Community co-design of digital interventions for primary prevention of ageism and elder abuse

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SWINBURNE UNIVERSITY In partnership with Eastern Community Legal Centre
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Executive Summary

The issue of elder abuse is becoming more prominent in Australia with both state and federal governments highlighting the need for prevention and response interventions. However, compared to other forms of family violence, elder abuse is not well understood by the general public, and continues to be underreported in Australia. Similarly, while there is a growing understanding and acceptance of elder abuse as a form of family violence, successful primary prevention strategies are lacking in many parts of the service sector.

The major issues facing policy makers, advocates and service providers engaged in this space are firstly, the dearth of publicly available evidence about drivers of elder abuse, and secondly, the lack of evaluated primary prevention strategies.

The Eastern Community Legal Centre (ECLC) has been a strong advocate for building capacity for identifying and responding to elder abuse in the Eastern Metropolitan Region (EMR). In 2018, Eastern Community Legal Centre (ECLC) together with Swinburne University received funding to trial a new primary prevention initiative by the Department of Health and Human Services for the Prevention of Elder Abuse Project funded under the ‘Free from Violence’ Grant Program.

The project entitled ‘Older People: Equity, Respect & Ageing’ (OPERA) focusses on understanding firstly, how ageism is perceived and experienced by older people in the EMR and secondly, how that evidence can be used to frame a co-designed digital intervention into community experiences of ageism in the Eastern Metropolitan region (EMR).

The assumption underlying this project was that ageism and ageist behaviours are drivers of elder abuse – this project evaluates a methodology for disrupting ageist assumptions and behaviours as one part of a primary prevention strategy.

The OPERA project was divided into two phases; firstly, Phase I completed community consultation about experiences of ageism among older people in the EMR. The findings from Phase I were subsequently used to inform Phase II, the co-design & development of a digital intervention (digital storytelling videos) led by Swinburne University.

This evaluation report will begin by presenting an overview of findings from Phase I with a specific focus on the experiences and expressions of ‘ageism’ as a driver of elder abuse and how these were then articulated in the subsequent digital intervention.

The evaluation will then report on the consultation and co-design processes used to create the digital intervention and how this methodology impacted on the creation of the approach to storytelling about ageism as a driver of elder abuse.

The key findings of this evaluation are that:

- Community co-design and digital storytelling are successful methodologies for development of primary prevention interventions at the local level;
- Co-design methodologies were successful in this context because they were responsive to the key demographic (older people in the EMR); this method gave agency to older people’s voices in construction of primary prevention strategies and directly represented their perceptions and experiences;
- The co-design methodologies indicated that existing representation of ageism and elder abuse did not resonate with participants because they perceived older people were characterised as victims, and as frail, unhappy and lacking independence or social connection.

Based on these findings, we make the following recommendations for future implementation of primary prevention strategies and campaigns:

- Co-design methodologies should be utilised as part of local and State-wide primary prevention strategies for elder abuse to best represent the issues, perceptions and experiences of older people in the community;
- Development of communication strategies around primary prevention of elder abuse and/or ageism should not focus on negative representations of older ‘victims’ of abuse;
- Development of strategies around primary prevention of elder abuse and/or ageism should focus on disrupting ageist assumptions by framing ageing as a positive experience and representing older people as active, positive and socially connected.
Introduction

The OPERA (Older People: Equity, Respect and Ageism) Project was one of 21 funded projects within the Department of Health and Human Services' Free From Violence Fund. The fund was an initiative to action priority area three of the First Action Plan addressing family violence – 'Innovate and Inform'. This priority area focuses on trialling, testing and evaluating a range of new and innovative initiatives to better understand what works to prevent family violence and all forms of violence against women. The OPERA project does not focus specifically on violence against women – but instead trialled a primary prevention initiative focussed on elder abuse as a form of family violence.

The OPERA project focussed on experiences of ageism and age discrimination as a framework for primary prevention of elder abuse as a form of family violence. The assumption underlying this project was that ageism and ageist behaviours are one of the drivers of elder abuse – this project evaluates a methodology for disrupting ageist assumptions and behaviours as one part of a local primary prevention strategy.

The project was conducted in two phases. The first phase of the project used a comprehensive consultation process with a diverse range of older people and service providers from across the Eastern Metropolitan Region (EMR). The consultations built on existing and emerging evidence to document seniors' experiences of ageism and age discrimination. Previous research (Harbison, 1999; Crichton et al, 1999; Phelan, 2008; Nelson, 2008) has emphasised that an ageist culture devalues older people, which helps perpetrators rationalise their actions and hide abusive behaviours from service providers and broader society. Much of this research has been preliminary, and more research is needed to better understand risk factors, theorise and substantiate possible causal mechanisms, and identify how causes differ between different cases (Volmert et al, 2016: 11). Furthermore, there has been a dearth of evidence around ageism as a framework for understanding elder abuse, and thus, a lack of evaluation of primary prevention interventions tackling ageism as a driver of elder abuse.

The OPERA project aimed to contribute to this evidence base by illustrating how ageism is expressed within community settings through the lived experiences of older people living and/or working in the EMR. By consulting directly with older people and gaining a deeper knowledge about how ageism is expressed and experienced, stakeholders and the community are better placed to understand the types of interventions that would be most appropriate and impactful in a community setting. Interventions based on diverse community consultation are also more likely to be representative of the diversity of experiences and attitudes in the EMR and to address equity, inclusion and intersectionality in the design, implementation and evaluation of subsequent primary prevention initiatives.

