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Report on the Interdisciplinary Webinar: COVID-19 – Reframing Ageing

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By

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Introduction

There are many emerging stories in the global crisis that is COVID-19, stories of sickness, death, lockdown, isolation, unemployment, alongside stories of human resilience, solidarity and hope for enhanced sustainability, social inclusion, and fairness.

However, from an early point, the discourse on older people was controversial and troubling.¹ While the intent was to a certain extent related to special measures to protect them from infection, this well-intended policy resulted in severely restricted freedom and mobility over an extended period of time, causing mental and other health issues. For example, in Ireland as in many other countries people over 65 were effectively sectioned off from the rest of society, regardless of their vastly differing needs, abilities, fitness levels, and their overall health. The massive contribution of this cohort to society as a whole was eclipsed in favour of a discourse that focused on the idea of their collective vulnerability. One striking feature of the discourse was its non-dialogic nature: the discursive homogenization and 'frailing' of the over 65s meant that people in this category were an object of public discourse rather than participants in the debate.

The debate about older people, and the categorization of 'over-65s' in the ongoing COVID-19 crisis invites analysis of the implicit and explicit methods of framing ageing by synergies between scholarship in arts, humanities and gerontology.

¹ S. Fraser, M. Lagacé, B. Bongué et al, 'Ageism and COVID-19: What does our society's response say about us?' [published online ahead of print, 6 May 2020]. See: *Age Ageing*. 2020;afaa097. doi:10.1093/ageing/afaa097. M. Schrage-Frueh, T. Tracy; 'Happy In? Ageing and Ageism in the Age of

Coronavirus and Cocooning.' See: <u>https://mooreinstitute.ie/2020/04/23/happy-in-ageing-and-ageism-in-the-age-of-coronavirus-and-cocooning/</u> (accessed 12 August 2020).

Our webinar COVID-19: Reframing Ageing² attempted to rise above sector debates by asking:

- What are the blind spots and biases that COVID-19 has revealed in public discourse, political rhetoric and narratives of experience?
- Is the widespread policy of 'protecting' a particular group by means of chronological age a necessary defence against a virus whose impacts are highly age-sensitive, or is it a radical and disturbing reframing of older people in society?
- Is the language used to identify particular cohorts of the population appropriate? Is it consistent with the kind of normative discrimination that typically frames (and writes off) people in this age-group as 'elderly'?
- What kind of exchange and consultation with the particular cohorts has taken place?
- What learnings can governments, policy makers and wider society take from this situation?
- Reform of the nursing home sector is a hot political topic currently: will this last beyond COVID-19, and if yes, what form will reconceptualization take in future?

The critique of the homogenizing view of older people and of the language used to describe them must be reflected in an alternative methodological approach which develops a multiperspectival outlook on ageing and does justice to vastly differing experiences and sociocultural settings. Four panels were set up to discuss the blind spots and biases of public discourse about older people from interdisciplinary perspectives, straddling gerontology, sociology, gender studies, history, art practice, and literary studies. In so doing, the webinar participants attempted to reframe negative perceptions and representations, particularly in the media, of ageing as an overwhelmingly disabling process that erodes people's autonomy, agency, and dignity.

The public need for this debate was underlined by the high registration number: over 300 people enrolled from Ireland, the UK, continental Europe, the USA and South America, and over 190 people attended the seminar on the day, filtering their comments and interventions through the chat function on Zoom.

Panel One

The webinar opened with a reflective talk by Ailbhe Smyth, a life-long women's rights advocate and LGBT campaigner who, at the time of speaking at our webinar, had spent 93 days in isolation. Entitled *Unseen, Unheard, Untouched: A View from the Interior*, her talk probed the lack of human touch in the lives of those who had to spend the Covid-19 crisis in self-isolation. The internet and zoom meetings do not compensate for the lack of touch:

'Virtual touch is the ultimate oxymoron, leaving me with ineffable longing, an ache, a need.'

² This webinar is part of the Wellcome Trust funded research collaborative project *Framing Ageing*. For more information please check the following website: <u>https://framingageing.ucd.ie</u>.We would like to thank the Wellcome Trust for generously funding this interdisciplinary research project.

The absence of basic daily activities and human interaction created 'unfathomable depth of loneliness', the detrimental effects of which have yet to be fully analysed. Smyth observes a direct link between the excess rate of deaths of dementia sufferers in nursing homes and the fact that they were cut off from visits and activities.

For Smyth self-isolation was compounded by the admonishing rhetoric of the government and its public health representatives: the employment of a 'severely monitory' language peppered with modal instructions cowed people into acquiescence, even though the curtailment of the freedom of movement had no basis in law. This ageist approach to the over 70s found symbolic expression in the notion of 'cocooning', a patronising term which reveals society's deeply entrenched ageism.

Public bodies, the government, and the media overwhelmingly represented all older people as frail, vulnerable, and dependent, lumping a very diverse age group together in a 'one-size fits all' box with no regard to vast variations in their lives and circumstances. The problem was further compounded by the complete lack of consultation: Smyth criticized the composition of NEPHET (the National Health Emergency Team in Ireland) which had no members aged over 70 and no representatives of NGOs working with older people.

