<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>4</td>
</tr>
<tr>
<td>The Context of Care</td>
<td>6</td>
</tr>
<tr>
<td>Demography</td>
<td>7</td>
</tr>
<tr>
<td>Service landscape</td>
<td>7</td>
</tr>
<tr>
<td>Expenditure</td>
<td>8</td>
</tr>
<tr>
<td>Recent policy landscape</td>
<td>8</td>
</tr>
<tr>
<td>Family Carers and informal care</td>
<td>9</td>
</tr>
<tr>
<td>Summary of Each Presentation</td>
<td>10</td>
</tr>
<tr>
<td>Morning session</td>
<td>11</td>
</tr>
<tr>
<td>Morning Q&amp;A session</td>
<td>14</td>
</tr>
<tr>
<td>Mid-morning session</td>
<td>15</td>
</tr>
<tr>
<td>Mid-morning Q&amp;A session</td>
<td>16</td>
</tr>
<tr>
<td>Panel discussion</td>
<td>16</td>
</tr>
<tr>
<td>Afternoon session</td>
<td>18</td>
</tr>
<tr>
<td>Afternoon Q&amp;A session</td>
<td>22</td>
</tr>
<tr>
<td>Common Themes and Reflections</td>
<td>24</td>
</tr>
<tr>
<td>Next Steps</td>
<td>28</td>
</tr>
<tr>
<td>Conclusion</td>
<td>30</td>
</tr>
<tr>
<td>References</td>
<td>32</td>
</tr>
<tr>
<td>Appendix 1 - Symposium Programme</td>
<td>34</td>
</tr>
</tbody>
</table>
Introduction

In a little over ten years from now there will be almost one million people aged 65 and older living in Ireland. Population ageing matters to all of us, either directly, as anyone aged over 55 years now will be in that cohort, or indirectly as loved ones of older people who may need our support as they grow older. We need to realise our own sense of self-interest in the demographic changes that are occurring, as we are all, in one way or another, in planning care for our future older selves, family and friends.

The Citizen’s Assembly on Ageing (2017) made important recommendations in relation to current and future arrangements and responsibilities for the provision and financing of long-term care in Ireland. More recently, the Department of Health has completed a review of home care services (Institute of Public Health 2019), following which plans for a new statutory scheme and system of regulation for home support services for dependent older people will be developed. The Health Service Capacity Review (PA Consulting, 2018) has also recommended a recalibrated integrated model of acute care provision that emphasises community-based alternatives, while expanding home care services and supports is also a core strategic objective of the Sláintecare implementation plan for a new health and social care system in Ireland (Department of Health, 2018).

As a contribution to the ongoing debate around the future of long-term care in Ireland, the National University of Ireland Galway, in collaboration with the University of Notre Dame, brought together a small group of policymakers, practitioners and researchers, including national and international experts, to consider some of the big questions facing Ireland in the coming decades around resource allocation, priority-setting and social justice in relation to the care and support of dependent older people in Ireland. This one-day symposium explored some of the key questions in regard to the care of dependent older people in Ireland including:

1. Who should bear primary responsibility for the care of dependent older people in Ireland?
2. Where should care be provided?
3. How should the care of dependent older people be financed?
4. What lessons can be learned from the way other countries provide and pay for care?

It was agreed at the symposium that a brief account of the various presentations and discussions would be produced by NUI Galway and made available to a wider audience. The proceedings are summarised in this document and provide an account of the main issues covered during the symposium.

Many of the speakers at the symposium covered several common areas in setting the context for their presentation, and before presenting a summary of each speakers’ presentation, information on demography, service landscape and expenditure are drawn together here to create a shared context for the more detailed and specific account of the proceedings. A brief overview of key policy developments in ageing in Ireland is also presented. Since many participants referred to informal/family care, some figures on family carers in Ireland are also included. All the presenters spoke of the centrality of the person’s voice and the increasing imperative to pay attention to the preferences of older people. The contributions of older people at the symposium are summarised in the section on the panel discussion.
This symposium brought together national and international policymakers, practitioners and researchers, to consider some of the big questions facing Ireland in the coming decades regarding the care and support of dependent older people.
The Context of Care
Demography

