out of psychology applied in education, such as the work of Russian psychologist Lev Vygotsky (1978; 1987), Jerome Bruner (1976), and Barbara Rogoff (1990). Social scaffolding refers to individuals' support structures ranging from family and carer support to social interaction and collaboration, and this concept is now being examined in relation to people with dementia (Hydén, 2014) and in exploring how people with dementia engage with artworks (J. Bennett, personal communication, March 16, 2016). It recognises the impact of the individual's support framework and collaborative and social experiences on the individual's ability to achieve. For example, individuals can be supported in achieving a greater understanding of the artworks through a relaxed environment; interaction that models normalcy; and the creation of an inclusive environment, which welcomes and accepts all responses to the artworks and proceeds with an expectation that attendees have something to contribute — regardless of the stage of their condition. Social scaffolding — that is, how others in a social situation support the individual in, for example, responding to a challenging work of art — is a key aspect of enabling individuals to gain the most from their experience.

Operational findings

Experienced facilitators often gave careful consideration to the seating arrangements, how to make conversations flow, and how and when to ask questions. They were also able to work with group dynamics and the energy levels of individual attendees. Care

staff were encouraged to participate in discussion, particularly if they were expressing their own opinions or views. However, on occasions care staff were at risk of speaking for an attendee, making assumptions about what an attendee's response might be, or inadvertently putting pressure on an attendee to speak out. Experienced and trained facilitators were able to carefully manage situations and are key to how the experience unfolds for attendees:

- All facilitators observed as part of this study had undergone training and had prior experience of delivering the program. It was clear that the more experienced facilitators could 'think on their feet', adapt quickly to the audience, and create positive experiences.
- Danielle Gullotta as Art Access Program Producer demonstrated guidance and leadership of best practice approaches for facilitators. These included, being organised, adaptable and open to change; being cognisant that access programs for people living with dementia required different approaches to general Gallery tours or educational visits; being patient; and sometimes remaining silent to encourage attendees to talk.
- Experienced facilitators were able to create special 'moments' by remaining quiet and not speaking, for what seemed like a long period of time. This encouraged the quieter attendees to speak up (as exemplified by 'Karl', who had been reluctant to speak, but given time, proactively commented on a painting).
- Experienced facilitators were mindful to ensure the volume of their voice did not fall, which could cause difficulties for people with hearing difficulties and careful not to ask questions that focussed on memory and reminiscence (i.e., do you remember?), which could be confronting for attendees who were aware of their own issues with memory. They were also careful to contextualise information about a painting in terms of why the details might be of interest or relevant to the attendees.

Running the Art Access Program during normal public opening times is key to normalcy for people with dementia. However, this sometimes causes challenges:

- At times the noise levels, particularly when school groups were in the Gallery was high, making hearing a problem. Signage asking people to be quiet or using Gallery staff to ask people to be quieter in the vicinity of the program would help address this matter.
- Behaviour of other Gallery staff (i.e. security staff etc.) varied. It was extremely helpful, courteous and a positive contribution to the overall experience.
- Care needs to be given with regard to where and how the seating is positioned in front of paintings to ensure that everyone can see the painting clearly and hear

the facilitator. This could be resolved with more administrative assistance, or assistance from other staff (i.e., security staff or invigilators).

It was evident that the relationships between all stakeholders (Gallery staff, care staff, carers and family members) are not only professional and courteous, but mutually supportive, and show a real intent to 'get the job done' and to give the attendees the best possible experience. However it was noted:

- Attendees sometimes needed time in the Gallery to 'warm up'. They were often quiet at the first viewing, more lively at the second, and "really getting going" (D. Gullotta, personal communication, November 4, 2015) by the time they were looking at the last painting. The logistics such as meeting bus or lunch deadlines sometimes meant that attendees were pulled away from the artwork when they were benefiting most from the experience. Therefore, flexibility is needed across all stakeholder groups to ensure that the attendees are able to maximise their experience of the Gallery.
- Visits were tiring for some attendees and it was noted that the facilitators and care staff needed to manage the experience of the group as a whole.

Findings in relation to methodology

This study noted there were limitations with the use of surveys and questionnaire when working with vulnerable groups and people living with dementia, as shown in other evaluative studies of Art Access Programs. This study sought to make completing the forms less arduous and therefore less detracting from the overall experience by asking attendees to complete surveys in a less formal setting while socialising over coffee, making the questionnaires appear less formal through the use of colour and simplified language, and by providing support and assistance for participants. The completion rate of the questionnaires from family members was lower than expected. In addition, there were marked differences between some attendees' responses recorded in questionnaires and what was observed during the journey to and from the Gallery, and in the Gallery space. Learnings in relation to methodology are:

- Findings from the survey and questionnaire data and the observation of researchers was sometimes largely inconsistent, as suggested by 'Harry's' and 'James'' experiences when they suggested in the survey immediately after the visit that they did not want to return to the gallery or were "Very Unhappy". This could not be reconciled with any analysis of their behaviour at any time during the visit.

- Inherited assumptions and generally held viewpoints about dementia, meant that attendees' family members and carers placed emphasis on whether the attendee would remember the experience, and if not felt there was little point in completing survey questionnaires. More explanation of the importance of 'in the moment' pleasure and nuanced behavioural change would be useful and important in future research.
- The completion rate for all survey and questionnaires by family members was low. While there are learnings to be made, it must also be acknowledged that changes of personal priorities, circumstances and external influences inevitably impact people living with dementia and their stakeholders, and low return of surveys and questionnaires may be an inevitable consequence of working with vulnerable groups whose priorities change on a daily basis.
- The majority of stakeholders — that is professional care staff, family members, carers, Gallery staff and people living with dementia — were supportive and eager to take part in the evaluation study. However, it was apparent that there was a preference for interviews and talking about their experiences and reluctance to complete questionnaires and surveys.
- Completing survey questionnaires was stressful for some attendees and potentially impacted on their experience at the Gallery.
- *Process consent* was important for the study as exemplified by 'Ingrid', who changed her mind about whether or not she would complete surveys forms and take part in the study. This approach allowed for democracy and promoted normalcy.
- Observation provided rich narrative that is transferrable to other contexts. Analysis, however, is labour-intensive and time-consuming.
- The study revealed that there is a need for further research and drill-down investigation with regard to how particular art experiences can be curated for people at various stages of their journey through dementia.

Other findings

Further findings are reported in the following sections that discuss ethnography, interviews, and responses to the survey questionnaire in detail.

Conclusions

This study builds on the findings of existing research. However, in analysing and evaluating the impact of Art Access Programs for people with dementia, this study looked more broadly at the context in which the programs took place. The study looked at the physical, social and cultural influences on people with dementia attending the Art Access Program; recognised the importance of how the gallery as an organisation responds to people with differing abilities; sought to gain an understanding of who was attending the program; and examined how attendees arrived in the space ready to engage with the artworks and what artworks were viewed. The study found that a number of stakeholders were involved in providing a positive experience for people with dementia, these included care staff, gallery staff and facilitators, and family members and primary carers. The study also highlighted the importance of organisation, structure, and planning; specialised training; and flexibility and adaptability across all stakeholders. The relationships between gallery staff, professional care staff, family members and carers and people with dementia were a key component of the success of the program, with many of these relationships being built up over a number of years.

This study found that all attendees had a positive experience of the Art Access Program for people with dementia at Art Gallery of New South Wales. This was evidenced by behaviours that were consistent with 'Gallery-goers' in the greater population such as smiling, laughing, pointing and gesticulating at paintings, talking, asking questions and commenting on paintings, quietly contemplating the works, and the occasional exaggerated exclamations associated with liking or disliking the work or gaining new insights. In attending the Gallery attendees were able to gain access to material and experiences not available in their everyday lives. There were opportunities for social interaction and engagement with their peers (as observed with 'Fiona', 'Joan' and Norma), care staff and facilitators, and times of quiet reflection (as observed with both 'Sylvia' and 'Joyce' wandering away from the group to quietly look at a painting in more detail). Attendees expressed in the moment joy through behaviours such as clapping, thanking facilitators, and by commenting on their joy in gaining a new understanding about a painting (for example 'Anna's' response to *My garden*). The visit provided opportunities for attendees to tell stories and reminisce and for periods of self-identification ('Paul', 'Richard', 'Adam' and 'Daniel' and 'Fiona' all self-identified with people depicted in the paintings). For those who remembered the visit it provided opportunities for reflection and conversation with their peers, care staff and family members. For those who did not remember the events in the gallery there was a lingering sense of having had a good time (as observed with 'Adam' who suggested he knew he liked one of the paintings but did not recall which one). While not everyone was exuberant in the Gallery space, it is

important to recognise that for some individuals the Gallery provided a calm, comfortable environment that was safe (as observed in the behaviour of both 'Anita' and 'Karl', who did not engage in talking, but appeared content in the space). While 'Daniel' claimed not to like the Gallery, there was no evidence of this in his behaviour in the space. These examples show how 'in the moment' pleasure was observed in the relaxed state of these individuals who appeared content and secure. In addition the study found that professional care staff and facilitators also had positive experiences in the gallery space, which they reported, impacted their understanding of what it means to live with dementia.

The importance of the selection of the artworks to be viewed is significant for the experience of the attendees. The 'Australian themes' selected during this study were able to call on aspects of reminiscence, and cultural familiarity for the attendees. However, artwork can be selected that may challenge and prompt an array of responses. In this environment the artwork can act as the 'third person' in the discussion between attendees and facilitators and activate different conversations and discussions to what might normally take place between care staff, facilitators, family members and people living with dementia.

Sabat (2006) suggests that implicit memory remains even after explicit memory of an event is lost, therefore the sense of feeling good 'in the moment' may be retained. This study found that there were no negative responses observed for any of the attendees in the Gallery. There were, on the other hand, many examples of pleasure expressed in words, laughter, and behaviours that involved leaning the body towards paintings and people as they spoke. There was an observed familiarity, ease, and speed of response for some attendees, who had been to the Gallery on several occasions before, but who were not able to provide any details about specific visits. Therefore, this study shows that the Art Gallery of New South Wales Art Access Program provides opportunities for experiences in the 'here and now' and 'in the moment' pleasure that can have an impact on people with dementia even when the events are no longer remembered.

Findings from ethnography

Visits 1 and 2: Diversity in living with dementia



Figure 3. A viewing of 'Australian Landscapes' as part of the Art Access Program. Elioth Gruner. *Spring frost* 1919, oil on canvas, 131 x 178.7 cm, Art Gallery of New South Wales. Gift of F G White 1939. Image: Katy Fitzgerald

Context

The first two Gallery visits observed as part of the evaluation study involved attendees from a community centre located in the Eastern Suburbs of Sydney, which runs programs for people with memory loss and has a dementia-friendly action plan. Attendees were brought to the community centre by family members or carers to board the bus to the Gallery, or were picked up from their homes. Two groups of attendees were observed on two consecutive days. All attendees viewed the same artworks.

For the study, researchers immersed themselves in the entire experience of the Gallery visit by travelling to and from the venue with the attendees, professional care staff and volunteer guides. Researchers met the Community Care Team Leader supervising the Gallery visits at the community centre café 90 minutes before the proposed arrival time at the art Gallery. They took notes and made audio recording throughout the journey. This allowed researchers to gain a greater understanding of the overall experience, how the activity fitted in the context of participants' everyday lives, and revealed how the experience unfolded for the attendees. It also gave insights into how and why attendees might arrive at the Gallery in a state where they are open and responsive to engaging with artworks, or otherwise. Travelling with the attendees also gave researchers the chance to meet family members, who had already been briefed on the study, answer any questions, and ensure that consent forms had been completed.