'There is a number of crises confronting — in fact already erupting — all around our post-pandemic world: from late consumer capitalism to racism, migration, and of course health, the economy, and the future of our planet. One raised surprisingly rarely but of immense importance is the crisis of care.'

She observed that in Ireland (as elsewhere) more than 60% of deaths occurred in residential care home settings. Even though care home residents represent the most vulnerable group in society, their needs were overlooked or ignored.

'Living behind closed doors, they were unseen, unheard, untouched – and too many died as a consequence.'

For Smyth this scandal brings to light society's abrogation of our shared responsibility towards those in our society who are frail, debilitated or disabled:

'One of the key lessons from the pandemic is surely that it is our collective responsibility to ensure that such a care-less and, bluntly, uncaring catastrophe will never happen again.'

Smyth concluded her statement with a reflection on the key term of our seminar: the notion of framing. When asked to take a family portrait in a photography class, she took a picture of

herself with a paper bag over her head and called it 'Not in the Picture'. While at the time the photo captured how she experienced her life as a lesbian in Ireland, the paper bag photo and its caption still apply to older adults who spend much of their later lives 'unseen, untouched and unheard'.

Panel Two

The first respondent, Thomas Scharf, responded from a social gerontology perspective, noting that the pandemic has been a transition point in the field in terms of a pre-COVID gerontology and a post-COVID gerontology. Both versions are going to have to come to terms with the deep-seated ageism exposed over the course of the pandemic. In the UK, 90% of the over 63,000 so-called excess deaths have been among people aged 65+, with over 20,000 deaths in care homes: we have to ask fundamental questions about what has gone wrong and why older people's lives don't appear to matter.

This takes us back more than fifty years in gerontology from the coining by Robert Butler of the term ageism³ up to contemporary concepts of age and ageism as negative constructions of old age which takes place at the individual and societal levels⁴.

'Today, there are around 600 million people aged 60 years and over worldwide. This number will double by 2025 and will reach two billion by 2050, with the vast majority of older people in the developing world.'⁵

The pandemic has confirmed the continuing broad acceptability of many forms of ageism in the UK and in many other countries. While gerontologists have challenged this for many years, they have been taken aback by the speed and extent to which ageist language has reemerged and been accepted, and by the types of things that people have said about age and ageing over the course of the last three months. Scharf pinned a substantial part of the blame on the UK government but also on media representations of age and older people. An independent public inquiry is needed to explore what has gone wrong. There is a lot of evidence that that will reveal widespread institutionalized forms of ageism. In the UK, public messaging emphasized that science was guiding government through the pandemic, but there were no geriatricians or social gerontologists on the scientific advisory group. For a condition that disproportionately affects older people, the question is: why is there is no expertise on ageing feeding in to the scientific decisions that are supposedly informing government decision making?

³ Robert N. Butler, 'Age-ism: Another Form of Bigotry.' *The Gerontologist* 9 (4, Part 1) (1969): 243–246; Robert N. Butler, Ageism'. *Generations* 29/3 (2005): 84–86; see also: Margaret Morganroth Gullette, *Agewise. Fighting the New Ageism in America* (Chicago: University of Chicago Press, 2011); John Macnicol, *Age Discrimination.* (Cambridge: Cambridge University Press, 2009); Erdman B. Palmore, Laurence Branch, and Diana K. Harris (eds), *Encyclopedia of Ageism* (Binghamton, NY: Haworth Press, 2005).

⁴L. Ayalon, L. and C. Tesch-Römer, 'Taking a closer look at ageism: Self- and other-directed ageist attitudes and discrimination.' *European Journal of Ageing* 14/1 (2017): 1-4. doi: 10.1007/s10433-016-0409-9 ⁵ WHO: 'Ageism and Life course.' See: <u>https://www.who.int/ageing/features/faq-ageism/en/</u> (accessed 30 July 2020).

Initial suggestions about restricting all people aged over 70 to their homes revealed the extraordinary lack of gerontological literacy within government, with a substantial proportion of people needlessly locked down. Blanket use of chronological age reinforced negative associations of old age with vulnerability, frailty, ill health, disability and proximity to death.

This was paralleled by institutional ageism in care settings: while care homes have been neglected over many years, the pandemic outcome is new in terms of excess mortality. The release of 25,000 people from hospitals into care homes without any testing for coronavirus resulted in an enormous number of deaths, exacerbated by casualized and underpaid careworkers continuing to move in and out of care homes even when risks of infection and cross-infection were known. People with loved ones in care homes are still unable to visit them at this point and to contact them so their relationships have been severely curtailed: essentially, older peoples' lives have been shown not to matter.

Recent research shows how the media shapes and perpetuates negative attitudes and stereotypes of ageing. $^{\rm 6}$

Visual representations through numerous stock images dehumanize people, reducing them to no more than a series of isolated body parts such as wrinkly hands.

There was also the obsessive focus on a perceived epidemic of loneliness among older people. Evidence points strikingly in the opposite direction: in the UK loneliness was more prevalent among working-age than among older people⁷. We have to use this knowledge in the future as an opportunity to do something much better for reframing ageing and its positive values.

In his contribution Paul Higgs described the bifurcation that the COVID-19 crisis has brought to light in the older population: everybody is grouped together within the category of 'over seventy'. This reverts back to an older form of ageism: old age is seen as a chronological problem associated with illness and disability.