In common with most other developed countries, Ireland’s population is ageing. The proportion of the population aged 65 years and over was 13.4% in the 2016 Census compared to 9.1% in 1926. The population aged 65 years and over increased by 102,174 people to 637,567 in 2016, an increase of 19.1% since the previous Census.1

The distribution of older people is unequal across the country due to factors such as internal population movements within Ireland and the emigration of younger people. Old age dependency ratios give a useful indication of the age structure of a population with people aged 65 and over shown as a percentage of the population of working age (15-64). In 2016, the top two counties with the highest old age dependency ratios were Mayo (28.3) and Leitrim (27.4) in the Western part of the country. The counties with the lowest old age dependency ratios were Fingal (13.8) and Kildare (15.0)2 in the Eastern part of the country. This unequal distribution of older people needs to be taken into account in spatial service planning and provision.

It is projected that the population of Ireland will continue to increase over the next few decades and that the number of people aged 65 years and older will be in the region of 1 million people by 2031 and 1.4 million people by 2046 (i.e. people born in 1981). Similarly, the population aged 85 years and older is projected to increase to around 133,000 by 2031 and 256,000 by 2046 (i.e. people born in 1961). The ageing of the population in Ireland is the result of the continued decline in fertility rates and increased life expectancy. Average life expectancy in Ireland was about 57 years in 19263 and has increased to 83.6 years for females and 79.9 year for males4. This demographic change has resulted in increasing numbers and proportions of people who are aged over 60 years; there will soon be more older people than younger people in the country for the first time in the history of the State.

Ireland’s population ageing is not unique in an international context; in fact it is occurring later than that of many other countries. For example, 25% of Japan’s population is already over 65 years, as is 21% of Germany’s population. We can learn from the developments and responses of other countries in addressing the issues associated with an ageing population.

Service landscape

Several presenters described what we know about the health and social care service landscape for older people. The landscape is complex as older people have different needs at different times and care is delivered in many different settings. Primary care, social care, mental health, wellbeing and acute hospital care are in different divisions within the HSE, creating difficulties in relation to the planning and co-ordination of care for older people. The recent reorganisation of the HSE is designed to assist in integration of these different strands of healthcare. The main elements of health and social care for older people are shown in Figure 1.

Figure 1: Main elements of health and social care services for older people.

In addition to the complexity within the health and social care service landscape, these services exist within the wider ecological context, including: supports provided by the person’s family, their neighbourhood and local community; services provided by the voluntary

---

sector and non-governmental organisations; and other state services such as transport, social protection, housing and many more. All have a role to play in supporting older people in different ways. Service data was presented at the symposium for the main community-based services for which data is readily available:

- **Home support services**: approximately 17m hours are provided for 50,500 people over 65. Average weekly hours per recipient are 6.5 (range 4.5-10.3) and 7.9% over 65s received home support (HS) hours (4.7% to 12% variation by CHO) (HSE, 2018a)
- **Day care**: 320 day centres provide 31,478 places per week (1 place for 1 day) which is a rate of 4.9 places per 100 persons over 65. Unique attendees were 14,497 per week (HSE, 2018b)
- **Residential care**: 30,683 places in HIQA registered designated centres for older people which is a rate of 48.7 places per 1,000 older people. This rate puts Ireland roughly at the average rate for all OECD countries; at the extremes, Japan has a rate of 24 residential places per 1000 older people, while Sweden has 65 places per 1000 (OECD 2019)
- **Acute hospital care**: Approximately 53% of bed days in acute hospitals in 2017 were for people over 65 years and 40% of day cases were people over 65 years (Department of Health 2018).

While this data gives us an overview of service provision in health and social care, the lack of specific data for a wide range of community services places an important constraint on our understanding of the care system for older people, in terms of both process and outcomes. We know, for example, that older people are a significant part of the workload for PHNs, but we have no data on visits by PHNs to older people or resulting outcomes. This is also the case for many other services, particularly in relation to psychosocial provision. The latter plays an important role in the health and wellbeing of older people, but because we have limited information on their availability, they have limited visibility and therefore rarely feature in priority-setting discussions.