Getting to the Gallery

Getting to and from the Gallery was an important and complex logistical exercise and it was evident that it was tiring for some attendees, which has relevance for the effectiveness of the program. Attendees began arriving at the community centre more than two hours ahead of the scheduled Gallery visit delivered by family members, who also had other demands on their time. For example 'Ingrid', who was 98 at the time and smartly dressed in a leopard skin patterned coat and neat grey bobbed hair, arrived at 8:30am, as her daughter had to leave for a medical appointment. Similarly, 'Fiona', whose son works full-time, arrived early and was sat waiting quietly. For the most part, attendees appeared content to sit and wait. However, 'Fiona' began to show signs of annoyance and irritation when a staff member in the café began noisily sorting cutlery. This type of a response is not uncommon in people diagnosed with dementia, who experience a reduction in the spatialisation of sound (Hayne & Fleming, 2014).

'Joyce' also arrived early at the café accompanied by her husband 'David' aged 85, who is her primary carer. 'David' was keen to chat with the researchers and explained that both he and his wife loved art. Both 'Joyce's' father and mother had been painters and their work is in the Art Gallery of New South Wales collection. 'David' had substantial recall of galleries they had visited and artworks they had seen. For example, he spoke about works in The Chicago Institute of Art and exhibitions they had "loved" on the west coast of America. 'Joyce' was involved and engaged in the conversation and was able to add details about specific artworks and about her parent's work. As the conversation drew to a close, she asked 'David': "What are we going to do today?" She then asked the same question without variation three times in less than five minutes, seemingly without any awareness of having asked the questions previously or being given an answer.

On both days of the community centre visit the weather was particularly bad due to heavy rain. This made getting to and from the bus difficult for the less mobile attendees reliant on walking frames, sticks, or wheelchairs. Care staff and attendees negotiated potentially slippery surfaces and had the added difficulty of holding umbrellas. In addition, arrival times needed to be precise and pick up points very specific to avoid people standing out in the rain. The pick-up point was also where information was exchanged in relation to the current medical or physical conditions of the attendee and their general wellbeing. Reassurance was given to family members that the attendee would be well cared. It was clear that there is a strong and trusting relationship between community care team leaders and staff and the attendee's family members and carers. All attendee's family members and carers were open to talking to the researchers during the Art Gallery of New South Wales

visit. Some reported that the person in their care loved going to the Gallery, while others suggested that the attendee did not like the Gallery at all.

A number of attendees' family members expressed reticence in relation to completing the pre- and post-visit survey questionnaires, suggesting that it was of little use as they "knew" their family member would not remember anything on their return and so there would be "little point" in answering the questions. (NOTE: Observations in relation to completing the pre- and post-visit survey questionnaires are reported here. Data collected and findings from the survey questionnaires are reported in the following section '[Findings from the survey questionnaire](#)'.)

The journey to the Gallery took in excess of 90 minutes, as the bus toured suburbs to pick up individuals at a number of pick-up points including private residences. Coffee orders were taken on the bus and relayed to the Gallery to be ready for their arrival, and lunch orders were taken so that the community centre café could prepare food ready for the attendees' return from the Gallery. Each nominated family member was called by phone 10 minutes before the bus arrived at their house, and Art Gallery of New South Wales was notified of arrival of the group as the bus pulled up to the back entrance, allowing undercover access to the Gallery which is important during rain and so that wheelchairs can be made available for those who need them.

There was a great deal of 'chatter' between the carers during the travel time and attendees were encouraged to join in. This conversation seemed to entertain some attendees, but annoy others. For the most part attendees were quiet, looking out of the window or fighting off sleep. For example, on the first visit, Karl frequently 'nodded off'. He looked out of the window, but did not appear particularly engaged with anything, and on the second visit 'Anita' was woken several times by her carer who showed concern about her level of comfort.

The cohort

Professional care staff shared information about attendees that was not of a sensitive nature in order to provide insights into the responses of attendees to the stimuli provided by the artworks. In addition, family members were keen to share information. As a result, it was apparent that many of the attendees suffered comorbidity, such as a brain injury, Down syndrome, or depression. All of the attendees were living at home, either alone or with a family member, and none of the participants were employed at the time. No medical, clinical, social, or cultural history was requested of attendees or their families. Participants were selected for the study because they are attendees at the community centre and included in

memory loss programs and able to consent as per the guidelines detailed in under the section marked 'sample'.

Coffee and form-filling

Existing evaluation studies of Art Access Programs and activities have noted that there is a general dislike of completing questionnaires by study participants (Mittelman & Epstein, 2006). Form-filling can potentially impact on individuals' moods, cause confusion or stress, or simply not be a fun activity to be engaged in. Therefore, to minimise the impact of form-filling on attendees' moods attendees completed the forms while being served coffee or tea in a social setting. In addition, questionnaires were kept short, the formality of the questionnaires was minimised, and the forms were designed to be visually attractive. All questions were presented in an A5 colour printed booklet format with no visible differentiation in format between questionnaires for attendees, professional care staff, and Art Gallery of New South Wales access program facilitators. See '[Findings from the survey questionnaire](#)'.

All attendees were given the opportunity to complete questionnaires and give consent to take part in the study. Care staff and Art Gallery of New South Wales program facilitators had been briefed on the study and were available to assist attendees complete questionnaires if required. Care staff and Gallery facilitators were also asked to complete questionnaires.

Any sign of stress in an attendee completing the paperwork was deemed a withdrawal of consent and completion of the questionnaire ceased immediately. However, the use of a 'process consent' approach allowed for the consent to be re-addressed for each activity – e.g., the survey questionnaire, observation, and video recording (Dewing, 2007). Therefore, attendees who were uncomfortable completing questionnaires were not excluded from continuing their visit to the Gallery space and remaining part of the study. For example, 'Ingrid', the 98-year old woman, who had been the first to arrive at the community centre earlier in the morning, advised a member of the care staff in no uncertain terms that she did not want to complete any forms, which was perceived as a withdrawal of consent. However, as the form-filling began around the table she changed her mind, without any coercion and wanted to complete a form, although she insisted that she did not want to be recorded because what she did was "nobody's business". This constituted consent to attend and be observed, but not recorded.

The café where the form-filling took place was open to the public. The study participants were seated at two large tables away from the main thoroughfare. The space was lively and sometimes noisy. All attendees appeared comfortable as they

drank coffee or tea. For the most part the cohort retained somewhat neutral expressions, with no visible sign of joy or sadness in the behaviour of any of the attendees. There was very little chatting or peer-to-peer interaction. Engagement that did take place was between attendees and care staff, facilitators, or with the researchers. For example, it became apparent that 'Joan' was very keen to talk. However, she ignored the attendees on either side of her and physically grabbed one of the researchers' arms insisting that she sit down next to her. She talked about her early childhood, her mother, and her eight siblings, seven of which were boys. 'Joan' recounted with pride and joy each of their names. She then repeated the same story almost word for word to another researcher and a member of the care staff. 'Joan' was laughing and clearly enjoying the attention as people listened to her story. However, when asked to complete the questionnaire, 'Joan' became anxious and did not want to engage in any way. The questionnaire was not completed.

Experiencing the paintings

For each of the two visits, attendees were divided into groups of four to five people with two Art Gallery of New South Wales facilitators in attendance. Attendees were escorted to the public Gallery where the viewings took place during normal opening hours with members of the public, including school visits in the vicinity. Chairs were set up around each of the paintings to be viewed. The attendees appeared relaxed and seemed to be familiar with the environment and processes. They took their seats and immediately looked at both the painting and the facilitator, in turn. Care staff and other Art Gallery of New South Wales facilitators stood close by where they could observe, hear, and take part in the proceedings. The paintings chosen for the first two visits were based on the theme of 'Australian Narratives'.

The new house

The first painting viewed was John Brack's *The new house* (1953). 'Paula' was the facilitator for this session. She had a clear voice and calm approach and began by introducing the painting by name: "So this is called *The new house*." She then focused primarily on the content of the painting, talking about the couple depicted, their surroundings, and other objects in the painting. She later went on to provide details about the artist and the date of the artwork.

'Fiona', who had been annoyed by the noise at the café earlier in the day and uncomfortable on the bus, became animated and responded immediately to 'Paula's' introduction to the painting. She commented on the woman leaning against a man in the painting saying "she feels safe." This was a theme that 'Fiona' repeated many times in discussions. An interaction developed quickly between 'Joan' (who had repeated the same story several times during the form-filling and became anxious when asked to complete a questionnaire), 'Fiona' and the facilitator 'Paula'. It

continued for several minutes. Neither 'Joan' nor 'Fiona' waited to be asked questions. Their level of eye contact and speed of responses suggested they were both very engaged.

One researcher noted:

[The talking] seemed to occur so fast and naturally, there was a big shift in activity and enjoyment compared to when they were having coffee (Researcher 2, personal communication, November 4, 2015).

Both 'Fiona' and 'Joan' continued to engage in discussion about the content of the painting. Each used their observations to illustrate their point. 'Joan' commented on the strength of the male character saying: "He has his arm around her ... he holds her close to him". She continued: "He is a gentleman. He does not show his feelings." 'Fiona' responded: "She is lady-like". As 'Paula' (the facilitator) engaged others in the conversation, 'Norma', who had been quiet until this point, suggested, "they don't look happy". A conversation ensued between the three attendees as to whether the couple depicted were happy or not. It was noticeable that there was repetition of the words and phrases used, and in the topics covered.

'Adam' had been articulate on the bus and had completed a questionnaire unaided. He smiled and looked animated, but did not immediately engage in conversation during viewing of the painting. To draw him in, 'Paula' directed a question to him, asking him if he thought the couple were happy. He responded briefly with "I think so". He then shook his head and appeared to be thinking. 'Paula' continued with a question asking, "what is it like to have a new house?" 'Adam' replied: "I don't remember". 'Paula' rephrased the question to "how do you think you would feel in a new house", to which he responded



Figure 4. John Brack. *The new house* 1953. Oil on canvas on hardboard, 142.5 x 71.2 cm .Art Gallery of New South Wales. Purchased with funds provided by the Gleeson O'Keefe Foundation 2013. © Helen Brack.

quickly and readily. 'Joan' was keen to be involved in all conversations – for example, she asked “what did he say?” when 'Adam' was speaking.

'Fiona' and 'Joan' did most of the talking. 'Norma' and 'Adam' said very little, but they sat calmly and relaxed with their eyes focussed on the facilitator or the painting. 'Paula' drew attention to objects in the painting and 'Norma' and 'Adam' both became proactive in pointing out small details, identifying the flowers in a vase, noting how clean the fireplace was, and commenting on the clock on the mantelpiece. Discussion ensued about the time on the clock in the painting and whether 1:30 pm is a good time for lunch in their experience, and whether this suggested a “lunchtime liaison” in the world of the painting. All attendees appeared to be confident and were proactive in commenting or asking questions.



Figure 5. Attendees engage with each other talking about the artwork

The second group to look at John Brack's *The new house* on the following day were calmer and quieter than the first, but still very responsive. With the exception of 'Anita', who remained quiet, gave no sense of being engaged and did not speak, they all looked at the painting and asked or answered questions. The facilitator was 'Cathy', who had a similar style of presentation to 'Paula'. She was patient, sometimes allowing for long silences to give people time to formulate questions. As with the first group, the attendees were only too willing to speak up as soon as they were given the opportunity. However, for the most part, unlike the first group, conversations were mediated through the facilitator with less peer-to-peer interaction.

The focus of attention of this group differed significantly to the first. This group included 'Joyce', who was an artist herself and whose parents had been artists. She asked questions about who the artist was, and fixated on the painting on the wall of the house depicted in the Brack painting. 'Cathy' explained to 'Joyce' that the painting in the painting was a copy of a well-known artwork of the same era. 'Joyce' seemed pleased to hear these details. Within a few minutes she again asked about the painting and received a similar answer. This happened several more times. Each time 'Joyce' was seemingly not aware of having asked the question previously. 'Joyce' continued to focus on the painting as art object rather than the content. For example, she commented on the colours used and was visually pleased when provided with details about the artists.