The bifurcation in the discourses around ageism separate those who could be described as in the Third Age from those who are seen as existing within the Fourth Age.⁸ The latter group was particularly affected by the government's complete lack of interest in those in care homes, as evidenced in the catastrophic decision to send people back to nursing homes

⁶ Hannah J. Swift H and Ben Steeden, 'Exploring representations of old age and ageing' (London: Centre for Ageing Better, 2020). See: <u>https://www.ageing-better.org.uk/sites/default/files/2020-03/Exploring-representations-of-old-age.pdf</u> (accessed 8 June 2020).

⁷ 'Coronavirus and Ioneliness. Great Britain: 3 April to 3 May 2020.' (London, Office for National Statistics, 2020). See:

https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/bulletins/coronavirusandlonelinessgreat britain/3aprilto3may2020 (accessed 18 May 2020).

⁸ On this issue see Paul Higgs and Chris Gilleard, *Rethinking Old Age: Theorising the Fourth Age* (Basingstoke: Palgrave, 2015).

without testing them for COVID-19. This appalling lack of interest in the well-being of the Fourth Age indicates that in many ways ageism has concentrated on older people in nursing homes, in contrast to Third-Age older people who were seen as continuous with the rest of the population. This is an important cultural phenomenon and also reflects in some parts the re-emergence of generational conflict as a theme within society.

Generational bias was further reflected in attitudes to herd immunity, a disastrous policy that implied pushing the numbers of old people dying a bit faster than would have occurred normally.

A further example of generational bias were proposals in the UK for age-segregated unlocking of lockdown. Some policy makers suggested to release people in their 20s, 30s and 40s first because they were deemed to be more important to the economy. While these arguments were not necessarily popular, the fact that they have been proposed highlights the need for vigilance: we need to be aware of the many complex ways in which ageing is being represented

The questions following this section related to vulnerabilities. Scharf noted that we need to think very carefully about the language that is used to adequately describe the heterogeneity of later life. Social gerontologists need to step back and recognize a failure to communicate a view in the public domain that represents ageing as something more than vulnerability.

Social gerontologists need to take time to sit down with policymakers, politicians, and media organizations to provide gerontological literacy that would enable them to overcome negative stereotypes.

Fuchs noted that many members of the audience were critiquing the widespread usage of the category of vulnerability because, as blanket term, it often prevents older people from enacting their own agency under the pretext of protection. A whole cohort of people including people with disabilities are then being policed by government policy. This underlines once more why the language matters so much. 'Cocooning' is a metaphor that prevents any kind of critical engagement with government policy and type of policing.

Smyth added that the term vulnerability is very interesting because we are all often vulnerable and vulnerable in all kinds of different ways at different points in our lives. For example, women living with violent partners during the pandemic were extremely vulnerable to emotional, physical and psychological abuse.⁹ However, there is something problematic about using vulnerability in relation to older people. We have to bring back that concept of vulnerability as a reality in human living and not be afraid of it. There is a fear of vulnerability.

⁹On vulnerability see Judith Butler, *Precarious Life: The Powers of Mourning and Violence* (London: Verso, 2006); Catriona Mackenzie, Wendy Rogers, Susan Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford: Oxford University Press, 2013).

But the term 'vulnerable' should not be censured. Instead, we have to dissociate it from blanket application to old age. This is very important because the vast majority of deaths of over 65s from COVID-19 was also associated with an underlying medical condition indicating a pre-existing vulnerability which was not just about older age. This discussion demonstrated the importance of multi-disciplinary discussion and interpretation of such critical terms.

Higgs added that ageing is also a physiological process and this has sometimes that has been missing from some of the gerontological discussion: the older you are, the more vulnerable and more likely you are to die. Old age as a category does actually come with a risk of dying and therefore a government has to also take this into consideration. We can't just discuss this in terms of the rights of people: we also have to think about protecting people. 'Lockdown' is not a good term in any language but it was designed to stop the transmission of a virus and we have to accept that was actually about the physiological process rather than the social process.

A final point from Scharf highlighted how inequalities were reflected as a key dimension in the UK in the manner in which risk of dying from COVID-19 was patterned along the social gradient, and especially among people living in very disadvantaged urban communities. Vulnerability isn't just a feature of old age: it is a risk, but one that occurs alongside many other risk factors. When we get to a formal inquiry we must hope that we also can look at some of the combination of risks that people have experienced and the poor way in which we've responded to them.

Panel Three

The next panel opened with presentations by Susan Pickard and Andrew King, two sociologists specializing in the relation between age and identity factors like gender, sexuality and class, and closed with gerontologist Desmond O'Neill. Pickard focused on what she has called 'Age War Discourse':¹⁰ COVID-19 did not create this Age War discourse but it was pervasive in the UK media coverage and served as a simplistic and conflict-based way to interpret the crisis. For Pickard this mode spans the political spectrum: Age War discourse permits élite interests to avoid more problematic class war discourses. It also appeals to people on the Left who see youth as the engine of progressive politics, and old age as a site of conservatism.