Phase I of the project also collected evidence that could be used to frame a co-designed digital intervention aimed toward primary prevention of elder abuse. The second phase of the project created digital video interventions to enhance existing education and awareness raising strategies around elder abuse. Phase II of the project consulted with seniors aged over 55 in the EMR to gather data about how they experience ageism, and how it is expressed in their communities. The project consulted with a diverse group of older people including women, CALD communities and the physically disabled. The consultations used a co-design model that values the significant contributions of older people and foregrounds their experiences, stories and perceptions to inform the content, narrative and messaging in the videos.

Project Aims

The project aimed to create and evaluate a community-based digital intervention that could be shared within the EMR (with potential for broader application) to contribute to awareness and disruption of ageism and ageist behaviours. The intended outcome was a community-focused digital intervention that would strengthen a primary prevention strategy around elder abuse.

The aims of the video interventions were to:

- Use digital storytelling to increase awareness of ageism and age discrimination based on seniors’ lived experiences;
- Disrupt ageism and ageist behaviours by representing and celebrating older people’s stories, experiences and perceptions;
- Use representations of older people in the EMR to begin community discussion about ageism and elder abuse.

The digital intervention would thus contribute to a wider primary prevention strategy in the EMR. The video resource will be promoted widely using new and existing networks. This report evaluates the co-design methodologies used to create the digital video interventions. Using a qualitative analysis of participant consultation questions, surveys and feedback, this report maps the approach taken to the co-design process and evaluates its success as part of the broader ECLC primary prevention aims.

After the Introduction and Background, the report will outline the Phase I and Phase II methodological approaches. Analysis of the participant consultation data and results of the co-design part of the project will follow, and finally the Discussion will evaluate the success of co-design methodologies in community-focused primary prevention strategies targeting elder abuse.
Background

Elder Abuse and ageism

Elder abuse is currently defined as "a single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person" (Elder abuse, n.d.). The most commonly reported type of elder abuse is financial abuse, including abuse of powers of attorney (PoAs), misuse of an older person’s money, fraud, and appropriation of finances or assets without knowledge or consent. However elder abuse can also be physical (including sexual abuse) or psychological abuse (such as emotional blackmail, threats and abusive language). Elder abuse can also constitute social abuse when a perpetrator socially isolates an older person from their family, peers or medical and social services. Finally, neglect can constitute elder abuse when an older person is not provided with proper care or support. This may occur as a failure to provide adequate food, clothing, shelter, medical attention or dental care, improper medication, or keeping a person in a state of poor hygiene (Respect Victoria 2019). Elder abuse involves range of experiences and behaviours which may take place in different context such as family home or assisted living accommodation (See Note 1).

Preliminary research in Australia indicates between two and 10 per cent of the older population (aged 65 and older) experiences elder abuse, although neglect is likely to be occurring at higher rates (Kaspiew, Carson et al. 2016). While the prevalence of elder abuse in Australia is not known, data collected by Seniors Rights Victoria for a two–year period suggests that amongst their clients experiencing elder abuse, 92 per cent are abused by a family member and 67 per cent of abusers are the adult sons or daughters of the abused person (Joosten et al., 2015). In addition, a number of small studies from Australia have estimated that between up to six per cent of the older population has experienced a form of elder abuse in the past (Kurle and Naughtin 2008).

In 2016 the Victorian Royal Commission into Family Violence identified elder abuse as a serious form of family violence that required further research and intervention. Although family violence definitions predominantly refer to intimate partner violence by men against their current or former partners, the Victorian Government family violence reform includes elder abuse in the definition (State of Victoria, n.d). Elder abuse has some traits in common with other forms of family violence, including over-representation of women as victims and the under-reporting of experiences of abuse (Neave, Faulkner et al., 2016). Reasons for under-reporting of elder abuse range from not recognising behaviours as abuse (Dakin and Pearlmutter, 2009); believing abuse is a private family matter (Neave, Faulkner et al., 2016); feeling ashamed (Clare, Clare et al., 2014); feeling responsible for the abuser’s behaviour (Harbison and Morrow 1998; Moon and Benton 2000); or unwillingness to report because of potential consequences for a family member (Teaster, Roberto et al., 2006). Furthermore, unwillingness to report may occur if a person is dependent on the abuser and fear that they might be otherwise abandoned or put in a nursing home (Jackson and Hafemeister, 2014; Pickering & Rempusheski, 2014).

Given the recent recognition in Australia of elder abuse as a form of family violence, primary prevention of elder abuse is still an emerging area of research. There is some preliminary evidence around drivers of elder abuse, such as ageism, illness or disability, history of family violence, stress in care relationships; impact of different cultural or spiritual beliefs on elder roles and positions, and financial pressure (Joosten et al., 2017). Other research has suggested potential risk factors for abuse include functional dependency, social isolation and lack of social connections, physical isolation (living in regional and rural areas), living with a perpetrator, traumatic experiences, financial dependency, alcohol or illicit substance abuse, and being a cultural minority (Kaspiew et al, 2019). Elder abuse is nonetheless a complex issue that should be addressed through a range of factors such as ageism, family violence, gender, sexuality, and culture.

The National Ageing Research Institute’s Community Action Plan (Dow et al., 2018) targeting elder abuse has highlighted the following knowledge gaps and listed them as priorities for combating elder abuse – insufficient understanding of elder abuse, lack of older people’s voices, strategies for addressing ageism, information and access to services in cases of elder abuse, and mediation services for people in rural and remote areas, and also for culturally and linguistically diverse families. In addition, raising awareness about ageism and promoting positive images of older people and ageing have been identified as a priority for primary prevention of elder abuse (Dow et al., 2018).