**Expenditure**

In 2010, 12.2% of the overall health spending was allocated to older person’s services, decreasing to 10.3% in 2012, following general budgetary cutbacks associated with the financial crisis in the country at that time. By 2017, the proportion of overall health expenditure on services for older people had increased to 11% (of €15.3bn total spending). However, there were 19% more older people in the country compared to 2011, so the per capita spend has been declining steadily in recent years. Of course, the spending on older person’s services does not reflect all health spending on this cohort, as older people are significant users of other parts of the health service, particularly within the acute care sector (see presentation by Dr Kathleen McLellan).

**Recent policy landscape**

There is a rich policy landscape relating to older people in terms of health and wellbeing, much of which was referred to by speakers in the course of different presentations. A detailed overview of policy is not possible here, but more recent policies were covered in detail in several presentations given their relevance for service planning and delivery in the next decade or so, and are included here.

Sláintecare Report (Committee on the Future of Healthcare 2017) – the cross-party nature of Sláintecare is notable and reflects the desire to reform health services so that they are fit for purpose into the future. The key points from Sláintecare of most relevance to the issues in the symposium were:

- ...the best health outcomes and value for money can be achieved by re-orientating the model of care towards primary and community care where the majority of people’s health needs can be met locally
- ...new model of coordinated health and social care is needed to meet the needs of our older population
- ...expansion of most elements of service.

The Health Service Capacity Review 2018 undertook a detailed analysis of health demand and capacity requirements in Ireland to 2031 (PA Consulting 2018). The Review included detailed consideration of changes to social care provision as a way of taking pressure away from the hospital system. Recommendation 2 of the Review noted that: continuation of the current model of care is neither feasible nor appropriate and alternative scenarios of care offer the potential for a better way forward. Three reform scenarios were modelled:

- Improved health and wellbeing
- Improved model of care centred on comprehensive community-based services
- Hospital productivity improvements
The current capacity requirements in relation to services for older people are shown in Table 1, together with forecast capacity requirements in 2031 if there are no reforms and the forecast if reforms occur.

Table 1: Capacity forecasts for selected older person’s services (PA Consulting, 2018)

<table>
<thead>
<tr>
<th>Service</th>
<th>Capacity 2016</th>
<th>2031 Forecast without reforms</th>
<th>2031 Forecast with reforms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residential Care: Long term Beds</td>
<td>26,200</td>
<td>36,300 (+39%)</td>
<td>36,700 (+39%)</td>
</tr>
<tr>
<td>Residential Care: Short term Beds</td>
<td>3,800</td>
<td>5,600 (+46%)</td>
<td>6,300 (+62%)</td>
</tr>
<tr>
<td>Home Care Packages</td>
<td>15,600</td>
<td>26,600 (+70%)</td>
<td>34,600 (+122%)</td>
</tr>
<tr>
<td>Home help hours (millions)</td>
<td>10.6</td>
<td>17.8 (+69%)</td>
<td>23.1 (+118%)</td>
</tr>
</tbody>
</table>

Home care review and related consultation - the development of a new scheme for home care is underway in the Department of Health and is a high priority. The main findings of the consultation process were (Institute of Public Health 2018):

1. Home care needs to be placed on a statutory basis.
2. Person centred model of care is required to deal with the social and psychological needs of the person as well as physical care needs.
3. Integrated working across a wide number of agencies is needed to meet the needs of older people, with collaborative working among the HSE, private providers, social enterprises and the community and voluntary sector to get the best outcomes.
4. Greater investment in home care is needed, along with the development of a long-term approach to how it is financed.
5. Training is required for home care workers.
6. A new regulatory environment for home care will be required.
7. Closer integration between home care and housing policy is required.
8. The Single Assessment Tool will be essential to the delivery of this envisaged home care system.

Joint policy statement on housing - the recent report Housing Options for Our Ageing Population⁵, which is a joint policy statement between the Department of Health and the Department of Housing Planning and Local Government, is a good example of the kind of ‘joined-up action’ that will increasingly be required in the future to address the multifaceted challenges of population ageing.

The policy statement sets out the principles which are intended to inform strategic thinking and practical planning in developing housing options and supports for older people (see Figure 2).