The opposing value of older and younger generations has been starkly revealed by COVID-19, even more so than in previous moments of Age War discourse, including the important context of austerity, Brexit, and the conservative return. The Third Age has been blamed for climate change and capitalist excess, but this recrimination mischaracterizes the economic realities of Third Age life: one-sixth of all pensioners live in poverty—they are not homogeneously privileged. The Fourth Age is discussed solely in terms of the cost of paying for their health and welfare, a cost unfairly borne by younger generations. Pickard quoted prominent journalist and former editor of *The Daily Telegraph* Max Hastings, who referred in *The Times* to older people as 'monumentally selfish,' a 'deadweight upon the health system' and 'the past, not the future.' If these comments were directed at any other minority, they would be deemed a hate crime. Pickard concluded with the important point:

¹⁰ Susan Pickard, 'Age war as the new class war? Contemporary representations of intergenerational inequity.' *Journal of Social Policy*, *48*/2 (2019): 369-386.

Systemic ageism is exacerbated by the lack of value placed on women's lives. Death in care homes is not only a genocide but a female genocide when one considers that 72% of all care home residents are female, and figures are similar across Europe.

In his talk Andrew King focused on how COVID-19 has revealed an embedded chrononormativity in contemporary British and western culture. Chrononormativity entails the widespread acceptance that chronological age is *the* single marker that defines the identity of older people, rather than complex social and cultural factors. It also groups older people in one undifferentiated mass, making no room for example for LGBT experiences.¹¹ Elizabeth Freeman in *Time Binds* defines chrononormativity as 'the use of time to organize individual human bodies toward maximum productivity.'¹²

The logic of chrononormativity is at work in the characterization of over-70s as a mass in need of confinement, represented as unproductive or productive only in limited ways (ability to do volunteer work, care for grandchildren.)

Chrononormativity, importantly, is based on the heterosexual life course. Heteronormative media communication erases from view experiences such as older LGBT people and those without children.

While Pickard and King took up the COVID-19 discourse in the media, O'Neill focused on the problem of the integrity of academic and scientific responses and responsibilities during the crisis. The ethical pronouncements about older people in official Irish circles did not meet clear benchmarks of scholarly rigour, with no attributions of authorship or consultation, and no appreciable reference list.¹³ The general framework for COVID-19 encompassed prioritizing medical treatment based on the criterion of 'life years saved.' Had this been implemented, old people could have been excluded from life-saving treatment. Overt ageism obviously affects many people, but occult ageism abounds in the guidelines provided for care home settings. One example is the proposal that care home residents should conduct end-of-life-planning over the phone, without consideration for the necessity of face-to-face communication. How do those in gerontology but also philosophy, theology respond to the assumptions underlying these guidelines? COVID-19 has seen the degradation of academic standards. O'Neill concluded by asking:

¹¹ On this issue see Andrew King, *Older LGBT People: Minding the Knowledge Gaps* (London: Routledge, 2019), and Andrew King, Kathryn Almack (eds), *Intersections of Ageing, Gender and Sexualities* (Bristol: Policy Press, 2019).

¹² Elizabeth Freeman, *Time binds: Queer temporalities, queer histories* (Durham, NC: Duke University Press, 2010).

¹³ Desmond O'Neill, 'Covid-19: clinicians need continuing professional development in ethics.' *BMJ*, 370, m2793 (2020).

Are we at a #OlderLivesMatter moment where we can promote the longevity dividend?

The ensuing discussion took up the idea of the intersection between Black Lives Matter and the fight for fair and dignified treatment for older people. Discussion returned to the vocabulary of vulnerability, noting that it is a key aspect of this intersection. Earlier in the webinar the idea of older people's over-representation as frail framed the term 'vulnerable' as negative. The BLM movement, on the other hand, has reclaimed vulnerability as an urgent signpost for the violence to which Black bodies are subject. Can the discourse of ageing do the same?

King returned to the danger of seeing older groups as undifferentiated: For example, 'All LGBT people are vulnerable' is not the case. The danger is in labeling entire groups, using it as a blanket term. Pickard acknowledged that there is a vulnerability associated with Deep Old Age¹⁴ that's part of a continuum with human beings of all ages. But real physical vulnerability must be carefully disentangled from the kind of vulnerability that is imposed on people. Care home patients were vulnerable because of neglect. When these two ideas are conflated, then this signals ageism.

Comments from Dana Walrath and Ailbhe Smyth pointed to the intersection of racism and ageism through systemic, particularly economic, factors: The struggle for black lives and older lives are linked through a logic of capital that renders some lives disposable. In this sense, vulnerable people are at risk because, as Smyth put it, 'vulnerability and capitalism are in conflict.'

Panel Four

In the fourth and final panel of the 'COVID-19: Reframing Ageing' webinar speakers Ulla Kriebernegg (Austria), Rina Knoeff (Netherlands) and Dana Walrath (USA) offered a humanities-centred, interdisciplinary, and international perspective on the topic, giving insight into how Austria, the Netherlands, and the USA have been contending with the pandemic. All three talks emphasized the importance of Humanities research in helping to alter and refine some of the approaches taken to older populations in the pandemic. Knoeff and Walrath were particularly critical of any approach that is based only on bio-medicine. Walrath and Kriebernegg considered the position of care givers who are exploited and underprivileged (Walrath addressed this from the perspective of ethnicity and structural racism while Kriebernegg discussed it more from a gender and economic perspective).