The men in the group spoke about the man in the painting, about his job and his status as the boss. The group was able to make associations between the painting and aspects of their own life and introduced exogenous details. They began to talk about their own work and compare their clothing to the smart figure in the painting. At one point 'Paul', who had become anxious when the questionnaires were being completed, stood up excitedly and laughing, proudly suggested that the figure in the painting was well dressed, just like he was.

Breakfast piece

Logistically the second painting was not as easy for attendees to view. It was smaller in size and had a glass-filled frame. The daylight from the Gallery windows caused reflections, which sometimes made the painting difficult to view. In addition, the row seating made viewing difficult for those at the end of the row. This may have inversely impacted the level of engagement, particularly later in the viewing. Several people began to fidget as they tried to see the various details being pointed out.

The facilitator for this artwork had a noticeably different style and approach in presenting the work to that of 'Paula' and 'Cathy'. She began by introducing the painting as being “before the war, the second world war.” and provided a lot of information about the work upfront before addressing any questions to the attendees. It was not clear whether attendees were less inclined to ask questions because they had been provided with more information earlier in the viewing or whether, as one researcher suggested, this particular painting and approach caused the attendees to respond differently. Engagement took place, however, the audience were noticeably quieter and less dynamic than they had been previously.



Figure 6. Herbert Badham. *Breakfast piece* 1936. Oil on hardboard, 59 x 71 cm. Art Gallery of New South Wales. Purchased 1936.

When given the opportunity, 'Fiona' and 'Joan' again led the conversation and began by talking about the figure depicted in the painting. 'Joan' said: "She is a really poor person" and went on to suggest that the figure was "thoughtful". They continued talking, but their comments became lost in the ambient noise of the Gallery as a school group passed by. They were not distracted, however. The facilitator began to draw others into the conversation. She asked about the artist's favourite colour. 'Norma' replied "blue" and the group began listing the range of blue and white objects in the painting – cushion, dress, tablecloth, and white flowers. 'Adam' who had been watching and smiling, pointed out that there is a blue and white jug in the painting, but his pronunciation was not clear and his comment was not heard by the group. 'Joan' repeated what he said loudly so that everyone could hear and patted his knee. The facilitator led the conversation as attendees reminisced about home and dinnertime activities. She drew attention to the sugar bowl, the knife, and the bread in the painting. 'Joan', 'Fiona' and 'Norma' nodded as they

spoke. Suddenly 'Fiona' changed the conversation. Mimicking the position of the woman in the painting she suggested: "She is probably expecting a person".

All of the women began to talk at once. They did not hold back and were very comfortable as they chatted. 'Adam' appeared to become more alert and began to interject. However, the conversation was no longer cohesive. Towards the end of the viewing, some attendees appeared to be getting tired, they fidgeted, and some had difficulty hearing the facilitator's voice. The facilitator continued drawing attention to objects in the painting including the silver teapot as she explained that a woman "standing in this very Gallery" had told her that the woman in the painting was her grandmother and the artist had been her grandfather. The facilitator explained that the silver teapot in the painting was a prized possession of the artist, the woman's grandfather, and a retirement gift from his years working on the railroad. The fidgeting stopped as 'Joan', 'Fiona' 'Adam' and 'Norma' followed the story closely. There were audible exclamations of "oooooh" and they were all visibly excited by the story and the connection between the Gallery in which they were sitting, the artist's granddaughter, and the artist.

The second group to observe the painting began talking immediately. 'Joyce' wanted know the title of the painting and which newspaper was depicted in the painting. The facilitator suggested that the newspaper is an important part of the painting, but did not explain why. She suggested that they would talk about it later. The facilitator went on to ask the group what they saw in the image and 'Joyce' again commented on the newspaper, but still the facilitator did not explain the significance. 'Richard' suggested that it looked like "there is something wrong" (referring to the painting) and while the facilitator acknowledged that this was a good point, she changed the subject again. 'Joyce' and 'Richard' began talking between themselves as 'Richard' was keen to talk about what he thought was wrong. The facilitator talked about the colours used and when asked his thoughts 'Daniel' simply said "she looks like she has a lot of trouble on her mind". It was only much later in the session that the facilitator drew attention to the text of the newspaper in the painting, and picked up on the foreboding that 'Richard' and 'Daniel' had intimated. The group overall did not interact with each other to any great extent. Both 'Paul' and 'Joyce' were proactive in asking questions and commenting. There was, however, no building of narrative or coherent relationship between the questions and comments. Some members of the group seemingly wanted to engage with the content, while for others identifying colours and objects appeared to fully engage them. As they moved away from the painting, 'Daniel' suggested that the painting showed the "good old days". 'Joyce' stayed behind to have a closer look as the group moved on.

Important people

The facilitator, 'Paula', who had introduced one of the groups to John Brack's *The new house* earlier in the day, facilitated the viewing of George Lambert's *Important people*. As the attendees gathered in front of the painting 'Norma' was placed in her wheelchair next to 'Karl' who was already seated. 'Karl' had had very little exchange with peers, facilitators or with the artworks. However, on a number of occasions 'Norma' and 'Karl' exchanged looks and a few words that were inaudible. Both smiled broadly at each other before looking away.



Figure 7. George W Lambert. *Important people* (1914-21). Oil on canvas, 134.7 x 171. Cm. Art Gallery of New South Wales. Purchased 1930.

The final painting viewed by this group was close to the Gallery shop and the Gallery entrance. Noise levels were significantly higher than for the previous viewings, which sometimes made it difficult for people to hear. In addition, the single row seating arrangements for this viewing was not ideal for peer-to-peer interaction and most of the interaction occurred between the attendees and the facilitators. The attendees appeared more distracted and seemed to look around more often than

previously, and there was signs that some attendees were becoming tired. However, despite these challenges, the conversation was dynamic and did not slow down. 'Paula' began by asking the attendees if they liked the painting. This strategy of asking for opinions worked well as a starting point each time it was used. Five out of the six attendees nodded, and only 'Karl' did not respond. This painting seemed potentially more complex than the previous paintings viewed because of its allegorical content. However, it appeared to provoke a greater range of discussion. 'Adam', who had been very considered and measured in his response previously, was considerably more engaged and proactive in asking questions about the characters depicted and their relationships.

The conversation ranged between personal associations with the characters in the paintings and interpretation of allegory. For example, 'Fiona' focussed on the welfare of the baby, with 'Norma' and 'Joan' being in strong disagreement about whether the characters were happy or not. Happiness was a theme that was revisited several times during the day. The male attendees in both the first group and the second group on the following day were all interested in talking about the wealth of the men depicted in the painting; how "smart" they were; their jobs; their attire; and how this related to the title *Important people*. Richard pointed out that the painting depicted "three very different people". There were several jokes and little asides about who was the father of the baby in the picture. The attendees remained excited and talking even after the viewing was over.

Laughter in the Gallery

On occasions, a viewing seemingly took on a 'life of its own'. While observing a group in the Gallery space, it became apparent that there was a great deal of hilarity taking place close by in another group not being closely observed as part of this study. A researcher was able to move into a position to observe the group. A particularly vibrant care staff member was engaged in conversation with attendees who animatedly responded to her comments, interjecting and disagreeing with great humour. The conversation was about the formal construction of Meere's painting *Australian beach pattern*. 'Mark' pronounced that the painting was "unrealistic, too posed, and the bodies were too beautiful". The group discussed (in non-technical terms) aspects of the painting including its form, colour palette, and the artist's intent. 'Nigel' copied the poses of the people represented to show how they were not realistic. As the group moved to view another painting 'Sylvia', who had laughed constantly but spoke little, walked up to a nearby painting and viewed it in close up for several minutes, before being called away.



Figure 8 Viewing *Australian beach pattern*, Charles Meere. © Charles Meere Estate. 1940 and Freda Robertshaw. *Australian beach scene c 1940*. Oil on canvas, 112 x 125 cm. Collection of Joy Chambers-Grundy and Reg Grundy AC, OBE. © Estate of Freda Robertshaw

The participants

Having explored group dynamics during viewings of the paintings, it is useful to have a more detailed understanding of the attendees and their experiences. The following summaries are assembled from the observation schedule of positive and negative verbal and non-verbal responses of attendees viewing the artworks, the notes made by researchers, content analysis of the audio and video recordings, as well as information provided by families and care staff. The findings have been condensed to reflect a narrative view of the individuals' experience.

'Fiona', who had shown discomfort at the community centre café while waiting for the bus, was also uncomfortable on the bus and several times suggested, "the bus [trip] is too long". She showed distinctive signs of not being happy as the group reached the Gallery, fidgeting and scowling. While completing the questionnaires she was reserved and neutral in her expression. She was able to answer questions in the survey with assistance from care staff. However, in the Gallery space 'Fiona' smiled the entire time. No negative responses were observed throughout the visit. Her eyes moved back and forth from the facilitator to the paintings. She followed

conversations with her eyes and head and was not distracted at any time by anything else in the Gallery. She listened to what other people were saying and leaned her body in towards the facilitator (a positive body language sign). She engaged with all of the paintings and the facilitator and answered any and all questions put to her. She also began speaking proactively, and initiated new strands of conversations. For example, when viewing *Breakfast piece*, she suggested that the woman pictured at the breakfast table was waiting for someone.



Figure 9. One attendee remains to take a closer look at a painting that has caught her eye. Freda Robertshaw. *Australian beach scene c 1940*. Oil on canvas, 112 x 125 cm. Collection of Joy Chambers-Grundy and Reg Grundy AC, OBE. © Estate of Freda Robertshaw.

When viewing *The new house 'Fiona'* focussed on the content of the painting and talked in broken sentences about the closeness of the couple depicted. She spoke with a strong European accent that suggested English was not her first language. She was animated, she pointed and gesticulated, and sometimes spoke with annoyance on the role of the woman depicted in the painting such as how "she was working for him". Similarly, she became animated when viewing *Important people* as she focussed on the figure of the baby, pointing out the lack of coverings or blankets and the roughness of the basket in which it was placed. As the group left the Gallery and headed downstairs in the lift, 'Fiona' told one of the researchers, with

tears in her eyes, that the baby had reminded her of her babies, and continued: “The women work hard, always the women, not the men”.

‘Joan’ was a very smartly dressed woman, who was accompanied to the bus by her daughter. ‘Joan’ walked with a stick, but was independent and resisted any help. On being offered assistance by a member of the care staff she responded curtly, “I can do this myself”. She was alert on the bus looking at people, looking out of the window, and responding each time a carer or volunteer pointed to objects of interest out of the bus window. During coffee break and the form-filling her responses were mixed. She was happy to tell stories to researchers and care staff, but became anxious when asked to complete a questionnaire. However in the Gallery space, she once again relaxed. ‘Joan’ was the most vocal and energetic in her group. She responded quickly to the facilitator’s questions and prompts, and answered every question asked. She was proactive in asking the facilitator to repeat questions if she did not hear them. She listened to other attendees and added comments. She nodded as people talked and smiled throughout all of the viewings. She ‘looked’ happy. On at least five occasions ‘Joan’ pointed to the painting as she talked and on two occasions turned her full body, while remaining seated, to look at and respond to people behind her as they talked. No negative responses were observed in the Gallery space.



Figure 10. Attendees engage with each other, with the facilitator and the artwork

Travelling to the Gallery and during the form-filling ‘Norma’ maintained an alert, but neutral expression. ‘Norma’ was happy to complete the questionnaire with assistance. However, while doing so she asked on several occasions “what are we going to do today?” Her questions were monotone and did not suggest any concern or nervousness, or any real curiosity. In the Gallery space ‘Norma’ followed the conversation moving her head and eyes constantly to see what was being talked about and to hear what was being said. One researcher noted that she seemed to be a “true listener” as she focused intently on other attendees as they spoke, smiling and nodding as she followed the various conversations. ‘Norma’ had some hearing difficulties and this became more apparent as ambient noise in the Gallery increased. However, it did not seem to affect her focus or intention to be part of the conversation. ‘Norma’s’ comments were less frequent than others, but seemingly more considered. Her body movement was not free and uninhibited. She did not point or gesticulate but, held her bag tightly on her lap, a behaviour often observed in people living with dementia as it provides a sense of security (Buse & Twigg, 2014) However, she did not appear uncomfortable or concerned and no negative responses were observed throughout the visit.