Family Carers and Informal Care

All of the presenters referred to informal/family carers and their central role in providing support and care to older people. The key data presented in relation to informal care were as follows:

- Between 195,000 and 360,000 people provide care in Ireland (CSO Census 2016 & Irish Health Survey 2015)
- Average of 38-45 hours per week – total 6.6m hours of care each week
- Women provide almost two thirds (65.9%) of all care hours
- Of the €2bn cost of dementia in Ireland – almost half borne by informal carers (O’Shea et al, 2017)

---

Summary of each Presentation
The programme with biographies of the speakers is in Appendix 1.

Morning session

The President of NUI Galway, Prof Ciarán Ó hÓgartaigh, opened the day and highlighted the demographic issues about to unfold in Ireland, the importance of values and community in responding to the challenges posed by an ageing population and the commitment of NUI Galway to supporting research on ageing.

Dr Fiona Keogh made a presentation on ‘Current and Future Landscapes of Care’ and encouraged attendees to engage with the ‘big questions’ on home care during the day. She stressed the importance of the wider economic, social and cultural context and how this is changing in ways that are difficult to predict. Dr Keogh began with an exercise to encourage attendees to start thinking about the support they or their relatives and friends may need in 10 to 15 years’ time and then in 20 to 30 years’ time, in order to highlight that we are planning care for our future older selves, relatives and friends. She recommended that action is taken now, otherwise the window of opportunity for reform currently open to us will be quickly closed. As each year passes, the context changes, so that in 10 to 15 years the policy landscape will have changed quite significantly, given the demographic changes that are about to happen.

Currently, older people access and use a wide range of health and social services across primary care, community care including home care and day care, mental health care, acute hospital care, long-stay residential care, and palliative care at the end of life. The Integrated Care Programme for Older People has been established to develop and implement integrated services and pathways for older people with complex health and social care needs, shifting the delivery of care away from acute hospitals towards community based, planned and coordinated care. Another way of looking at home care is as part of a wider ecological system of care, involving biopsychosocial elements and a wide range of agencies in providing support, incorporating community and cultural dimensions.

The available data on health and social care raises several questions and issues for consideration. Given that the per capita spend on older people in the health budget has reduced in recent years, a key question is; what is the appropriate share of total health budget that should be spent on the social care of older people? Moreover, although information is available on the current supply and use of home care services, little information is available on the quality of these services, or whether the services are actually highly valued by users. The balance between home care and residential care is also important. There is much variation across the world with respect to the use of long-stay residential care for older people, and while Ireland’s use of long-stay residential care is close to international averages, expenditure is biased towards residential care, with 55% of total expenditure for older people spent on the Nursing Home Support Scheme (O’Shea et al 2017).

It is not often acknowledged that older people themselves are heavily involved in the production of care for themselves and others. Most older people take care of themselves and make use of home care services only as required, which can range from minimal involvement of others, including family and friends and formal care services, through to moderate or intensive involvement of family and formal care services, as ability to self-care reduces. When older people need care and support, most of it is provided by family members. Moreover, the bulk of formal home care is now provided by approved private providers, with public sector playing a smaller role in production, although still providing the finance to support private provision. There is also a small but growing trend of older people funding private provision out-of-pocket from their own resources.

In this sense, services and supports for older people are very much ‘co-produced’ and complex in relation to both production and finance. However, the focus of important policy documents and reports setting out the future orientation of, and needs for home care, e.g. Sláintecare Report or the Capacity Review, is often narrow and fails to take into account the role of sectors other than the public sector, or the types of services and supports that are, and can increasingly be, provided outside of the formal care system. In planning home care services therefore, there is an opportunity to think more broadly about, and to describe what community care services might look like if a broader range of services and supports were considered as part of the production function of social care for older
people. There is also an opportunity to use the model of co-production in a more formal way in developing a future home care scheme.

There is a need in planning home care for older people to interrogate the key assumptions that are typically made. Three fallacies are commonly made when home care for older people is being discussed. A first fallacy is the ‘head in the sand’ approach that the ‘ageing crisis’ won’t come to pass. However, we are in the middle of significant population ageing in Ireland, and its implications cannot be underestimated. The good news is that Ireland has a window of opportunity for reform and a chance to learn from other countries that have already experienced significant ageing of the population. A second fallacy is that families will continue to provide the care that will be required in the future. Family care may not continue to be available to the extent that it has been due to the increasing participation of women in the workforce, smaller family sizes and changing attitudes to family responsibility. This presents a strong imperative for the formal care system to work in partnership with families to ensure the continuation of family care into the future. A third fallacy is that the current system of care is adequate and that all that needs to be done is some tinkering at the margins, for example, more resources for home care through additional home support hours. This kind of ‘muddling through’ thinking can prevent much needed innovation in relation to the organisation, delivery and funding of care for older people in the country.