Kriebernegg approached the topic of ageing from a literary and cultural angle, with a particular focus on cultural, media and literary representations of ageing. Noting how COVID-19 functions as a magnifying glass for existing societal problems, she addressed three related matters during her talk. First was the theme of care, and in particular the overlooked figure of the care-giver. Kriebernegg pointed out that especially 24-hour care-givers, who mostly

¹⁴ Susan Pickard, 'Biology as destiny? Rethinking embodiment in 'deep'old age.' *Ageing & Society*, 34/8 (2014), 1279-1291.

care for those in the 'Fourth Age' are a 'public secret', but the problems raised by Covid-19 had exposed elements of this secret.¹⁵

Most of these care-givers in Austria are women and come from eastern European countries, such as Romania. These workers are underpaid, underappreciated and mostly invisible.

However, due to restrictions that came into force in the wake of the pandemic, the unfavourable circumstances under which these women work came to light.

Many of them had to work in six-week shifts punctuated by two-weeks of self-financed quarantine. Media representations of these women tended overwhelmingly to gloss over this circumstance, however, representing the care-givers as 'naturally inclined' to give care.

Kriebernegg noted that this speaks to a gender bias,¹⁶ but is not just about gender; intersectionality is at play here too. Thus the women were represented as adhering to traditional values and being family-oriented, which also naturally predisposed them to giving care to older people. In this vein, the media coverage mentioned how some care givers, who may have needed to travel home or self-quarantine, were reluctant to leave their patients behind in Austria, as they would likely end up in the 'black hole' of the nursing home.

Kriebernegg echoed prior panellists in highlighting the danger of representing care homes exclusively as places of 'gothic' horror. Such cultural framing of this Fourth Age location is connected to a commonly held view of old age as a burden. However, there is evidence-based research emerging from a project on reimagining old-home care at Nottingham Trent University which suggests that there are many good long-term care homes that strive to embrace ageing and rewrite the last chapter of life in a positive manner.¹⁷

Kriebernegg's final point picked up on Susan Pickard's discussion of Age War Discourse in the previous panel: the aggravation of existing intergenerational conflict as a result of COVID-19. Grievances already held by younger generations today against those generations that went before them include concerns about climate change as well as intergenerational economic inequality – both of which have worsened in light of COVID-19.

¹⁵ See Kathleen Woodward, 'A Public Secret: Assisted Living, Caregivers, Globalization.' International Journal of Ageing and Later Life 7/2 (2012): 17-51.

¹⁶ See the contributions in Kathleen Woodward (ed.), *Figuring Age: Women, Bodies, Generations* (Bloomington and Indianapolis: Indiana University Press, 1999); Susan Pickard, *Age, Gender and Sexuality through the Life Course: the girl in time*' (London: Routledge, 2018)

¹⁷ This research is led by Prof Sally Chivers. See the open-access publication:

https://library.oapen.org/handle/20.500.12657/30552. See also Sally Chivers, Ulla Kriebernegg (eds), Care Home Stories: Aging, Disability and Long-Term Residential Care (Bielefeld: transcript, 2017).

The pandemic came about as a result of humankind's encroachment over several generations on the natural environment, and the extent of the recession that has already emerged as a result of the pandemic is unknown. This plays into worries for the future of younger generations but it also has the capacity to stoke resentment and intergenerational conflict — already apparent in the 'ok boomer' meme.

In this vein, Kriebernegg noted the cynicism of referring to COVID-19 as a 'boomer remover' phenomenon. This last point plays on and intensifies longstanding pejorative views of older people as a drain on resources. A powerful cultural representation of this kind of thinking is Margaret Atwood's story 'Torching the Dusties' which tells the tale of younger people torching nursing homes full of expensive 'parasites' (in *Stone Mattress: Nine Wicked Tales*, 2016).¹⁸

In conclusion, Kriebernegg observed with concern that the good work undertaken in recent years by cultural gerontologists to recast ageing as a process that can be imagined differently and in a more positive way than 'decline narratives' has likely suffered a setback due to the pandemic. COVID-19 has put pressure on this good work; scholars must renew their efforts to work against these developments.

Rina Knoeff's talk offered a critical view of the approach taken in the Netherlands to protecting care home residents (and in this respect confirms the negative view of care homes critiqued by other speakers).

The protection in the Netherlands of a 'vulnerable' population in care homes bordered on a violation of the human rights of that population, as many residents suffered sharp emotional and cognitive decline as a result of the loneliness and neglect that ensued from being cut off from family and friends during lockdown.

Lockdown rules enforced ostensibly in order to protect older people thus achieved the opposite effect, which led to a national outcry in the Netherlands. Some care homes went so far as to fence off care-home premises so that residents could not even hold hands with loved ones. This captures what webinar keynote speaker Ailbhe Smyth described in her opening talk: the detrimental effects of lack of human touch over an extended period, something that in particular older people in many jurisdictions the world over had to contend with during the

¹⁸ See Ulla Kriebernegg, ,'Time to go. Fast not slow': Geronticide and the Burden Narrative of Old Age in Margaret Atwood's 'Torching the Dusties'.' *European Journal of English Studies* 22/1 (2018): 46-58. doi:<u>10.1080/13825577.2018.1427200</u>

first lockdown phase. Such policy decisions are based on a problematic understanding of vulnerability and human need, argued Knoeff. She further pointed out that the lockdown rules for care homes in fact increased the vulnerability of older populations because the lack of contact with family and friends was so detrimental in emotional and cognitive terms.