Co–design principles for mobile digital storytelling

Digital storytelling is defined by narrative formats that are created and shared using digital tools and formats (Davis et al, 2018). Digital Storytelling most often uses low–cost digital equipment and editing software and to create short, personal stories made for online publication and distribution (Meadows, 2003). Digital stories differ from traditional broadcast in that they are generally first–person stories, shot and edited individually and have a more intimate quality of production. More recently, use of mobile phones and editing apps has been an increasingly important part of the digital storytelling process, in particular the ‘keitai’ aesthetic of digital stories, which emphasises the way camera phones shape filmic experiences of the location, time and subject (Schleser et al, 2013). Baker et al (2008) suggest the ‘keitai’ aesthetic is an important aspect of digital storytelling because: “Mobile devices make the mundane interesting...The sense of intimate connectedness to the message, its subject and the author, has emotional implications in everyday art experience, making one feel special, important and inspired”.

Much recent research about digital storytelling has been focussed on its use as a tool for education, especially the possibilities for engaging students with complex concepts (Robin, 2008), encouraging personal research and reflection in learning (Perry et al, 2015) and subsequently, the possibilities for increased student comprehension (Burmark, 2004; Sadik, 2008). However, given the increased possibilities for intimate connection with audiences, mobile phone-enabled digital storytelling has also grown as an important community engagement tool. In particular, co-designed digital storytelling has been presented as an important method for working with otherwise marginalised communities, for developing digital literacies, and for supporting social impact projects (Schleser, 2012).

For the purposes of the project evaluation, we focus on a specific tradition of digital storytelling produced in intensive collaborative workshops with mediation by project leaders or producers. This form of digital storytelling originated at the University of California at Berkeley’s Centre for Digital Storytelling in the late 1990s. This particular form of digital storytelling also refers to a particular methodology which engages a more participatory process. As Meadows (2003: 192) suggests: no longer must we tolerate media being done to us. No longer must we put up with professional documentarists recording us for hours and then throwing away most of what we tell them, keeping only those bits that tell our stories their own way and, more than likely, at our expense”. Common to this tradition of storytelling is an ethic of collaboration and participation: that is providing people who are not necessarily expert media makers an opportunity to produce, or contribute to, a media product that can be shared with an online audience. While most online content creation relies on individual participation and peer learning, digital storytelling techniques rely on collaborative methodologies that attempt to broaden participation (Klaebe et al, 2007).

A co-design methodological approach for digital storytelling is defined by its inclusion of the subjects of study in the process of designing and implementing that study. Thus, a co-design process is distinguished by its non-hierarchical method of designing a project, where the power imbalance between the subject of the video and the creators is mitigated by the much more active role participants take in directing the content and sometimes in producing the project (Waycott et al, 2017). The co-design methodology is most often used within communities because it forefronts inclusiveness, and celebrates and accommodates a variety of diverse voices (Copeland, 2012).

While the co-design process is valuable in providing a horizontal structure process that ensures participation amongst diverse—and sometimes marginalised communities—it requires a great deal of researcher flexibility. Complexity can arise when working within the limits of institutional or organisational expectations, as well as catering for the unique requirements of individual community groups. The co-design process can also be somewhat problematic, especially in working with marginalised communities if there are social or cultural knowledge gaps between professionals and communities or perceptions of low efficacy or lack of consensus from participants (Sabiescu and Memarovic, 2013). The co-design process often needs to be flexibly designed and continually redeveloped in response to diverse communities and their experiences (Davis et al, 2018), which requires a great deal of researcher/producer engagement and flexibility.

The methods used to co-design a digital storytelling project can affect both the types of stories that are told, and the participants themselves. In this project the digital storytelling process was shaped during interaction between researchers and participants, and was therefore an emergent process, guided in a loop by participants’ initial input, researcher translation and participant feedback. This more emergent and flexible method was chosen because it focussed on giving agency to community experience and voice. As Lorini et al (2017) suggest, a more emergent process is useful because it allows more context-specific ways of engaging communities in production and therefore has the capacity to lead to more engaged collective participation in distributing the outcomes.
The findings of the Phase I consultations were documented in a report and distributed to the Swinburne research team for integration into Phase II. The report was also distributed to broader sector and community.

The Phase I methodology took a mixed-methods approach to gather both qualitative and quantitative data about seniors’ experiences of ageism, including:

- Individual interviews with community & sector representatives;
- Diverse community focus groups including Culturally and Linguistically Diverse (CALD) community groups in the EMR including Chinese, Indian and Hakha Chin communities (See Note Three). Focus groups were also held with the Aboriginal community, a Neighbourhood House and the Manningham Dementia Alliance.
- One EMR Community Consultation Forum in a large discussion group format;
- A community Survey with hard copy and electronic versions available.

**PHASE ONE RESULTS**

**Sector and other service providers**

The following recurrent themes emerged during consultation and surveys amongst sector and other service providers:

- Ageism is pervasive and socially accepted.
- Ageism was suggested as ‘socially accepted’ form of discrimination with discriminatory humour, images and behaviours perceived as fairly commonplace in the community. Some participants suggested that ageism was so pervasive that ageism is internalised amongst many older people who perceive that their capacity is diminished because of their age despite no change to their abilities.