It is important therefore to consider who should be involved in the future production of care and in what combination? Finding an appropriate funding model to support additional resources for the care of older people, including new technologies, will also be important. Dr Keogh left conference attendees with three key questions to consider throughout the course of the day:

1. Who should primarily be responsible for the care of older people in Ireland – older people themselves, families, state, or some combination?
2. If additional funding for the care of older people were to become available, where should it be spent?
3. What policy and/or legislative change above everything else would change the lives of dependent older people for the better?

Dr Kathleen McLellan presented on ‘Reforming Home Care in Ireland’ and emphasised that there should be broad ownership of any new home care scheme. Reforming home care is taking place in the context of demographic change in Ireland, which is leading to changes in the age structure of the population. As life expectancy increases, we need to ensure that people remain in good health for as long as possible. While 85% of people in Ireland self-rate their health as good or very good, the proportion of people in this category decreases with age, falling to 62% of those aged 75+.

Older people are significant users of our health services. For example, the average number of GP visits per annum is higher among older people. HIPE data shows that the number and proportion of older people (65+) presenting at the Emergency Department (ED), discharges of older people from hospital, both in-patient and out-patient, and bed days used by older people are all increasing. Frailty is a major contributor to health and social care resource use in older age. Frail older people have a greater risk of falls, leading to attendance at ED or admission to an acute bed. TILDA data shows that frailty is more common among women, those with lower education, and those who are widowed or living alone. HIPE data shows that the number and proportion of older people (65+) presenting at ED, discharge of older people from hospital, both in-patient and out-patient), and bed days used by older people are all increasing. For these reasons, when we consider health spending on older people we need to look beyond the health and social care older person’s budget. For example, one-third of the hospital budget is spent on older people, with falls within the home a big factor contributing to admissions to trauma unit.

The development of a statutory home care scheme is taking place in the context of the National Positive Ageing Strategy and its four goals, and the recent Joint Policy Statement on Housing Options for Our Ageing Population and its six principles. To inform the Department of Health’s work on developing a Statutory Home Care Scheme, the HRB has undertaken a review of approaches in four other countries and has identified guiding principles of service provision: standards, transparency, consultation, choice, equity and sustainability (Kiersey and Coleman, 2017). A public consultation on improving home care services highlighted the lack of a statutory entitlement to home care, variation in service provision, unregulated
services, heavy reliance on family carers, central importance of the single assessment tool (SAT) and the need for a co-ordinated, integrated, person-centred approach.

Dr McLellan stressed the importance of partnership and collaboration and that reforming home care involves engagement with a wide range of collaborators and stakeholders, illustrated by the range of voluntary and community bodies involved in the home care coalition. The Department’s approach to developing a statutory home care scheme involves key steps:

• review existing provision
• ongoing stakeholder engagement
• design the scheme
• set out the eligibility model
• develop the case for investment in home care
• design the resource allocation model
• develop the system of regulation.

Key issues in designing the scheme are needs assessment, and the use of single/standard assessment tools, and sustainability regarding both funding and standards. The question of how much to invest remains and determining eligibility is another key issue. Dr McLellan strongly emphasised the role and contribution of stakeholders in developing the new model.

Care for older people is a busy policy landscape, and there is a plethora of policy documents and reports with increasing number of actions that have to be taken into account and implemented. Nevertheless, there are key priorities and commonalities across these policy documents and a common goal is for older people to have access to the services that they need when they need them – right services, right care in the right place at the right time - to enable them to live as full lives as possible in their communities as close to home as possible. The big question however is how to translate policy into practice and to consider what success will look like?

To this end, there will be a 10-year social care strategy that will set out a roadmap for the three main outcomes: health and social care outcomes; patient/caregiver outcomes; and value for money.

Comprehensive public–health action on ageing is urgently needed. Although there are major knowledge gaps, there is sufficient evidence to act now, and there are things that every country can do, irrespective of their current situation or level of development. Priority areas for action are: to improve measuring, monitoring and understanding; align health systems to older populations they now serve; develop long-term care systems; and ensure that everyone can grow older in an age-friendly environment.