What policy makers completely missed was that older people do not so much fear death as a lonely death.

Knoeff thus asserted that society today could learn much from pre-modern lifestyle medicine with its careful discussion of human beings and their needs, emotional and social wellbeing. Pre-modern understanding of the ageing body tended to view it as an *ailing* body; as a result, approaches to ageing in the eighteenth century (for example) focused on cheerfulness, comfort and a tranquil mind in older age.¹⁹ Today this is an area where humanities scholars and cultural gerontologists (rather than those working in bio-medicine) can offer expertise, insight and advice to governments and policy-makers; however, the team in charge of the Dutch response to the pandemic did not feature any humanities scholars, social scientists or cultural gerontologists (much like SAGE in the UK or NPHET in Ireland) who could advise on how to manage the pandemic in a more rounded, intuitive and humane way. At a local level, however, mayors, police leaders and community workers have invited Knoeff and her colleagues to speak on how to approach the new situation. This is a positive development that suggests that a broader move towards lifestyle medicine as a way of coping with COVID-19 might be taking off in the Netherlands; however, it needs to be included at higher levels of policy development. Both Kriebernegg and Knoeff agreed that

There is a strong case for the role of Humanities scholars in resisting the rise of negative and cynical 'decline' narratives of old age and renewed intergenerational conflict.

Humanities scholars can advise policy makers and officials about how to approach the care of older people, and older people themselves, in a more humane way that is attuned to mental and emotional needs of older people during the pandemic.

The last speaker of the webinar, Dana Walrath, made a strong case for the urgency of reframing ageing as a global human right. Walrath was speaking in light of the murder of George Floyd who died in Minneapolis in May 2020 due to police brutality.

Floyd's dying words 'I can't breathe' ask us to address the systemic and structural racism that predispose different ethnicities to violence and death; in the context of COVID-19 this baked-in racism means that black and brown people, for

¹⁹ See J. Kennaway and H. Knoeff (eds), *Lifestyle and Medicine in the Enlightenment: The Six Non Naturals in the Long Eighteenth Century* (London: Routledge, 2020).

structural reasons, are more likely to be infected with and die from the virus than privileged white people.

In this respect, Walrath spoke of the privilege of her mother Alice's death; Alice had been in a care home for three years when she died, having lived with Alzheimers disease for two decades.²⁰ While she arrived in the US as the poor 'brown' daughter of refugees of genocide, she died a 'white' privileged death in a care home surrounded by excellent staff and family. A question raised by Prof Walrath's talk thus concerned how we can change things so that that kind of death can become everyone's experience.

Walrath's talk also reflected Kriebernegg's focus on the unfair circumstances of care givers; while Kriebernegg spoke more about gender and economic injustice, Walrath emphasized the ethnicity of care givers from a global perspective. Care givers in the global north often come from the global south, the Philippines, or as in Kriebernegg's example, eastern Europe. In the US they are overwhelmingly African American, indigenous peoples from the global south and some poor whites. Walrath argued that if we are serious about reframing ageing as a human right, then the exposure of these essential workers and the communities they live in to long-term health problems needs to be taken on board. Walrath's talk also chimed with Kniebernegg and Knoeff's emphasis on the potential of Humanities research to improve and enhance our approach to ageing:

If we are to reframe ageing as a global human right, then we must also recognize the limitations of bio-medicine in charting this path. The response to the pandemic which relied on technological interventions, focused just on physical bodies rather than on the whole person and introduced a dehumanizing world of masks and ventilators, thus masking the real political, economic and historical injustices at the root of sickness which expose some ethnic groups to illness and death much more than others. In this sense, the anti-black racism that gave rise to George Floyd's murder is also a public health crisis.

Questions that were raised in the discussion concerned gender and ageing: why are carers mainly women? Why do women get dementia more than men? This connected back to Pickard's 's description of the death of so many older women in UK homes as a genocide – the Fourth Age is predominantly female, she argued, and even the Fourth Age for men is feminized. Pickard sees the ageism directed particularly against older women as a cause of the high number of female deaths in UK care homes.

²⁰ Dana Walrath, *Aliceheimer's: Alzheimer's Through the Looking Glass* (Pennsylvania: The Pennsylvania State University Press, 2013).

Looking at the high proportion of women who are care givers, Walrath made the case for reframing caring as a partnership:

We need to change the discourse from care-giving to carepartnerships, whereby it is made clear that we all benefit from care.

Langbein picked up on an audience question whether touch and company could be defined as human rights in a re-framed understanding of ageing. As a possible response to a further audience question re: how older people can survive until the end of 2021, O'Neill concluded that we have to continue to make a stronger case for 'older lives matter'.