‘Karl’ was escorted to the bus by his father and uncle. While travelling to the Gallery on the bus ‘Karl’ yawned constantly, appeared bored, and fell asleep for a time. He did not show any engagement with anyone on the bus or anything out of the bus window. He smiled and laughed if people spoke to him. However, he did not speak without being spoken to and needed help in choosing what he would have to drink at the Gallery and for lunch after the Gallery visit. ‘Karl’ has early younger onset dementia (usually YOD refers to people under 65 years of age, but ‘Karl’ was significantly younger), and also exhibited comorbidity with a likelihood of Down syndrome. During the form-filling period ‘Karl’, who had been very sleepy on the bus, became alert and responsive. He nodded in response to question he was asked, but it was not clear if he understood them. The only question completed with any level of reliability on the questionnaire was the mood survey scale.

In the Gallery space ‘Karl’ was quiet, but appeared calm and content. He did not actively engage with the facilitator, the paintings, or any of the other attendees. He did not look at people when they spoke, and he frequently looked around the Gallery. It was not possible to tell whether he was listening to or following any of the conversation. However, he did not seem entirely disengaged from his surroundings and there was no suggestion that he was sleepy or bored. He looked at passers-by and paintings in the space, but seemingly without intent. He was not restless and sat still. When asked a question by the facilitator he was hesitant to respond. When a second facilitator moved close by and touched his shoulder, he responded by touching her arm and they began to talk about the painting one-to-one. ‘Karl’ seemed

to develop more confidence through this exchange and when the facilitator asked him what he thought the man in the picture (*The new house*) was doing, he replied that he thought the man was going to play golf! The response and the confidence of the reply caught attendees, care staff, and facilitators by surprise and prompted some laughter and ongoing discussion. 'Karl' appeared briefly to be enjoying the attention and the conversation.

'Adam' lives alone. On the bus journey he appeared articulate, engaged, quietly confident and contained. He was able to answer questions about what he would like for lunch later that day, confidently and without hesitation. He engaged in conversations with care staff and volunteers. At coffee he was able to complete the survey questionnaire unaided. He smiled throughout the entire visit to the Gallery. 'Adam' spoke less than other attendees, but his responses were coherent and precise. He looked constantly at the facilitator and the painting and was not distracted even when there were noisy schoolchildren in the Gallery. He responded enthusiastically to questions put to him about the artworks, and on occasions spoke proactively as he made independent observations. Towards the end of the first viewing he appeared tired, as his face briefly had a neutral expression and his eyes were less focussed. It was noticeable that his soft voice was not being heard over the chatter of the females in his group, and he seemed to withdraw from the conversation. An Art Gallery of New South Wales facilitator sat close by to talk one-to-one and to relay his comments to the lead facilitator so that the group could hear his responses. As a result, he again became active in the conversation. No negative responses were observed.

'Joyce' clearly has a love of art. This was apparent from the conversation that had taken place in the community centre café earlier in the day. She, together with her husband, had explained that her parents had both been artists. She appeared very comfortable and confident in the Gallery space. She sat, leaning forward intently in her seat and appeared very focussed. She looked at both the artwork and facilitator and continuously followed the conversation as other attendees spoke. She responded quickly to questions and on several occasions spoke proactively. 'Joyce' also asked questions. She listened intently to the facilitator's response to her questions and then a few minutes later asked the same questions again. Each time the facilitator calmly answered the question as if she had not been asked it before, and 'Joyce' listened to the response with the same intensity. She was not aware that she had already asked the same question several times before. No negative responses were observed.

'Richard' lives alone, but has family who visit often. He appeared quiet and self-contained, articulate and engaged. On the bus he talked with the care staff about a

film that he had seen, was able to name the actors, talk about the plot, and recommended the film to everyone. 'Richard' remained quietly confident and somewhat aloof in the Gallery as he quietly and calmly looked at the painting. He followed the conversation, nodded, and answered questions from the facilitator. He did not talk much, but all comments were thoughtful and considered. For example, after some ongoing discussion 'Richard' proactively stated that he did not like the painting (*The new house*). When asked why, he gave the question careful consideration. He said that he was not sure of what it was he did not like, but he talked about the subdued colours and the absolute stillness of the figures. His dislike of the painting did not appear to be any reflection on his enjoyment of the viewing. 'Richard' began to comment more frequently as he seemingly became more interested in the focus of various conversations. In particular, as *The Important people* generated comments about the roles of the males depicted in the painting, 'Richard' responded frequently, enthusiastically, and without being prompted. He took a lead in the discussion. He was clearly listening to other people's comments and responded directly to his peers. He smiled and became particularly excited, as seen by a dramatic change of facial expression when the facilitator made reference to *Pygmalion*. No negative responses were observed.

'Paul' was accompanied to meet the bus, by his wife. Both were very stylishly dressed. His wife was very keen to complete the questionnaires and to talk about 'Paul's' experience of the Gallery. She explained that 'Paul' has aphasia and had lost some speech and the ability to write. He had however, started to regain some language skills. 'Paul' was very affable and smiled as he asked his wife where they were going that day. While the meaning of his comments could be understood, his sentence structure was convoluted. As the care staff escorted 'Paul' to the bus he joked and smiled, but seemed unsure and confused. However, he seemed visibly happy on the bus as he was smiling, interacting with care staff, pointing at things out of the window, and talking. But, he became anxious when asked if he would like to complete a survey questionnaire and asked about his mood that day. He made it clear that he did not want to answer any questions. He pointed to himself and said, "I know, I know". The combination of words and body language suggested that he knew how he felt with an insinuation of 'what business is it of yours'. The questionnaire was withdrawn to avoid further distress. He remained anxious in the café space while the other attendees finished completing the forms.

On moving into the Gallery 'Paul's' demeanour changed significantly and he was visibly less stressed and more excited. He was vocal from the moment he sat in front of the first painting. He answered questions from the facilitator and proactively raised questions. He gesticulated with his arms and hands and stood up on several occasions to point at elements of a painting. His pronunciation was not clear and the syntax of

his sentences not always correct. Hence it was difficult to understand what he was saying on occasions, which clearly caused him some frustration. 'Paul's' head and eye movement suggested that he was less interested in group conversations or peer comment, but very focussed on looking at and engaging with the artwork. At the end of one viewing, as the group moved from one painting to another, 'Paul' became very animated and took one of the researchers to the window where he provided details (not completely coherently) about a naval ship docked in the harbour and visible from the Gallery. On sitting down, 'Paul' again was the first to answer questions put by the facilitator and on viewing *The Important people* Paul nodded excitedly as the conversation moved to discussion of *Pygmalion* and the musical *My Fair Lady*. There was no sign of 'Paul's' previous anxiety and no negative responses were observed in the Gallery. At the end of the visit 'Paul' walked up to the facilitator and enthusiastically exclaimed, "Thank you, thank you".

The community centre team leader had advised researchers that 'Daniel' "hated" going to the Gallery. She explained that she often sat next to him in the Gallery, as her presence close by was calming for him. When picking up 'Daniel' from his home, his wife 'Geena' reiterated how 'Daniel' felt about the Gallery stating: "He hates going to the Gallery, he hates it. Even when we used to go when the children were 13 he hated it". This conversation took place out earshot of 'Daniel', who asked his wife "where are we going?" She replied, "You are going to the Gallery", to which he replied, "I hate the Gallery". 'Daniel' boarded the bus and immediately engaged in what appeared to be (and was confirmed later as) familiar 'banter' with the community centre team leader. There was no sign of 'Daniel' being unhappy, stressed or disliking the bus journey as he laughed and asked if she had any money in her handbag and laughingly suggested he would look after it for her.

In the Gallery space no behaviours could be observed that supported 'Daniel's' apparent dislike of the gallery. He was very quiet during coffee break and the form-filling period. He became more animated in the Gallery, answered all of the questions asked of him, and spoke proactively. His answers, questions, and comments appeared carefully thought out. He looked intently at the artwork, followed all of the conversations and interacted on a one-to-one basis with both the facilitator and his peers. When looking at *The new house*, he laughed and commented: "The way the man and woman are holding each other – a bit too much for this time [of day]!" When viewing the second painting (*Breakfast piece*) 'Daniel' was sitting at the end of the line of chairs and may not have been able to see the painting very well due to the reflecting glass in the frame. He was also positioned next to one of his peers, who was not engaged in the group interaction. He seemingly became isolated and was noticeably quieter. He seemed to lose attention. He hung his head and did not always turn his head to look at the person speaking. He looked around at other visitors

passing by. Nevertheless, he did also look at the artwork, responded to questions when asked, and talked with the one of the care staff about the painting. At the final painting (*The Important people*) 'Daniel' was sat next to 'Richard', who was fully engaged in discussion about the painting. It was easier to chat at this viewing because of the seating arrangements. 'Daniel' responded more frequently and with greater expression. Towards the end of the visit he began to look tired and yawned. However, overall, throughout the visit no negative responses were observed and, while at times he appeared to withdraw and remain quiet, there was no sense that 'Daniel' was not comfortable being at the Gallery or that he "hated" going to the Gallery. For much of the time he appeared to be enjoying the experience.

'Anita' had arrived at the community centre cafe early to wait for the bus. Her primary carer is her husband, and she also has a dedicated personal carer who accompanies her on all excursions and stays with her at home each day. She appears well cared for with a close and loving family. 'Anita' is no longer able to speak and her ability to use non-verbal communication is also limited – for example, she did not gesture, move her hands or feet, or change expression. She looked at people intensely and watched their movements without comment, change of demeanour, curiosity or inhibition. On the bus she was not able to answer questions about what coffee or lunch she would like and was not able to make a selection from the menu provided. She looked out of the window, seemingly without purpose. She was very sleepy on the bus and had to be woken several times. During the coffee break and form-filling period 'Anita's' carer worked with her to complete the questionnaire. However, 'Anita' showed no verbal or physical response to any questions put to her. Therefore, 'Anita's' carer completed the questionnaire based on her extensive and intimate experience and knowledge of 'Anita' over a long period. While this was useful in providing insights into 'Anita's' behaviour in the Gallery, the data could not be used in the survey summary data.

In the Gallery 'Anita' appeared alert and comfortable, and there were no signs of the previous tiredness, boredom or sleepiness. She looked around the Gallery and at the other attendees. She was calm and did not fidget. However, her behaviour changed very little throughout the visit. She did not appear to look intensely at any of the artworks; she scanned them briefly and then her eyes moved on. Her facial expression was fixed and there was no talking, smiling, nor any expression of attention. One researcher noted that during the viewing of *The new house* 'Anita' did not communicate directly, but turned her head to look at other attendees and conversations as they took place. The researcher noted: "She briefly seemed to focus on the conversation and her eyes followed the facilitator and another person speaking".

In addition to the above participants there were also a number of attendees who were not part of the group under close observation. However, they did complete questionnaires or had questionnaires completed by family members and primary carers. They included:

- **'Julie'** is very quiet and self-contained. She appeared to be aware of her condition and commented on her memory loss on a number of occasions. She was neatly dressed and, in response to a conversation on the bus between care staff about hair and clothing, she proactively recalled, seemingly fondly, how she used to dye her hair when she was young. She appeared to be proud about being able to contribute to the conversation.
- **'Christine'** and **'Mark'** are mother and son and they live in the same house cared for by 'Mark's' wife. 'Mark' has a brain injury from an accident and his mother has dementia. 'Mark' was sprightly and answered questions for his mother. They operated as a couple in talking about what 'they' wanted rather than answering as individuals. They selected exactly the same drink at the Gallery and the same food for lunch.
- **'Sylvia'** is of Chinese ancestry. She was very quiet on the bus, but smiled and responded to questions put to her. It was apparent that English was not her first language and it became evident that her communication difficulties may be because of her limited command of English rather than a result of her condition.
- **'Mary'** lives alone and was recently widowed. She brought this into conversation during introductions and explained that she still misses her husband greatly. 'Mary' was alert, able, and engaged.