- Cultural shifts have contributed to the invisibility of older people in the community.
- Reliance on service provision to look after older parents and family members meant families have lost the skills to care for older people, and older people are seen as a burden to already stressed households.
- Generational tensions around wealth.
- Many participants articulated assumptions that older people were wealthy or privileged – or that younger people were struggling more than older people. Many articulated common encounters with the attitudes from younger generations who believed “older people are taking up space where younger people should be” or were a “blockage to housing and jobs”.
- More work on planning the ageing journey and the subsequent shifts in family power dynamics. Participants noted different periods within the ageing process and suggested that there were risk factors involved in subsequent shifts in family power dynamics that could lead to elder abuse. Participants suggested social power decreased with age, which also reduced social visibility, respect and relevance. Participants suggested further work was needed to understand how these shifts play out in families and to interrogate attitudes around power and inheritance impatience.

**PHASE ONE RESULTS**

**Community Response**

Key themes identified from Phase I community consultations around the expressions and experiences of ageism centred on:

- Images and stereotypes of ageing – how older people are portrayed in the media, children’s picture books, in film and literature and birthday cards;
- Social and infrastructure barriers to equal participation in the community;
- Community attitudes and behaviours that directly or indirectly discriminate against older people.

**Images & Stereotypes of ‘Ageing’**

Overwhelmingly respondents expressed negative associations with the word ‘elderly’ or ageing. Some of the associated words or images included: frail, hobbling with a walking stick, physical weakness, feeble or having diminished capacity, and “losing your marbles”. Language used primarily centred around:

- Decline or deterioration including poor health, infirmity, slower movement, loss of memory or “having a senior’s moment”;
- Loneliness;
- Irrelevance or invisibility in society;
- Dependence on others or vulnerability;
- Ageing as something to fear;
- Loss of identity including loss of role in the community or workplace.

A significant number of participants highlighted the role of the media including film, literature and advertising, in perpetuating negative stereotypes whilst also glamorising culture centred around youthful constructs of beauty, being physically active and able bodied and young people as progressive and technologically savvy. In contrast, older people are portrayed in a negative light, including images of being weak, infirm, forgetful, the centre of a joke, or shown alongside advertisements around retirement villages, superannuation and funerals.

The notion of ageing, in and of itself, seemed to trigger strong feelings for participants. Some talked about a fear of ageing and the perceived associated traits of physical and mental decline, vulnerability and loneliness. However, some respondents also talked about the positive stereotypes and strengths associated with ageing including:

- Learned wisdom and life experience
- Freedom of time to do enjoyable things

**Barriers to being able to participate equally in the community**

Perceived barriers to participation in the community for older people included:

- access and ease of movement in urban and built environments;
• access to and use of technology;
• access to and use of public transport, and;
• opportunities for employment.

Community attitudes and behaviours
A number of ageist attitudes and behaviours were discussed as being experienced by older people in the EMR, with the strongest themes around feelings of social invisibility, lack of prioritisation in health and social settings and ageist behaviours.

• Visibility & relevance:
One of the most prominent themes that was discussed, particularly among female participants was the experience of invisibility and perceived irrelevance. These experiences were largely characterised by feeling ignored, talked over, left behind or pushed to the side.

• Feeling like a low priority
A number of people felt that as an older person you are treated as low priority and this was most often felt in health and social settings.

• Ageism as disrespect, disregard and impatience
Condescending attitudes and language including being spoken down to, treated like children or ignored. Examples included being referred to as ‘love’, ‘dear’ and ‘darling’ or people assuming they need to shout to be heard.

• Health professionals who talk to an older person’s companion rather than the older person themselves. This was reported as common for a person with dementia or a disability.

• Ageist humour in the media and at birthdays or other significant events.

• Lack of courtesy on public transport and generality impatience with older people with mobility issues.

PHASE TWO
Creating a digital intervention
Aims:
The aim of Phase II was to create a digital video intervention developed through a co-design process with older people in the EMR. The co-design method was informed by the preliminary findings for Phase I of the OPERA project and used to frame activities and discussion in community workshops, attended by interested senior participants from across the EMR. As a result of the co-design process, Phase II of the OPERA Project developed into a digital video intervention to both bring awareness to – and to challenge—age discrimination as part of a wider an elder abuse primary prevention strategy. In addition to this, the video intervention would be shared across the sector to assist in building capacity around understanding and identifying drivers of elder abuse. The Swinburne University research team led Phase II of the OPERA Project, including a) the design and implementation of the co-creation workshops; b) the production and filming of the digital video intervention, c) the editing labs required to professionally produce the videos and d) the evaluation of the co-design methodology and digital intervention.

PHASE TWO
Workshop Methodology
The research questions that framed the methodological approach were as follows:
1. Do co-design strategies help diverse communities of older people articulate experiences of ageing and age discrimination?
2. Is co-designed digital storytelling appropriate to communicate to diverse communities?
3. Did older participants agree that the digital intervention represented their perceptions of ageing and age discrimination?
4. Did the co-design digital intervention methodology raise awareness of how age discrimination might frame the normalisation of abuse behaviours towards seniors?

The co-design process was facilitated using six community workshops held at Box Hill Town Hall in April and May 2019. ECLC and Swinburne recruited interested participants through existing community networks including the Eastern Elder Abuse Network (EEAN) and local council Active Ageing networks. The co-design process required interested older people in the EMR to participate in two co-design meetings, framed by the research conducted in Phase I, about the key messaging needed in the digital intervention.

We recruited 27 participants with an equal split between the 61-70 and the 71-80 age groups. Participants were predominantly female (21 females to 6 males) and retired, receiving a pension and living in their own home. Participants were predominantly from the Whitehorse region of the EMR and there was a good representation of different ethnic and Indigenous groups. A quarter identified as having a disability. Almost all participated in some kind of recreation, hobby or exercise group, a reflection of the strong community service participation amongst the participants in the EMR. Participants were incentivised with a $50 Readings voucher to attend both workshops.