Appendix: Webinar Participants

Chairs:

Anne Fuchs (FBA, MRIA) is Professor and Director of the UCD Humanities Institute. She has published widely on German cultural memory, modernist literature, contemporary German literature and, more recently, on modern regimes of time and temporality. Her monographs include *Phantoms of War in Contemporary German Literature, Films and Discourse: The Politics of Memory* (2006, 2010, CHOICE title); *After the Dresden Bombing: Pathways of Memory, 1945 to the Present* (2012), and *Precarious Times: Temporality and History in Modern German Culture* (2019). Fuchs was co-author of the successful PRTLI3-application for the foundation of the UCD Humanities Institute and its five-year programme on *Memory and Identity in 21st Century* (2002-2007). She has received numerous research grants, fellowship and guest professorships. She is a member of the Royal Irish Academy and a Fellow of the British Academy. Fuchs is the PI of the Wellcome Trust funded project *Framing Ageing: A Clinical, Cultural, and Social Dialogue* in collaboration with the TCD Medical humanities network and colleagues in Ireland, the UK, Europe and the US.

Desmond O'Neill (MD FRCPI) is Professor of Medical Gerontology at Trinity College Dublin. His research centres on gerontology and the neurosciences, with a strong emphasis on the humanities. One of the most widely published scholars in medical humanities in Ireland, he is a co-founder and past-president of the European Union Geriatric Medicine Society (www.eugms.org), and currently Chair of the Humanities, Arts and Cultural Gerontology Advisory Panel of the Gerontological Society of America, co-chair of Medical and Health Humanities at TCD, and Section Editor for Geriatric Medical Humanities in *European Geriatric Medicine*. He was awarded the All-Ireland Inspirational Life Award in 2010 for advancing the cause of older people in Ireland, and the Joseph T Freeman prize by the Gerontological Society of America in 2014.

Mary Cosgrove is Professor of German at Trinity College Dublin. She is the Co-Chair of the Medical and Health Humanities research network. Her research interests include cultural memory, trauma, melancholy, and depression. Her publications include Born under Auschwitz: Melancholy Traditions in Postwar German Literature (2014, Choice recommended title); (with Anna Richards, ed.), Sadness and Melancholy in German-Language Literature and Culture, Edinburgh German Yearbook VI (2012); (with Anne Fuchs and Georg Grote, eds.), German Memory Contests: The Quest for Identity in German Literature, Film and Discourse since 1990 (2006, paperback 2010; winner Choice Outstanding Academic Title, 2007); Grotesque Ambivalence: Melancholy and Mourning in the Prose Work of Albert Drach (2004). Her research had attracted funding from the IRCHSS (IRC), the AHRC, the British Academy, the DAAD, the ÖAD, and the Carnegie Trust for the Universities of Scotland. In 2011 and 2012 she organised public engagement events on the topics of melancholy and sleep under the auspices of the Scottish Mental Health Arts and Film Festival. In 2019 she co-organised a Neurohumanities public engagement event at the Trinity Long Room Hub: 'Melancholia and the Brain: Conversations between Neuroscience and the Arts'. In 2014 she was Visiting Fellow in the Centre for the History of Emotions at the Max Planck Institute for Human Development, Berlin. From 2016 to 2020 she was Germanic Editor of the Modern Language Review.

Julia Langbein is Research Fellow in Trinity College Dublin. She is an art historian specialising in the nineteenth-century art and visual culture. She received her PhD in 2014 from the

University of Chicago, held a postdoctoral research fellowship at Oxford University 2014-2018, and is now a Research Fellow at Trinity College, Dublin. She is the author of *Laugh Lines: Caricature and Painting in Nineteenth-Century France* (Bloomsbury, 2021), the first major study of the public mockery of fine art, and is now working on a monograph entitled *Ageing in the Age of Modernism*, which re-examines developments in pictorial modernism in the context of nineteenth-century fears about population ageing.

Panellists:

Paul Higgs is Professor of the Sociology of Ageing at University College London where he works in the Faculty of Brain Sciences. He has published extensively in social gerontology, medical sociology particularly on the issues surrounding the Fourth Age. He has been involved in a number of EU and UK government funded research programmes studying the social contexts of dementia and has been elected a fellow of the Gerontological Society of America and the UK Academy of Social Sciences. His research interests stem from work he conducted with Dr Chris Gilleard which has been published in four books: *Cultures of Ageing* (2000), *Contexts of Ageing* (2005), *Ageing, Corporeality and Embodiment* (2013) and *Rethinking Old Age: Theorising the Fourth Age.* He is currently a co-investigator on two five-year NIHR/ESRC projects (MARQUE and PRIDE) investigating the social aspects of dementia. Higgs is editor in chief of the journal *Social Theory and Health* and co-editor of the 2017 *Sociology of Health*. He is a fellow of the UK Academy of Social Sciences and of the Gerontological Society of America.

Andrew King is Professor of Sociology at the University of Surrey where he is also Co-Director of the Centre for Research on Ageing and Gender and Co-Chair of SGS (the Sex, Gender and Sexualities Research Group at Surrey). He leads the Norface funded project, 'CILIA-LGBTQI+' which is comparing intersectional life course inequalities amongst LGBTQI+ people in four European countries and has been actively researching LGBT+ ageing for over fifteen years. He has published widely in the field, including: *Older Lesbian, Gay and Bisexual People: Identities, Intersections, Institutions* (Routledge, 2016), *Older LGBT People: Minding the Knowledge Gaps* (Routledge, 2019), and *Intersections of Ageing, Gender and Sexualities* (Policy Press, 2019). Andrew is an associate editor of *Ageing and Society*.