The return journey

The return journey to the community centre following the Gallery visit was quiet. The attendees looked tired; they were yawning or closing their eyes. The care staff initiated conversations about the Gallery asking questions such as "what was your favourite?" 'Mark' went into great detail about the construction of Meere's *Australian beach pattern* and the beautiful bodies in the painting which were "too posed and unrealistic". 'Adam' responded with quiet annoyance stating: "See, this is what happens. I can't remember". One of the care staff prompted him by mentioning *The Important people* and he finished her sentence saying "yes, when you remind me I can remember, this is what happens". Similarly, in response to the same question, 'Julie' declared: "This is what I do, what I do. I like ... but I can't remember".

Visit 3: People who know they love art, music and culture

Context and cohort

The group participating in the third visit to the Gallery under observation were from a residential aged care facility on the North Shore of Sydney and had been coming to the Gallery regularly. When they arrived at the Gallery it had been raining heavily and there was a flurry of organisation to get umbrellas up and wheelchairs ready to get people quickly off the bus and out of the rain. As 'Rita' walked into the Gallery she declared loudly: "I love coming here. It is the highlight of my week. You are always so nice to us."

Coffee and form-filling

The Art Gallery of New South Wales facilitators and the care staff accompanying the attendees had been briefed with regard to the procedure for completing the forms. A larger number of people in this group were able to complete the forms unaided compared with the two previous visits. However, assistance was on hand for those who needed it. Conversations took place between the facilitators, care staff, and attendees, who all spoke coherently. 'Elaine' joked that it was good that we were making a note of everyone's names (in completing the questionnaires) "in case someone decided to steal an artwork!"

'James' proudly announced as he completed the questionnaire that he was 92. He enjoyed completing the questionnaire, but explained that he could not be completely honest as modesty prevented him from being answering that everything was "excellent" which he would like to do. He began to reflect on his own experiences and recalled a time when he was the person giving instructions and collecting forms. 'Rita' completed her questionnaire without assistance. Following on from her earlier declaration that she loved coming to the Gallery, she once again declared: "I love coming here. It breaks the monotony!"

Experiencing the paintings

Spring frost

'Australian landscapes' was the theme for this group and the visit began with a viewing of *Spring frost* by Eliot Gruner (1919). The large painting is a favourite with the general public and is in a prominent position in the Gallery. The seats were carefully arranged so that everyone in the group could see the painting and to also allow for the general public to pass by or view the painting without disturbing the group. The Art Gallery of New South Wales facilitator was 'Cathy', who had presented to attendees in visits one and two. Before seating everyone 'Cathy' invited attendees to take a closer look at the painting and to look at the brush strokes and the detail.

Each attendee took advantage of the invitation and physically moved closer. As they sat down, the group were immediately engaged as 'Cathy' began to talk about how the artist had painted the shadows and the light and shade. 'Samuel' immediately asked when the work was painted and wanted to know about the artist. The language in this group was noticeably more sophisticated than had been observed in the first two groups. 'James' suggested the trees were "voluminous" and that the painting was "devoid of sunlight". In addition, the group demonstrated understanding of the context of the artwork. For example, as 'Cathy' explained that the work was painted after the war, 'James' responded: "A return to normality."



Figure 11. Elioth Gruner. Spring frost 1919. Oil on canvas, 131 x 178.7 cm. Art Gallery of New South Wales. Gift of F G White 1939

Discussion in this group was more conversational than had been observed in the first two groups. It involved greater peer-to-peer interaction and, while the facilitator led with questions, there was turn-taking and an acknowledgement of each other's comments. Discussion was able to develop. For example, 'Samuel' pointed out the importance of sunlight in the painting as it came through the trees. 'James' suggested that the painting is "devoid of sunlight" sparking a great deal of discussion between

'Cathy', 'Samuel' and 'James' until 'Cathy' was able to establish that 'James' was apparently pointing out that the sun itself could not be seen.

The group dynamic meant that attendees began to finish each other's sentences, and that they were comfortable enough to disagree. For example, 'James' disagreed that this painting was a landscape, as had been stated in the introduction. He argued that the focus of attention was on the animals and the farmer, and not the land. 'James' spoke forcefully and suggested that the cows look like they are dead. This seemed at odds with the content and tone of the conversation so far. However, the facilitator interpreted 'James's' comment as meaning that the cows appeared to be very still. 'James' nodded enthusiastically at her interpretation and continued to talk about the stillness, calm, and how realistic the painting is.

The conversation revisited the topic of light and shadows and there was some disagreement as to whether the image depicted early morning or evening. Each person pointed to elements of the painting that backed up their particular argument. 'Zoe' confidently suggested that the shadows are stronger in the evening and therefore it is evening. 'James' suggested that one clue to the time of day was that the cows had already been milked. Similarly, in response to 'Cathy's' question "what time of year was it painted?" 'Samuel' replied "spring, because you can see the blossoms on the trees", pointing out small almost insignificant blooms in the painting.

'Cathy', the facilitator, began to talk about how the artist used colour and 'Rita' informed the group that she painted and was therefore very interested in the colours used. She used language consistent with that of people with knowledge of painting. She went on to point out how dark the tree trunks were and how this showed that the light is coming from behind the trees. She gesticulated with regard to the direction of the sunlight in the painting. There was laughter all around as 'Cathy' highlighted a patch of bright red paint on the farmer's ears suggesting that the sunlight was shining through them. The group was very focussed as they looked at minute details in the artwork. 'Cathy' held up coloured pieces of cards she had brought with her and asked the attendees if they could match any of the colours in the painting. Both 'Zoe' and Rita were adept at picking and matching colours and enjoyed identifying how they had been used in the painting. 'Zoe' talked in depth one-to-one about the painting to an Art Gallery of New South Wales facilitator sitting close to her. When asked if she would like to have made this painting herself, she responded, "[I am] quite satisfied just looking".

Sofala



Figure 12. Russell Drysdale. *Sofala* (1947). oil on canvas on hardboard, 71.7 x 93.1 cm. Art Gallery of New South Wales. Purchased by the Gallery Trustees from Macquarie Galleries, Sydney 19/12/1952.

As the group moved to the second painting in the Australian Landscape series the facilitator, 'Karen', introduced the painting, suggesting it was very different to what they had just been looking at. 'James' responded with "yes, this is an entire village". 'Zoe', seemingly reflecting on the discussion in relation to *Spring frost*, asked whether the painting depicted morning or evening.

'Karen' asked each of the attendees to simply look at the painting and say words that they associated with it. They took turns responding:

"Very Brown."

"Loneliness."

"Deserted."

"Destitute."

27

"Failure."

'Samuel' suggested that the painting represented the "spirit of Australia".

The group no longer waited to be asked questions. 'Rita' said, "I love the sky, there are so many different colours in it" and the group started drawing parallels between the town depicted in the painting and contemporary Australia. 'Samuel' commented "I like the balcony, the detail of the balcony" and the group began to discuss the wrought ironwork and noted that it is similar to that which can still be seen in Paddington, NSW.



Figure 13. The group listened to a reading of "The roaring days" by Henry Lawson

'Karen' introduced the history of the town depicted in the painting and talked about its gold mining past. As she talked, the attendees finished her sentences, "yes, gold", "the gold rush". They talked about the mining town, the hard lifestyle, and what it might be like to live in such a bleak landscape. As they talked, they began to relate their thoughts to elements in the painting and started to discuss how the painter created this sense of loneliness. 'Karen' asked why the painter painted this way and 'James' responded, "to show no humanity" and repeated that the painting is about "failure". 'Rita' continued suggesting that the artist "wanted to show what the place was like with no people around, and to show how they lived in difficult circumstances". As each person took turns, they talked about the landscape and the heat suggested by the painting. All eyes were fixed on the small painting. 'Zoe' appeared more activated when looking at the Drysdale painting compared to the

previous painting. She responded and interjected without being prompted and paid great attention to what her peers said. Her facial expressions indicated quiet excitement.

The space was quiet with very few members of the general public around. 'Karen' asked the group if they minded if she read them a poem. 'James' immediately replied, "please do!" 'Karen' said she would like their opinion as to whether the Henry Lawson poem *The roaring days* epitomised this artwork for them. She read:

The night too quickly passes
And we are growing old,
So let us fill our glasses
And toast the days of gold;
When finds of wondrous treasure
Set all the South ablaze
And you and I were faithful mates
All through the roaring days!

'Zoe' looked intensely at the reader and 'James' and 'Rita' alternated between looking at the painting and the reader. 'James' responded immediately with "yes!" 'Rita' smiled from "ear to ear" and suggested that she never appreciated the painting as much as she did at that moment. She nodded and exclaimed: "Excellent". One researcher recorded that watching the attendees looking at the painting and hearing 'Karen' reading the poem was "spine tingling".

My garden

As the group arranged themselves around the third painting of the day, all attendees were very comfortable and 'in the flow'. There was no sense of waiting to be asked about their thoughts they seemed both physically and mentally engaged as they leaned forward in their chairs and looked at the painting and the facilitator. The painting was introduced as being painted in 1965 and 'Rita' immediately began to talk about the vegetation and the trees. 'James' picked up on this theme and suggested that the painting was about the birth of life and about nature. 'Samuel' suggested that the painting depicted bushfire and 'Rita' continued with insightful comments making reference to fire and rebirth. 'Zoe' turned her head and noticed a couple with a young baby in the Gallery. As the facilitator asked her what the painting reminded her of, she made associations between 'Rita's' comment about rebirth and the people she has seen in the Gallery and commented "kindergarten" and "innocence". 'Rita' continued to smile excitedly as she looked at the painting. She seemed to enjoy

all of the artworks, but the second painting had seemingly activated her interest further. She appeared to be "in her element" as she sat in front of the third painting of the visit. 'Samuel' joined the conversations with concise comments that reflected a keen eye. He nodded frequently. 'Zoe' responded less frequently than her peers, but her comments were deeply felt. Her eyes followed each person as they spoke and she looked intently at the artwork.



Figure 14. Fred Williams. *My garden* (1965-67). oil on canvas, 152.6 x 183.3 cm. Art Gallery of New South Wales. Purchased with funds provided by the Art Gallery Society of New South Wales 1999.

As the visit was drawing to a close, the energy levels seemed to have dropped and the facilitator talked more frequently. 'James' suggested that the painting "is powerful" and 'Rita' said the painting would "remain with her" as she lifted up her hand in an intense gesture. 'James' asked if he could give the facilitator a kiss to thank her. 'Samuel' thanked the facilitators for the intellectual conversation and stimulation.

The participants

'Rita' likes to paint but is modest about her abilities. She proactively announced on several occasions that she loved going to the Gallery, that people treated her so well, and that it broke the monotony of the week. She was knowledgeable about aspects of painting, which was demonstrated in the sophistication, elaborate detail, and depth of some of her comments. She smiled throughout the visit to the Gallery.

'Samuel' was quietly spoken and spoke less frequently. However, he asked thoughtful questions about the artworks and wanted to know details such as dates and artists names. He remained focussed on the conversations and the artwork throughout the visit.

'Zoe's' facial expression varied little during the viewing of the first painting. She sat with her hands firmly grasping the hand of an Art Gallery of New South Wales facilitator who sat next to her. However, she followed the conversation closely and nodded in agreement, with occasional interjections. As the visit progressed, she began to speak more without prompting and to answer questions confidently. Her body language and closeness to the facilitator seemed to belie her confidence in the space.