Finally, the evaluation of the OPERA project had several aims:
1. To provide an evaluative analysis of community consultation about experiences of age discrimination in the EMR to provide an evidence base for ageism as a potential driver of elder abuse
2. To provide an evaluation of community co-design practices for the design of prevention strategies around elder abuse
3. To provide an analysis of whether a community co-design digital intervention was an appropriate prevention strategy around elder abuse

To complete the evaluation aims, a tiered evaluation was completed around each stage of the project.
During Phase I of the project, a discursive content analysis of the key themes emerging from the interviews was conducted and summarised to contribute to the framing for the Phase II workshops. The interview data from the face-to-face interviews, community consultations and surveys was subsequently analysed, thematically organised and documented in a report, which was published separately to this evaluation.

During the completion of the Phase I data collection and analysis, but prior to the beginning of Phase II, a stakeholder governance group was also established. This group evaluated the design and implementation of the co-design workshops and gave feedback on methodological, ethical or other research issues.

During Phase II of the project, co-design feedback workshops were conducted with participants to evaluate and approve the key messages and design of the videos. This evaluation was conducted with direct questioning methodologies and a flexible feedback model to allow researchers to change and develop video messaging and production style to accommodate the participant evaluations.

Finally, post-screening surveys were also conducted with audiences at video screening events to analyse and evaluate whether the key messaging and stories were understood and supported by audiences and whether a digital intervention might be an appropriate aspect of elder abuse prevention strategies in the EMR.

In designing this methodology, it was important that the co-design process was structured to allow researchers to be flexible and responsive to the participants’ suggestions for the video production. Allowing this flexibility prioritised the voices and agency of the participants and ensured a shared approach to the creation of the intervention. Continual community re-evaluation through secondary workshops and draft video screenings were time consuming, but gave the researchers an opportunity to be responsive to community, to celebrate and acknowledge participant involvement in the production process and ensure community perceptions of ‘ownership’ of the project – thereby increasing the likelihood of continued sharing and discussion of the key messages in the videos after the project’s completion.

Findings and Discussion

FINDING ONE
Community co-design and digital storytelling are successful methodologies for development of primary prevention interventions at the local level;

Phase II of the OPERA Project leveraged the findings from the Phase I consultations to inform a series of co-design workshops that led to production of the digital storytelling videos produced for ECLC’s digital intervention into elder abuse. Based on the Phase I consultations ECLC provided the Swinburne Research team with identification of major themes that emerged from the consultations. These included sector understandings of some of the structural frameworks for age discrimination such as:

- The pervasive and socially accepted nature of ageism in terms of negative attitudes and behaviours towards older people;
- The social and cultural change in the perceived role and purpose of older people;
- Increased difficulty in making transitions in post-work life due to social roles linked to economic contribution;
- The gendered nature of ageing meaning that ageist attitudes were experienced differently by men and women.

The community consultations with older people reinforced these structural frameworks with experiences and impacts of age discrimination including:

- Feelings of decreased purpose in society and thus power, which impacting also on social visibility and perceived relevance;
- Feelings of being defined by negative stereotypes portrayed in the media;
- Experience of structural barriers to being able to participate equally in the community, such as accessibility issues, or access to technology;
- Community attitudes and behaviours that directly or indirectly discriminate against older people, such as lack of respect for special needs, impatience and condescension when asking for customer or public services.

While Phase I of the OPERA Project was focused on contributing to an evidence base around experiences of ageism as a potential driver of elder abuse, Phase II was focused on using a co-design process to draw out experiences and stories that could be used in the digital intervention videos. This meant a slightly different approach to the Phase I consultations, in that the co-design workshops were attempting to elicit personal stories, descriptions of everyday experiences, feelings and perceptions that could be used to construct a video story world. Thus, the activities were aimed at eliciting individual and group perceptions and experiences of some of the themes that emerged from the Phase I consultations.

The Swinburne research team structured the workshop around three levels of experience, trying to cover all aspects of the experience of ageism described in the initial Phase I consultations. Butler (1980) suggests that these three levels of experience of ageism are seen to encompass: prejudicial attitudes towards older people (including attitudes held by the elderly themselves) discriminatory practices against older people, as in employment or social roles; and finally, in structural or institutional practices and policies, such as lack of accessibility infrastructure, which reduce opportunities to navigate social and personal lives. We also wanted to draw out experiences of the impact of these types of discrimination, particularly how these attitudes might...
come to embody negative views of ageing which are then “internalised and reinforced across the lifespan developing into beliefs about, expectations for, and self-perceptions of, one’s own ageing process” (Sargent-Cox, 2017).

Given the limitations that Swinburne ethics protocols placed on discussing elder abuse, and the ambivalence with which older people discussed ageism in Phase I, the co-design process was much more successful in eliciting responses from participants by engaging with their everyday experiences and stories – which most people feel confident and comfortable sharing in a group. To do this, the co-design process was designed so that each participant engaged with a series of structured activities, followed by in-depth discussion around experiences of ageing. For example, some of the co-design workshop activities elicited stories through the following activities:

“Storyboard your life as an older person”
Participants were encouraged to use images, words, colours, descriptions or any other creative approach to represent their current lifestyle as a senior in the East. This could include personal or family life, social time, hobbies, responsibilities, jobs, etc – anything they felt was significant in their life.