Rina Knoeff is Associate Professor of History, University of Groningen, Netherlands and Director of the Groningen Centre for Health and Humanities. She works on the history of body and health in the Enlightenment with special reference to the influential medicine of the Dutch Boerhaavians. She recently completed a research project on Boerhaave's chemical-medical legacy and Dutch Enlightenment Culture and is now working on the history of healthy ageing in the eighteenth century. She authored *Herman Boerhaave (1668-1738): Calvinist Chemist and Physician* (Edita, 2002) and edited *The Fate of Anatomical Collections* (Ashgate, 2015) and *Lifestyle and Medicine in the Enlightenment. The Six Non-Naturals in the Long Eighteenth Century* (Routledge, 2020). In addition, she has a leading role in the Groningen Aletta Jacobs School of Public Health, bringing expertise from medical humanities into the School's research and policy advice.

Ulla Kriebernegg is Associate Professor of American Studies at the University of Graz, head of the Age and Care Research Group Graz, and adjunct at the Medical University Graz, Austria.

Ulla's emphasis in research and teaching is on age/ageing studies, literary gerontology, and medical humanities. She is project director of *Who Cares: Alter(n) und Pflege gemeinsam neu denken* and deputy chair of the European Network of Aging Studies (ENAS) of which she is also a founding member. She co-edits the Aging Studies book series and is an editorial board member of several journals such as The Gerontologist and the Journal in Aging Studies. Her forthcoming book, *Putting Age in its Place*, focuses on cultural representations of care homes in North American film and fiction.

Susan Pickard is Professor of Sociology at the University of Liverpool. Her research and teaching interests are located within the fields of sociological approaches to ageing, gender, embodiment, health and illness. Her research in these areas has been published in a number of high ranking academic journals supported by a number of grants including from Leverhulme, the Foundation for the Sociology of Health and Illness, AHRC and the British Academy. Her publications include Age Studies: a sociological examination of how we age through the life course' (2016); Age, Gender and Sexuality through the Life Course: the girl in time' (2018) and Ageing, the Body and the Gender Regime: health, illness and disease across the life course, (2019). She is currently undertaking final revisions on a book on midlife. Susan is an associate editor of Ageing and Society.

Tom Scharf is professor of social gerontology at Newcastle University. He is the current president of the British Society of Gerontology and sat on the advisory board of TILDA, the Irish Longitudinal Study on Ageing. His research addresses issues relating to social inclusion and exclusion in later life, often with a focus on the spaces and places in which inclusion and exclusion arise and on the policy responses to forms of exclusion. His research findings have been published in such journals as *Journal of Gerontology: Social Sciences, The Gerontologist,* the *European Journal of Ageing, Ageing and Society,* and the *Journal of Rural Studies.* His most recent book is *From Exclusion to Inclusion in Old Age: A Global Challenge* (2012, co-edited with Norah Keating and published by The Policy Press). A new book *Social Exclusion in Ageing Societies: Interdisciplinary and Policy Perspectives* (co-edited with Kieran Walsh, Sofie van Regenmortel and Anna Wanka) is currently in press with Springer.

Ailbhe Smyth is a feminist, LGBTI and human rights activist and campaigner. The founding head of Women's Studies at UCD, she has published widely on feminism, politics and culture. Ailbhe played a leading role in the same-sex marriage referendum campaign in 2015, and was co-director of the Together for Yes abortion referendum campaign in 2018. Nominated to various State boards over the years, she also chaired the National Lesbian and Gay Federation for a decade. Currently, she is Chair of Women's Aid, and of Ballyfermot STAR Addiction Services, and is a member of the board of Age Action (Ireland). She was named as one of Time Magazine's 100 Most Influential People in 2019 for her work in repealing the 8th Amendment. Ailbhe is a regular contributor to media and national debate on these and other issues in Ireland.

Dana Walrath is a writer, artist and anthropologist, who likes to cross borders and disciplines with her work. After years of using stories and art to teach medical students at University of Vermont's College of Medicine, she spent 2012-2013 as a Fulbright Scholar in Armenia completing *Like Water on Stone*, her award winning verse novel about the Armenian genocide. Her graphic memoir, Aliceheimer's about life with her mother, Alice and dementia, was featured in the *New York Times*, the *Los Angeles Review of Books*, and on National Public

Radio. Passionate about the power of art for social change, her installation View from the High Ground uses interactive artists books to counter dehumanization and genocide. Illustrated essays and commentary have appeared in *The Lancet, The Irish Times, Slate, Somatosphere, Foreign Policy,* and on *Public Radio*. She has shown her artwork and spoken about the healing power of stories throughout North America and Eurasia including two TEDx talks. A Senior Atlantic Fellow for Equity in Brain Health of the Global Brain Health Institute, Trinity College Dublin | University of California San Francisco, she is currently working on a second Aliceheimer's book that will blend personal memoir with anthropological discourse on the end of life, stigma, gender, labour flows, and dementia across the globe.