'James' was the least mobile of the group being in a wheelchair. However, he was both physically and mentally alert. He described himself as "sprightly". He also said, without any prompt, that he liked to have good intelligent conversations. He then went on to say, as he completed the questionnaire, that he did not have many friends anymore and so there were not many opportunities to talk. At times his questions, particularly in viewing *Spring frost*, appeared terse and were at risk of being misconstrued as argumentative or seemingly deliberate disagreement. However, it seems more likely that his manner had been impacted by his keen desire for meaningful engagement and intellectual stimulation. He was intense and focussed throughout the visit and, when not talking, his chin rested on his hands while he surveyed the artwork.

Visit 4: A diverse group—Younger Onset Dementia (YOD)

Context and cohort

The final group to visit as part of the evaluation study was a small group of attendees with younger onset dementia (YOD). Of the four visits observed, the participants in this group showed a greater range of symptoms associated with dementia. This group was for the most part more physically able and mobile. They were between the ages of 55 and 65. The group was made up of people who are living alone at home; living with family and are active, independent and able to drive; and two who have aphasia

and compromised language skills to such an extent that their speech is incomprehensible. The group of seven people arrived at the Gallery with four care staff in attendance after a short journey.

Coffee and form-filling

As the group sat around a table to complete the survey questionnaires and have coffee, it became apparent that there was a very wide range of abilities. While some of the group were able to complete the questionnaires unaided, several including 'Lesley' and 'Nina' were not able to complete any of the questionnaires. 'Harry' was able to answer all of the questions, but with some hesitation. His first language is Vietnamese and he was confused by some of the terminology. The atmosphere was chaotic but joyful and there was much merriment around the table. 'Nina', whose language skills are compromised, provided entertainment for everyone by singing and dancing and performing for anyone who would pay attention. 'Nina' noticed a researcher assisting 'Harry' with completion of his questionnaire and intervened by pretending to 'match make', putting their hands one on top of the other while laughing continuously. As 'Nina' finished singing 'Miriam', who was trained as an opera singer, was encouraged to sing.

Experiencing the painting

Spring frost

The Art Gallery of New South Wales facilitator for this group was Danielle Gullotta. As the Art Access Program Producer she is the most experienced of the facilitators and adept at working with a broad range of mental and physical abilities. As the care staff guided the attendees through the Gallery to the painting to be viewed, there was considerable energy and liveliness in the group. It became apparent that some members of the group were not ready to sit still. Danielle responded to these increased energy levels by inviting each of the participants to individually stand beside her and look at the painting. 'John', 'Oscar' and 'Harry' all looked closely at the painting. However, 'Nina' took the opportunity to perform and sang a song in front of the painting to the applause of the other attendees. She evidently enjoys performing and playfully "made eyes" at the security guards, who responded light heartedly, although not without some embarrassment.

After the impromptu performance, the focus returned to the painting being viewed and focus was directed towards the image of the farmer, the central figure in the painting. 'Oscar' began to make associations between his Irish background and the image depicted, suggesting that the farm looked like an Irish farm because of the damp and mist. He laughed as he began to associate the image of the farmer with the well-known European child's nursery rhyme (and now TV show) *The farmer wants a*

wife. The viewing was carefully handled to allow participants such as 'John', who is not able to see clearly, to take a closer look at the painting and also to create opportunities for the voices of quieter members of the group, such as 'John' and 'Harry', to be heard.

When Danielle asked whether the painting was painted a long time ago or recently, 'Lesley', who is aphasic, responded and seemingly answered the question with the intention of communicating. But her answer was not coherent. The group were told that the painting was nearly 100 years, to which 'Oscar' jokingly commented that the farmer looked good for his age. There was a lot of energy and some focus on the artwork. However, most of the interaction was between Danielle and the attendees, with some peer-to-peer interaction. Before moving to the next painting 'Nina', who had been singing constantly, looked at the painting, and gave a "finger kiss" gesture that suggested she thought the painting was "excellent" or "beautiful".

Sofala

As the group moved on to the next painting, 'Lesley' talked non-stop to one of the researchers. She was intense and pointed to various people and paintings in the Gallery space, but was unintelligible.

As with the viewing of *Spring frost*, there was a great deal of energy in the group. Each member of the group made a comment or carried out an action in response to the painting or the facilitator's comments. For example, 'Oscar' made a joke and everyone began to laugh. He constantly looked at the painting, Danielle and at the other attendees and responded to questions. 'Anna' exclaimed that she did not like the painting as there were no people in it and, she said "no life!" They talked about the colours of the sky in the painting. 'Harry' suggested that it was an evening sky and 'John' and 'Oscar' were clearly thinking and looking intently, as 'Oscar' suggested that there is a fire in the background. Danielle talked about the painting and told the story of the gold rush, to which both 'Miriam' and 'Anna' let out an audible "ooooh!" 'However, it was not possible to develop the fragmented comments into a full conversation or discussion.

Each participant was given a photograph of the modern-day town to look at. The attendees looked up and down to compare the picture and the painting. 'Oscar' observed the differences between the hotel depicted in the painting and the contemporary image and. 'Anna' commented on the number of businesses in the modern day town, pointing to the table and chairs of the cafés. 'John' and 'Harry' were the quieter members of the group and needed to be encouraged to speak. 'John' was asked if he had been to rural NSW and responded that he had been a

couple of weeks previously, but he couldn't remember where. He was seemingly reflecting on this question and the painting when he suggested that "coming in to town pulls you up a bit" – a term that is used by rural people in Australia to suggest that there are extreme differences between day-to-day life on the land and town-life. As the session finished, 'Nina' broke into spontaneous applause, which she directed at the facilitator.

My garden

The Fred William's *My garden* is a large painting. The size of the painting worked well for this diverse group allowing for all of the attendees to be spaced out in front of the work. The diversity of the group came to the fore as most people closely fixated on the facilitator and the painting and were clearly enjoying talking about the painting. However, two members of the group became increasingly distracted.

As they were directed to look closely at the painting the energy level of the group as a whole was high. When asked if they liked the painting 'Oscar' responded quickly saying, "it is very Australian". As Danielle began to talk about the horizon in the painting and how the painter might have applied the paint, 'Oscar' responded enthusiastically by gesticulating with his hands to show how the paint might have been applied. He was very animated and continued to talk about the birds, shrubs, trees, and colours of the painting. The conversation began to focus on gardens and particularly Australian gardens. When asked if he liked the painting, 'Harry' shrugged and said: "It looks very hot". As he was encouraged to speak more, 'Harry' talked about growing up in the hot, but green, jungles of Vietnam and how different it was to the Australian landscape.

'Anna' nodded and followed the facilitator closely as well as turning to look at anyone else who spoke. She regularly nodded, smiled, and responded to prompts from the facilitator. However, she spoke less when viewing *Sofala* as the men in the group seemed to talk more in front of this painting. At the end of the viewing, 'Anna' thanked Danielle and said that she would not have normally liked this painting but now she did. She explained that she appreciated the painting more now that she knew more about it. She went on to suggest that the painting was about "regeneration" – a word chosen by her and one that had not been used previously in the conversation.

It became apparent after a while that some attendees were getting tired and restless. 'Nina' yawned, raised her hand, and jiggled her legs. She also began to sing again as she told the facilitator she was happy. The only person who seemingly had not been happy with the viewing was 'Lesley'. She had become restless and began to take off her name tag. She sat talking to the carer beside her (unintelligibly). They

looked like students talking at the back of the class, Lesley was laughing with 'Paul' as if they had shared a private joke.

The participants

'Nina' was lively and energetic and was constantly active in the Gallery. She clearly enjoyed performing and the attention, and showed no inhibition about where and when she sang or danced. 'Nina' talked almost without stopping throughout the entire visit. However, nothing she said was intelligible. 'Nina' appeared to be speaking Spanish with occasional English words. But, care staff advised that Spanish speakers had confirmed she was not speaking Spanish or English coherently. Despite her penchant for performing, she was able to sit still for short periods of time, and was for those short periods engaged in looking at the artwork.

'Lesley' appeared as if she was deep in conversation with the care staff throughout much of the visit. But, like 'Nina', she had language difficulties and she exhibited rhyming aphasia and was unintelligible. She appeared nervous as she looked at the questionnaires being completed by other members of the group and did not complete any of the paperwork. While viewing *Spring frost* she appeared calm, but her behaviour began to change as the visit progressed. She answered questions when directly addressed to her, but nothing she said was coherent. Her eyes followed the facilitator and she also looked at other attendees. She sometimes smiled and reached out to the care staff sat beside her. On occasions she stood up as if ready to go and then sat down again. She did not appear stressed, anxious or upset, but increasingly restless. A post-hoc interview with care staff who accompanied her on the Gallery visit explained that 'Lesley' had an intense dislike of 'Nina's' "attention seeking behaviour" and her restlessness was often as a result of not wanting to be in the same space as 'Nina'.

'John' was very quiet. He spoke slowly and precisely. He had some visual limitations and was not able to see at a distance. At the start of the visit 'John' did not laugh along with everyone else and spoke very little. He followed Danielle closely with his eyes as she spoke, and also looked at the artwork and a photograph of the painting he had been given to refer to because of his poor eyesight. He increasingly began to respond to the facilitator and smile. 'John' listened closely to the conversation and nodded and responded verbally without being prompted. With encouragement, 'John' was able to draw associations from *Sofala* and to recall elements of a trip that he had made to rural NSW.

'Harry' is of Vietnamese descent and talked freely about his life growing up in Saigon. On the day of the visit he was particularly happy because he had passed a mandatory driving test the day before, which meant that he is able to maintain some

level of independence. He made jokes about his ability to drive and about travelling "only just over the speed limit so as not to get stopped by the police". His comments were indicative that he understood societal rules and also gave an indication of the understanding he had of his condition. He laughed knowingly as 'Nina' tried to "match make" him with a researcher. 'Harry' was very attentive when looking at the Fred Williams painting and seemed more engaged than at any time before. He followed the facilitator with his eyes and moved his head when other people were speaking. He responded to several questions and moved his body forward to hear what other attendees said.

'Oscar' was quietly spoken. He frequently joked and laughed in a focused and relevant manner. He appeared to enjoy engaging in conversation about the paintings and was a frequent contributor to discussion. He seemingly enjoyed all of the viewing, but was particularly energised when looking at the Fred Williams *My garden*. His comments were relevant and engaged.

'Anna', of Korean ancestry, was quietly spoken. She lives alone and appears independent and engaged. She sat throughout the visit with 'Miriam', a woman of Vietnamese ancestry. She appears to take on the role of carer for 'Miriam', answering questions for her and guiding her. They chat together and seem to be close friends. 'Anna' followed the facilitator closely through all of the viewings and responded to questions with enthusiasm and insight. 'Anna' turned her head to hear what other people said and regularly shook her head or nodded. While initially she mainly talked to 'Miriam', who was sat next to her, as the visit progressed, she became less focussed on 'Miriam's' wellbeing and more involved with the paintings.

'Miriam' had been trained as an opera singer and with encouragement sang in the café while the attendees drank coffee and completed the forms. She was more inhibited than 'Nina' and maintained an air of a professional performer as she sang. However, she appeared timid and seemingly looked to 'Anna' for guidance throughout the visit. 'Miriam' followed all of the conversations and looked at the facilitator as she spoke, and at other people as they answered or commented. But, when asked a question directly, 'Miriam' responded to 'Anna' who then repeated her response for the group to hear. At the end of the visit 'Miriam' spontaneously applauded.