“What does being older look like?”
Participants were encouraged to create a collage of words, images and experiences for discussion about some of the positive and negative representations of being an older Australian.

“Preparing for getting older”
Participants were asked to devise an ageing ‘cheat sheet’ that explained what they might say to prepare family and friends for getting older. Prompting questions included:
- What would they experience? What should families know about their older parents and friends’ needs? What are the things to look forward to in older age? How will relationships change?

“Your life versus their image of your life as an older person”
Participants were asked to compare their life as an older person to how they thought others might perceive getting older. This could include images, words, descriptions, advertisements or things heard or seen from peers or on the television or other media.

Participants shared what they had produced once activities were completed. This also allowed more direct questioning aimed at eliciting more information or were otherwise aimed at co-designing the video production approach more directly. For example, some direct questioning included:
- Having had this discussion today, who do you think we need to talk to about age discrimination?
- Who is most likely to need persuading the ageism exists or that they perpetuate ageist attitudes?
The feedback workshops were somewhat shorter than the first workshops, with activities dominated by participant discussion of initial findings and possibilities for digital storytelling themes and experiences. Responses were recorded and then discussed by the Swinburne Research team to help direct the subsequent video concept.

The workshop and co-design process was successful in that it led to development of two storylines for the video interventions based directly on the feedback and experiences of participants. The first storyline centred on a ‘call to attention’ to:

- combat negative stereotypes associated with ageing;
- present positive, active and empowered images of older people;
- present both negative and positive aspects of the ageing journey as being similar to other transitions in life.

The second storyline was framed focused on a ‘call to action’ to remind the audience that:

- Older people need a community engaged and empowered approach to the journey of ageing;
- There is a need for discussion in families and communities about people’s needs as they get older;
- The need for open discussions around age discrimination, prevention of elder abuse.

Creating this video concept with links to emergent themes from the workshops, as well as participant comments during the co-design process, the Swinburne research team was able to create a matrix of possible messages, stories and experiences that might best articulate the key messages of the digital intervention.

<table>
<thead>
<tr>
<th>MESSAGE</th>
<th>STORY</th>
<th>LINK TO PARTICIPANT COMMENTS / ACTIVITIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘I STILL ASPIRE TO MORE’</td>
<td>Point to issues around age discrimination in workplace, community.</td>
<td>“There is a need for me in the community because I have the time to give now.”</td>
</tr>
<tr>
<td>‘LISTEN TO US’</td>
<td>Point to issues around ‘help that hinders’ and feelings of lack of autonomy.</td>
<td>“There’s plenty of people who feel invisible but I’m happy to stand up for them.” “There are so many people just waiting to be asked how they can help.”</td>
</tr>
<tr>
<td>‘LIFE HASN’T STopped’</td>
<td>Planning as important for the ageing journey. Planning leading to more empowered and independent living for the future.</td>
<td>“You don’t prepare to age when you are 30, so you don’t feel old 30 years later because there’s still more to plan for.”</td>
</tr>
</tbody>
</table>

After the first workshops, key messages, stories and themes were developed into potential video story worlds. The workshop participants returned to Box Hill Town Hall one month later to discuss and give feedback on the story themes that the Swinburne research team formulated from the findings of the first workshop. This is an important part of a co-design process, where feedback and agreement are given throughout the development process. Rather than just informing the researcher’s findings, the co-design process allows community attitudes and experiences to be represented throughout the design, production and editing process.
Co-design methodologies were successful in this context because they were responsive to the key demographic (older people in the EMR); this method gave agency to older people’s voices in construction of primary prevention strategies and directly represented their perceptions and experiences.

There were a number of issues the team considered in creating the structured workshop activities and co-design process. Firstly, the team was concerned not to influence older people’s responses by framing ageing in an overly negative way, or in a way that dismissed specific experiences related to gender and cultural differences. Secondly, language was a critical feature of the workshop co-design process. Minichiello et al. (2000: p. 276) found that while older people may experience ageism, they may not use this term, or “have the words” to articulate their experience. Others may not “perceive the need” to describe their experience or may be “reluctant to classify” their experience as ageism for a broad range of reasons, including “being seen as old, [or] being discriminated or treated as old” (Minichiello et al., 2000 p. 275). These findings suggest the importance not only to consider community attitudes towards ageing, but also older peoples’ own perceptions of ageing and what it means to be older.

Thus, an important aspect of creating the intervention was understanding and representing the way older people think of themselves and their lives. In this respect, we also needed to be aware of differences between what older peoples’ experience of ageism, and its more formalised definitions.

In responding to the invitation to co-design a video concept for the digital interventions, the participant response and feedback was somewhat surprising. The research team were expecting stories about experiences of ageism and its negative impact on older people, but most participants rejected this approach. Instead most participants wanted to represent older people as positive role models who made important contributions to their communities. In representing this view, the research team worked with participants to design an intervention that focussed on disruption of negative stereotypes, as this was more important than drawing attention to negative stereotypes perpetuated through ageism.

The co-design process allowed the Swinburne Research team to re-conceptualise the approach to the video interventions, instead focussing on stories that depicted older people who were resilient, physically active, autonomous and independent; each video showed the different ways older people were making positive contributions to family, community and society. This would aim to disrupt the negative stereotypes about older people that so often frame ageist behaviours and attitudes. Furthermore, the stories that framed positive role models for ‘ageing well’ could also provide some protective factors against ageism and abusive behaviours by either prompting self-reflection, discussion or changed behaviours as a result of viewing the stories. These videos included:

**Never retiring from having an active life:**

Lesley’s story

Lesley has kept active and engaged in her community since retiring from work. She has committed to learning new things, keeping active regardless of her physical ability and pushing herself to do regular social activities. Being active in her community has created a support network that helped Lesley when she recently faced a tough time.