Findings from the survey questionnaire

Attendees' responses

Before the Gallery visit, attendees completed a **pictorial mood survey scale**. The completed surveys ranged from *Neutral* (5 responses) to *Very Happy* (6 responses), with most people indicating that they were *Somewhat Happy* (19 responses). This data included attendees who were not able to go on to answer any other questions. Of those who completed the post-visit data, the mood survey results varied from *Very Unhappy* (1) to *Very Happy* (8) with most suggesting they were *Somewhat Happy* (8). Not all attendees who completed the pre-visit survey form completed the post-visit survey. For those who did, no pattern could be observed in relation to attendees' pre- and post-visit responses. Responses included no change in pre- and post responses (4), that the attendee was slightly happier post-visit (four), and the attendee was slightly sadder post-visit (2), and one person suggested in the post-visit mood survey that they were significantly less happy.

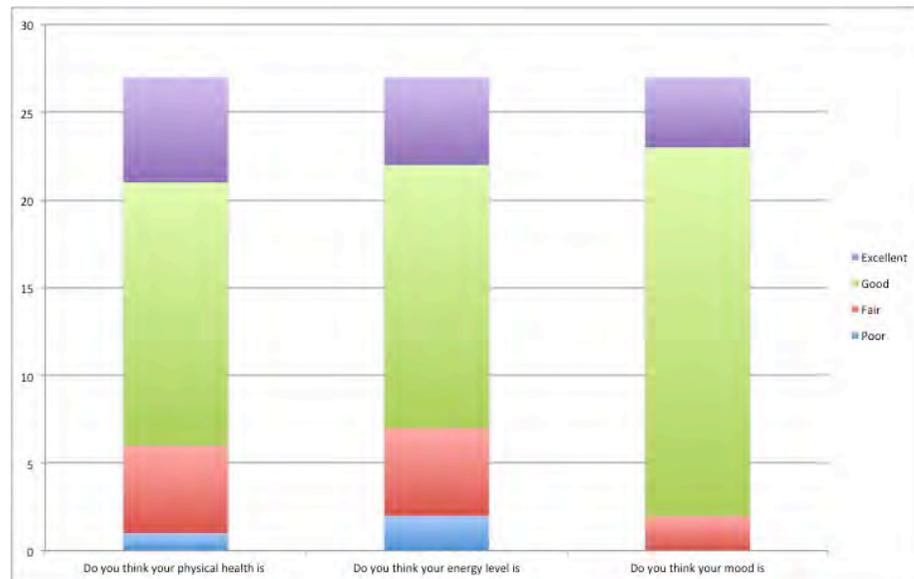


Figure 15. Responses to questions relating to perception of health energy and mood.

Overall, the majority of responses to **quality of life** questions and **self-esteem statements** were positive – that is, *Good* or *Excellent*, or they *Agreed* or *Strongly Agreed* with the statements provided. Figure 15 shows a breakdown of the responses to questions relating to health, energy, and mood. Most attendees thought their

health, energy and mood was good or *excellent*. While there was some acknowledgment of limitations in health and energy with attendees suggesting their health or energy was *Poor* or *Fair*, only two people suggested that their mood was less than *Good*.

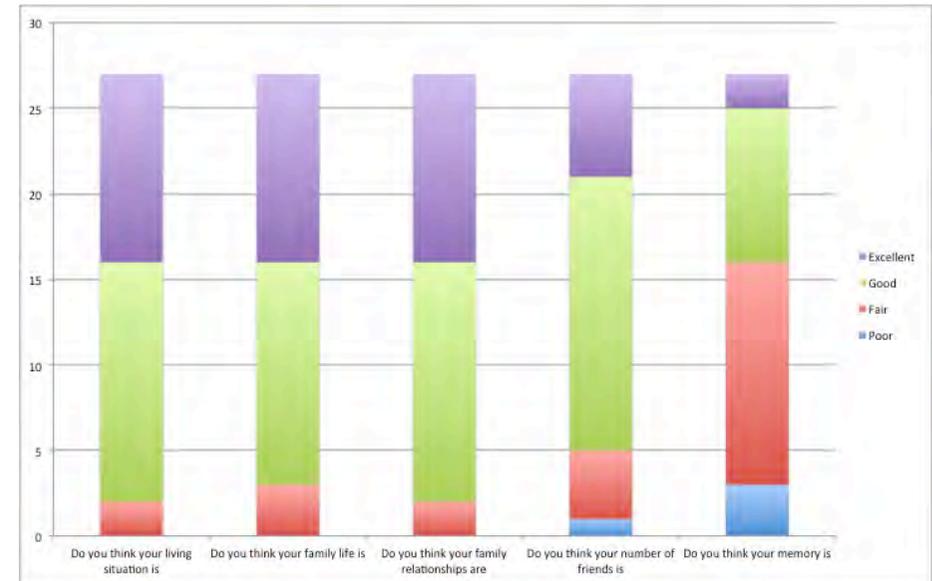


Figure 16. Responses to questions relating to day-to-day.

It is noteworthy in the responses to questions relating to day-to-day circumstances that, for the most part, people were satisfied and happy with their living situation, family and relationships (see Figure 16). However, some people expressed dissatisfaction with their number of friends. During completion of the questionnaire, one attendee verbally stated to the researchers: "I just don't have anyone to talk to, really talk about interesting things." Figure 16 also shows that the majority of respondents recognise their own limitations with regard to memory.

Responses to questions about individuals' personal satisfaction (Figure 17) revealed that the majority of people feel that they have an ability to have fun, have a positive sense of self, and think their life on the whole is good. However, on a practical level, more than 40% of people indicated that their level of money was *Fair* or *Poor* and their ability to do chores was considered *Fair* or *Poor*.

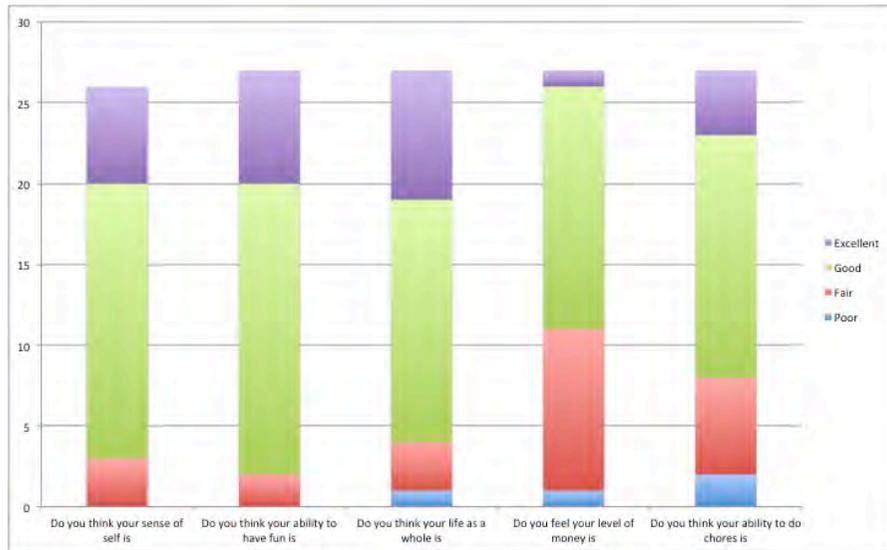


Figure 17. responses relating to personal satisfaction.

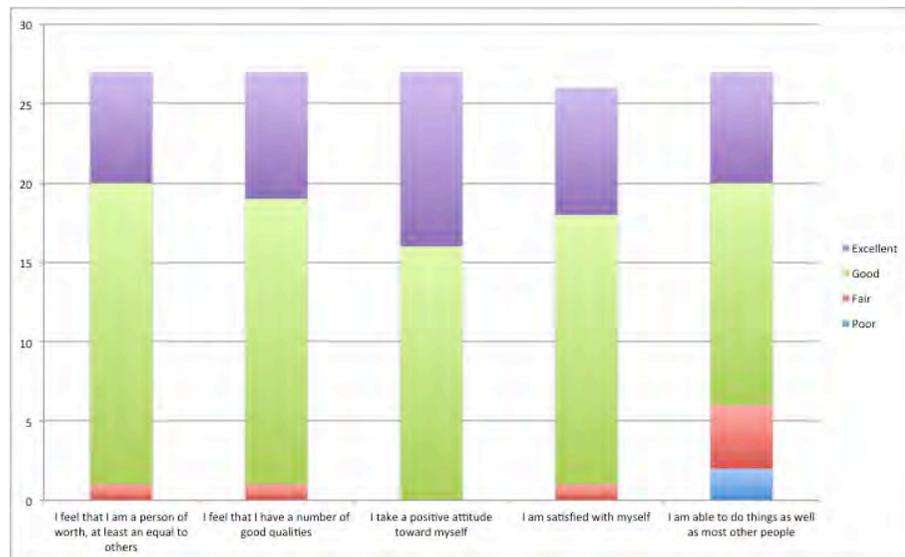


Figure 18. Responses to self-esteem questionnaires.

Responses to self-esteem statements (Figure 18) show that for the most part respondents feel good about themselves and overall have a positive attitude. It is noticeable, however, that it is in relation to practical issues of being able to “do things” is where some people show concern.

Figure 18 provides an overview of how responses to the mood survey (shown in red) correlates to the responses received to in relation to the Quality of Life questions and self-esteem statements. A short vertical line shows that the answers to questions and the answer to the mood survey closely align (e.g., Attendee 2). However, in some cases, mood survey responses were more positive than the QOL responses and self-esteem responses (e.g. Attendee 9) or less positive than the QOL and Self-esteem responses (e.g., Attendee 10), which can suggest a discrepancy in the true feelings of the person completing the questionnaire.

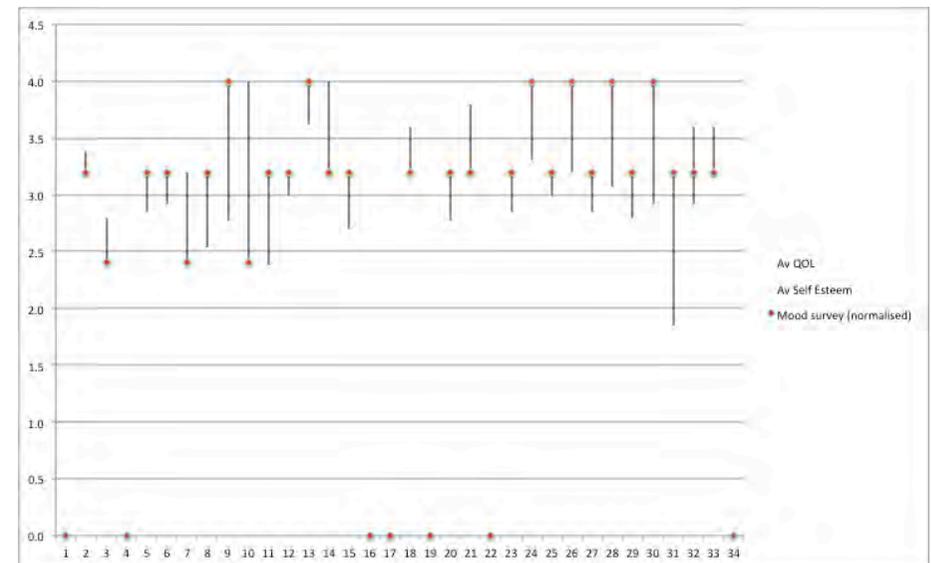


Figure 19. Comparison of mood survey, QOL and self-esteem.

Family members' responses

Family members were briefed on two occasions about the evaluation study and its aims. Some family members were happy for attendees to complete questionnaires at the Gallery immediately before viewing the paintings and consented to attendees being observed and recorded, but were reluctant to complete the pre- and post-visit

paperwork. The main reason given was that the attendee would not remember the visit the day after and therefore the data would not be of any value.

Despite reassurances that any information that they could provide would be useful and important, family members of four attendees did not complete questionnaires. One attendee chose to withdraw without explanation. Up to 10 attendees live alone and did not have a family member or carer to complete questionnaires. Two sets of paperwork were not received, despite self-addressed reply-paid envelopes being provided, and no explanation was given. Of the paperwork completed, a high proportion did not complete all questions and gaps appeared in the data. In addition, three attendees whose families completed questionnaires did not complete questionnaires during the coffee and form filing period because of anxiety or stress. Comparative data was available for 12 attendees.

In responding to the pictorial mood survey on the day of the visit 'how does the attendee feel today', 42% of family respondents and attendees were in agreement with 33% of family respondents saying the attendees were slightly worse than that rated by the attendee (for example if the attendee rated themselves as *Somewhat Happy* the family member rated *Neutral*) and two family respondents saying the attendees mood was slightly better than that rated by the attendee. One family respondent rated three points higher than the attendee's rating (they assumed that the attendee was feeling significantly better than the attendee stated).

Health, energy and mood

There were some notable differences in relation to how family members and attendees assessed the attendees' health, but less so for energy and mood.

	Health	Energy	Mood
Family estimates much worse		9%	8%
Family estimates slightly worse	25%	18%	17%
Complete agreement	33%	55%	67%
Family estimates slightly better	33%	9%	
Family estimates significantly better	8%	9%	8%

Day to day living

Interestingly, 67% of attendees' families assessed the attendees' number of friends as significantly worse than the attendees did, and 58% viewed the attendees' memory as worse than the attendee thought.

	Living situation	Family Life	Relationships	Friends	Memory
Family estimates much worse	18%	17%	27%	67%	
Family estimates slightly worse	27%	33%	18%		58%
Complete agreement	45%	33%	45%	17%	25%
Family estimates slightly better	9%	8%	9%	8%	8%
Family estimates significantly better		8%		8%	8%

Personal satisfaction

There was little consistency between the responses from family members and attendees in relation to questions relating to personal satisfaction. Some 42% of family members estimated the attendees' ability to have fun as worse than thought by the attendees, and 33% estimated it was better than the attendee thought. The greatest variation in responses was in relation to the attendees' sense of self with only 18% in agreement (45% rated it worse and 36% better). Two thirds (67%) of family members estimated attendees' ability to do chores as worse than the attendees' own estimation.

	Sense of self	Have fun	Life as a whole	Money	Chores
Family estimates much worse	27%	25%	8%	27%	17%
Family estimates slightly worse	18%	17%	33%	18%	50%
Complete agreement	18%	25%	50%	45%	17%
Family estimates slightly better	18%	33%		9%	17%
Family estimates significantly better	18%		8%		

Self Esteem

The greatest discrepancy in family member and attendee responses to self-esteem statements was in relation to the extent to which the attendees are satisfied with

themselves. In this regard, 42% of family members suggested that the attendee is less satisfied with his or herself than is borne out in the attendees' responses. The highest agreement was in assessing whether the attendee thinks they are a person of worth, with 58% in complete agreement.

	Person of worth	Have good qualities	Positive attitude	Satisfied with myself	Do things as well as others
Family estimates much worse	9%			17%	8%
Family estimates slightly worse	9%	42%	25%	25%	8%
Complete agreement	64%	50%	58%	33%	58%
Family estimates slightly better	9%		8%	17%	8%

Care staff responses

The care staff completed a mood survey scale after their visit to the Gallery. From 11 responses, most were *Somewhat Happy* (7), two were *Neutral*, and two were *Very Happy*. Care staff had most frequently been in the role for two to three years (5); with three people being in the role a year or less, and one person more than five years (two people did not respond).

Four care staff had careers in care work, and several had come to the care industry as a result of a change of career or as a result of caring for a family member. Most care staff came to their role because of their "passion for helping people", "a sense of community", and "wanting to improve people's quality of life". More than half of the care staff had no experience of art other than attending the Art Access Program with the attendees.

Care staff reported that the most rewarding experiences in relation to the Art Gallery of New South Wales Art Access Program was in seeing attendees "actively engage in meaningful activities", "concentrate and express themselves", and "witnessing the enjoyment clients get from the program". They enjoyed "getting the more quieter participants to voice their opinions on paintings" and suggested that they were able to gain an "understanding [of] clients' thoughts on art" and learn new things about the attendees, many of whom they had known for several years.

The care staff expressed admiration at "the way the volunteer guides draw the interest of the group participants" and in "seeing co-ordinators be able to keep our YODS clients focussed and interested". They commented "how wonderful the staff are", on "the level of personalised care and attention" and "the length of time spent by the guides on each painting while maintaining the interest of the participants". However, they also noted that some Art Gallery of New South Wales facilitators had soft voices, which were difficult to hear, particularly when there were school groups visiting, and that on occasions facilitators focused questions on memory. They suggested that such questions needed to be rephrased.

Care staff were asked if there was there anything they found frustrating about the Gallery visit. They suggested that: "the program was too short" and they "did not have enough time in the Gallery". One care staff member noted the frustration they all felt sometimes getting attendees to focus when they had "ratty behaviours" for reasons unconnected with the Gallery visit.

Care staff noted that the access program sometimes helped bring back memories, but mainly they liked "seeing people connect with art". When asked about what surprised them most about the Gallery visits care staff suggested: "The way people all interpret differently" and "the connection they make to art". They also noted: "How it makes the brain work" and "how deep the client imagination and observation skills are". They also suggested they have learned from the experience themselves and gained an understanding of "what a great medium art is for helping people engage in the here and now" and that "even people not interested in art can still contribute and get involved". Care staff also commented on "how different artworks change the moods of the clients" and "how well they connect to art", "the beauty of looking at art very visual - hearing their stories" and "that even in dementia participants still can appreciate art or learn to do so".

Some care staff recognised how their own behaviours could change to enhance the experience for the attendee, suggesting that they need "to sit and listen, no prompting". Care staff suggested it was "generally a wonderful experience and a great day out as care staff and satisfaction [for] the client"

Facilitators' responses

The facilitators were asked to respond to how engaged they were on the Art Access Program they had just completed. They all suggested they were *Very Engaged*. In response to "How do you feel now?" two people suggested that they were in-between *Happy* and *Unhappy* and qualified these responses with comments stating "Exhausted!" and "this is tiring work!" However, the majority suggested they were

very happy. When asked to rate how engaged attendees was at this last access program visit the rating overall suggested that the group were *Very Engaged*.

The 11 Art Gallery of New South Wales facilitators participating in the evaluation study had worked at the Gallery for between 18 months and six years with most having been there between three and five years. Before working at the Gallery as volunteer guides the facilitators had a range of jobs and experiences including training and education; art therapy; architecture; museum studies; graphic design; social work; nursing; wife and mother; flight attendant; public service; banking; and sales. Some Art Gallery of New South Wales facilitators on the Art Access Program also worked as volunteers for other organisations including teaching computers to older people; working for the local church; volunteering at the Cancer Council; driving for "earth angel" (taking seriously ill people to hospital) and they were also general art or children's guides at Art Gallery of New South Wales. Before working on the Art Access Program with people with dementia three facilitators had prior experience of dementia and eight people had prior experience in relation to art.

Facilitators said they had volunteered to work on the Art Access Program because they enjoyed the interaction with people, seeing people engaging with art and supported "equity access to the arts". For example, one facilitator suggested: "I like working and being with older people" and another "I have a passion for people and art". Facilitators wholeheartedly supported the program and the Gallery stating: "it is a worthwhile contribution" and "I really believe in the benefits of this program".

When asked at what point were they most engaged on an Art Access Program they had most recently been involved in, most facilitators suggested that they had been engaged "all the time" and most engaged when "listening carefully to responses", "when participants responded with comments" and "when talking and getting communication back". Facilitators shared the view that they were engaged right until the end of the visit and it was "impossible to be disengaged" noting that they were "observing all the time". One facilitator suggested: "it takes all of my focus to do one of the tours, you never really switch off, even walking between artworks we keep talking". Facilitators commented that "It is tiring working at this level of engagement and not knowing who you will get in the group" and added that "talking to people who are hard of hearing in Gallery spaces is also tiring".

Facilitators sometimes found it frustrating when there is "no-response from [a] participant or visitor", "if communication is not working", or when "trying to engage a visitor who is negative or keeping quiet". When asked what they disliked facilitators said sometimes, having "not enough time to spend with each person one on one" They also commented on the logistics of the program and the "inevitable changes"

and when "the organising of the program is a bit last minute and I find I don't have time to prepare". They also commented on the distraction sometimes caused by "loud noises from large school groups".

Facilitators suggested that the most rewarding part of their role was "personal interaction" and "engaging with the participants and encouraging conversation". They also suggested that they enjoyed "spending time with the participants in front of great works of art", "sharing [their] love of art", and "noticing how participants connected to the details of the painting". They noted that there was often "spontaneous conversation and enthusiasm by participants". The most surprising thing about the facilitators' roles was, they suggested, the "unexpected" "variety" and "spontaneity" of responses, particularly when it involved "comments and participation by those not usually verbal nor engaged". They also suggested, "[it is] good when one of the group opens up and really shows they are achieving something from the experience" For example, one facilitator recalled a "completely unexpected reflection on [a] work and increasing clarity of one participant during [the] program", she continued, 'Dean' "just gave an excellent summary of *Sofala*". Another facilitator at the same group visit also commented on her surprise at 'Dean' "seeing something different in the Fred Williams work, [he] saw a scientific lab with specimens in responses to *My garden*".

When asked what they had learned most from their role, facilitators suggested that: "you learn from the participants". They added that, they had learned to "be patient", "slow myself down", "wait for answers" and to "let people react to the work in their own time". One facilitator noted, "I am a much better listener", and another said, "I have learned [about] slow ART" and "to go slowly". Facilitators suggested that "it is important to listen and [to] quieten to engage people" and to "be adaptable, [and] phrase questions appropriately". For one person this brought about an "awareness of my reactions to difficult situations in the space" and an enjoyment at "being able to engage with people with dementia, being flexible, relaxed and non-judgemental". A facilitator also noted "[you have to] stop yourself from teaching". Sadly, one facilitator explained she had learned the need "to protect oneself from the emotional impact of seeing friends who are participants".

When asked if there was anything else that they would like add facilitators commented on how the attendees responded in the space and to the Gallery visit, and on their perception of an ongoing enjoyment by the attendees. For example, one facilitator suggested "following on from yesterday, I feel that the two groups are now more comfortable in the space from previous visits and are more actively engaged with the art work than other new groups" and added: "this program is extremely valuable".

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Author biography

Dr Gail Kenning BA Hons, MA, PhD is a researcher in the Faculty of Arts and Social Sciences (FASS) at the University of Technology Sydney (UTS) and Honorary Reader In Design for Ageing and Dementia at Cardiff Metropolitan University, Wales UK. Dr Kenning brings a unique combination of expertise to this project, namely:

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- At UTS she specialises in working with health professionals involved in policy, wellbeing, and the culture and humanities of health including Associate Professor Roger Dunston; and
- She is involved in an Arts Health Research Council Funded International collaborative research project working with people with dementia with Dr Cathy Treadaway at Cardiff Metropolitan University, Wales;
- She has recently undertaken art projects related to health and wellbeing of people with dementia in conjunction with Alzheimer's Australia and the Powerhouse Museum in Sydney.

Dr Kenning also researches at Art and Design, University of New South Wales and previously at the University of Wales, Cardiff in the UK, and maintains an active art practice with a studio in Marrickville, NSW. Her art practice has traversed multiple materials and multimedia including textiles such as thread, lace and weaving, installation works in a variety of forms and, most recently, digital art and design.

Recently she has presented research papers at major conferences including Arts and Health Australia 2014, Arts, Health and Wellbeing 2013, and the International Symposium of Electronics Arts (ISEA) in 2009, 2011 and 2013 and has academic journal articles published in *Australian Art Monthly*, *Leonardo*, *Media International Australia*, *Textiles: Journal of Cloth and Culture*.

In 2015 Dr Kenning was awarded a prestigious Visiting Fellow funded scholarship to Eindhoven University of Technology in The Netherlands.

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