**Strong relationships and stronger voices:**

Lynda’s friendship garden

Lynda has made a beautiful garden that reminds her of all the positive relationships she has with friends and family. She talks about the contribution that strong social and community connection has made to her active senior life.

**Keeping healthy minds, healthy bodies and healthy spirit:**

Coomi and Keki’s story

Keki and Coomi make sure they keep their minds, bodies and spirit healthy at every age. They maintain a spiritual connection by practising their religion, helping their neighbours and family, and maintaining a link to cultural traditions.

**Uplifting older men in community discussion groups:**

Phillip’s story

Phillip saw an issue in his community around the lack of consistent emotional support for older men, especially those suffering from dementia. He decided to use his time and skills to make a difference by setting up a men’s discussion group.

**Finding new friends and new communities:**

Ken and Gwen’s story

Ken and Gwen were empty nesters looking for a home that was more manageable and would also allow them to be safe and independent as they managed their health in their older years. They chose a home in a retirement village, but they never guessed that their minds, bodies and spirit healthy at every age. They maintain a spiritual connection by practising their religion, helping their neighbours and family, and maintaining a link to cultural traditions.

**My life, my way, my choices:**

Marilyn’s story

Marilyn is a practicing end-of-life doula, helping those at the end of their life. Marilyn is passionate about making independent and informed choices about the future as an important part of getting older. Making decisions about the future of your health, your home and your other assets makes sure that your wishes are respected even if you are not able to speak for yourself.
My life, my way, my choices: Marilyn’s story

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Uplifting older men in community discussion groups: Phillip’s story

Phillip saw an issue in his community around the lack of consistent emotional support for older men, especially those suffering from dementia. He decided to use his time and skills to make a difference by setting up a men’s discussion group.

Finding new friends and new communities: Ken and Gwen’s story

Ken and Gwen were empty nesters looking for a home that was more manageable and would also allow them to be safe and independent as they managed their health in their older years. They chose a home in a retirement village, but they never guessed that their neighbours would also become like a second family.

Sharing kinship and companionship over time: The Eastern region’s PAG group & Keeping active at any pace: Lyn’s story

Southern Health’s Planned Activity Group (PAG) offers an opportunity for older members of the Aboriginal community in the East to meet socially every week. Friendships have formed between members and they’ve maintained a strong social connection over a number of years. One group member Lyn also described her friendship with members of the indigenous community and her ability to keep up with the community group activities despite ‘slowing down’ a little as she grew older.

Independent choices: Wendy’s story

Wendy was surprised by the many misconceptions about living in a retirement village. Many of her friends and peers thought it was like an aged care facility. But choosing to live in a unit in a retirement village has given Wendy a sense of community, a way to maintain independence and a packed schedule of daily activities.

A total of nine videos were produced for the OPERA project.

FINDING THREE

The co-design methodologies indicated that existing representation of ageism and elder abuse did not resonate with participants because they perceived older people were characterised as victims, and as frail, unhappy and lacking independence or social connection.

One of the major emergent themes of the co-design workshops was the groups’ dissatisfaction with language and
terminology around ageing. In particular this dissatisfaction with the language used to describe ageing and older people led to some of their co-design recommendations. Most participants felt that the negative ‘baggage’ associated with ageing didn’t adequately represent their lives. For example, during the Storyboard activity describing their life as a senior, most participants were writing about and drawing images of very full lives – the variety of activities made up active lifestyles, though the activities themselves varied according to physical ability, work status and personal interest.

Many participants storyboarded active and happy lives, suggesting that getting older was the “time to see different people, places and differences”. For some this meant travel, for others, a much fuller sense of participating in their local communities. Some participants described days full of structured activities, including attending the gym, social events, reading and board games. Almost all of the participants described participating in some form of physical activity or exercise like gardening, tai chi or a physical hobby, suggesting it was important to “have a reason for moving”. Many others volunteered in their local communities, around areas of personal interest or social awareness, or had joined community groups like the U3A or local government groups.

Almost all participants described the importance of a regular connection with family and friends, and a number also took on caring responsibilities for grandchildren. Others took on pastoral care duties or caring for frail family members or neighbours. This loss of family connection due to bereavement or limited family time was seen as “painful” and a major contributor to feeling isolated or lonely in older age, especially in the evenings when some suggested they “only had the TV for company”. In this sense, pets were regarded by most participants as an important source of companionship, and the loss of a pet was felt very keenly. Finding other activities helped participants who had experienced loss, for example “listening to music saved me after my husband died”. Thus, participants suggested that much of the work of ‘getting older’ was ensuring the successful transition of one form of work, family and social life to another.

During the other structured activities during the workshops, many acknowledged that these incredibly busy lives they were describing were different from the stereotyped view of ageing, which they felt represented frailty and “going downhill”. One participant suggested that these stereotypes were a way of taking power from older people and that she was going to “grow older disgracefully!” In the structured discussion, a number of participants suggested that while older people and ageing was seen in a negative light, they had positive feelings about ageing and were ambivalent about experiences of discrimination. For example one participant suggested older people should be valued as everyday contributors to society: “...what we’re trying to present to the society, is that we are actually still members of society, don’t marginalise us ... don’t wait until you see someone who has been given an award, or who’s doing yoga at 100.” This may have been reflective of the kind of cohort of participants the workshops attracted – active, physically able and relatively high on socio-economic measures – many of the seniors suggested that again should not be seen through the prism of decline, but of transition.

**Recommendations**

**RECOMMENDATION ONE**

Co-design methodologies should be utilised as part of local and State-wide primary prevention strategies for elder abuse to best represent the issues, perceptions and experiences of older people in the community.

We recommend a co-design method to ensure firstly, that the unique experiences of the community are represented in primary prevention strategies. The most recent research (Seniors Rights, 2019: 52) into primary prevention of elder abuse has suggest that strategies deployed at a local level would be best situated to have positive impact, and that techniques would need to be deployed at multiple levels of society. The benefit of a local co-design methodology is that it includes the unique demographic of a local area, as well as the personal experiences with the services, infrastructure and people that make up this community. Therefore, a co-design method ensures that the unique voice and experience of diverse communities are represented in the production of a primary prevention strategy. Secondly, the co-design method also ensures that the key messages around ageing and age discrimination come directly from the experiences of seniors in the community, rather than the researchers’ own assumptions about what the content of the videos should be.

The experience of creating a co-designed digital intervention taught us that our assumptions or our imposition of a framework for creating a strategy would not be effective; giving voice and agency to the experience of older people meant that we had to change our approach to the digital intervention, but this flexibility meant we were better able to represent the issues, perceptions and experiences of older people in the community. We therefore recommend that any social impact campaign be informed by a co-design methodology that reflects the direct experiences and feedback of the demographic targeted by the campaign. This ensures that the variability in the way people think about ageing and ageism is captured and is also reflective and responding to the lived experience of older people. This project also found that co-designed stories are more likely to have social impact through community discussion. This is because the stories more
specifically represent a target demographic and audiences are more likely to feel that the stories appeal to their conception of themselves and their communities. Stories are also more likely to be shared within communities because audiences recognise locations, people and stories as representative ‘of them’.

RECOMMENDATION TWO

Development of communication strategies around primary prevention of elder abuse and/or ageism should not focus on negative representations of older ‘victims’ of abuse.

This project found that negative representations of older ‘victims’ of abuse were largely ineffective or poorly received by older audiences and their families (our audience focus for this project). This project found that negative or impact-driven messaging around elder abuse and ageism did not resonate with our participants. Participants suggested that the older people represented in the media did not represent their own active lives, or that older people were portrayed as “weak”, “frail” or as “victims”. Many of the participants also suggested stereotypical images of older people were unlikely to resonate with them. For example, one participant said: “We will no longer accept traditional, we will not accept traditional things, we are here to say ‘No!’ We are the new generation, and this is what our generation wants!” In this context, our recommendation is that development of social impact campaigns around primary prevention of elder abuse be more reflective of everyday lives of older people – including involvement in community groups, physical activity and in friendship and family groups. Further that representation of elder abuse should more readily target perpetuation of subtle forms of ageism, including familial decision-making, issues around housing and caring responsibility and social connections. For example one participant suggested that targeting familial and cultural assumptions about older people’s choices should be an important part of challenging ageism: “The decisions about your life… these decisions should come a lot earlier now because in the past it was on the kids to make those decisions… well now we want to make our own decisions.”

RECOMMENDATION THREE

Development of strategies around primary prevention of elder abuse and/or ageism should focus on disrupting ageist assumptions by framing ageing as a positive experience and representing older people as active, positive and socially connected.

We recommend that development of strategies around primary prevention of elder abuse and/or ageism should focus on disrupting ageist assumptions by framing ageing as a positive experience and by representing older people as active, positive and socially connected. Positive representations of diverse groups of older people in the community as a ‘norm’ will instead empower older people through positive role modelling. For example, many participants suggested that if older people were represented as contributing to a community, their needs would be considered an important part of community life too: “We live in a community and if you choose to live in a community you should give back to that community in whatever way you can…and as a member of this community I want something there for when I age as well, something that can be implemented to make life better for everybody.”

Negative representation of elder abuse or representations of ageist stereotypes may actually disempower older people. As one participant suggested: “…it’s that mindset I’m no good to anyone, I’ll never go any further I might as well curl up and die…but you just have to be convinced that there’s more to life.”

Notes

NOTE ONE

When discussing elder abuse in the Australian context, the term ‘elder’ can be considered problematic. The authors acknowledge that the current terminology is moving toward use of ‘abuse of older people’ in place of ‘elder abuse’ to distinguish it from the positive representation of the term ‘Elder’ within Aboriginal and Torres Strait Islander communities. The term Elder (with a capital E) has important significance for Aboriginal and Torres Strait Islander people as it refers to a person “who has gained recognition as a custodian of knowledge and lore, and who has permission to disclose knowledge and beliefs” (Making Two, n.d.). In traditional Aboriginal culture, age alone does not necessarily mean that one is recognised as an Elder (Making Two, n.d.). In that regard finding another term to address the issue of elder abuse is highly recommended. However, due to the lack of alternative nomenclature this review will use the term elder when discussing abuse of older people while respectfully acknowledging its distinction from the term Elder. Further this report uses the term ‘elder abuse’ in line with the original funding guidelines.

NOTE TWO

Aboriginal and Torres Strait Islander community members aged 50 and over were classified as older people eligible for participation in this study.

NOTE THREE

Interpreters were offered for all CALD consultations and were utilised for both the Hakha Chin and Chinese focus groups. Translation was not required for the Indian focus group. In addition to this, the demographic survey was translated into Simplified Mandarin for Chinese participants.
References


Older People: Equity, Respect & Ageing

The OPERA Project

Older People: Equity, Respect & Ageing