In this context of rapid population, ageing, health and social care expenditure needs to be viewed as an investment rather than a cost. The positive contribution that older people can and do make to society needs to be factored into this calculation.

Frailty is a key concern when reforming home care. It can be defined as ‘a condition characterised by loss of biological reserves, failure of homeostatic mechanisms and vulnerability to adverse outcomes’. Frailty is a long-term condition that occurs along a spectrum from mild to severe. It has key features of many other long-term conditions. Level of frailty influences people’s vulnerability to becoming dependent after a minor illness (Clegg et al, 2013). Its prevalence increases with age (Scarlett et al., 2014). Frailty is common among acute hospital in-patients, but some wards, e.g. stroke/geriatric and orthopaedic wards, have a higher prevalence of frailty than others. This is significant as hospitalisation leads to decline for frail older persons, greater risks of falls, delirium and infections, and increasing frailty is associated with greater care and support needs. There is a range of interventions depending on the severity of frailty. These include symptom relief, person-centred goal setting, family and caregiver support, exercise interventions, comprehensive geriatric assessment and intervention, in-hospital programmes, and at the end of life, hospice care to maintain dignity and comfort.

In Ireland the Specialist Geriatric Services Model of Care has been in place since 2012. Comprehensive Geriatric Assessment (CGA) includes diagnosis, capabilities assessment and coordinated, integrated care planning, and studies have shown the CGA is associated with higher likelihood of living at home. The national clinical programme on integrated care for older people has been ongoing since 2017. Collaborative working has been introduced to help support people to live at home. Key

Dr Diarmuid O’Shea presented on ‘Transforming Care of Older people in Ireland’ and opened his talk by highlighting the relevance of frailty and its roles as a lever of change.
amongst these is the development and delivery of appropriate education and training. Under the National Clinical Programme for Older People, a National Frailty Education Programme and the Insights into Frailty Programme has been developed in collaboration with TILDA. An education working group was established and it developed a resource pack and handbook. Key areas covered by the programme are delirium, continence, polypharmacy, falls, cognition, and comprehensive geriatric assessment. There are 140 national facilitators have been trained and have delivered education sessions locally to 1,800 health and social care professionals to date.

The national facilitators maintain a database locally of trained staff and also participate in the local governance group. Fifteen frailty facilitator’s networks have been established and education has commenced in nine sites. There is also a TILDA Frailty Education Day, which 320 inter-professional practitioners have attended.

Dr O’Shea stressed that implementing change is not easy. However, the aim for the future is to have a greater understanding of older people living with frailty as a long-term condition; to have timely identification of frailty; and to provide community-based person-centred care and coordination.

Morning Q&A session

The Q&A session started with a question asking presenters to give their views on how we, as a society, can best support carers of older people. Discussions took place on ways in which this can be done, including the use of personalised budgets which have been piloted in CHO 3, an approach supported by the Department of Health. The importance of supporting carers by providing home care on a continuum was also highlighted. Involving older people themselves in the development of a home care scheme was seen as essential.

Asked to expand on her points about the regulation of home care, KMcL responded that regulating home care was complex and a challenge, but that the approach adopted for the regulation of home care would need to be reasonable and cost effective.

With regard to the translation of policy into practice, the chair of the morning session, Tim O’Connor, highlighted the importance of flexibility and being open to learning and adjustment in preference to a linear approach of development and then implementation, without room for adaptation.

Participants were reminded in one comment that while we rely heavily on informal carers to provide the bulk of care, even for people with dementia and people with complex needs, carers are not provided with the appropriate education and skills that would enhance their capacity/resilience, and make the caring role more sustainable, for longer.

One participant argued that prevention is better than cure. Another comment in this vein was the need to offer tailored psycho-education to carers shortly after diagnosis of dementia in particular. This should be proactive (and a dyadic approach – carers need support too).

It was reiterated that any reform of the homecare system can’t all be about health and social care – other sectors have a role to play, and must commit and agreed amount of their budgets (for example, the housing budget) to support the non-health needs of older people in their homes and communities. All actors have to accept responsibility and collaborate to support our ageing population to live well. What we need in terms of the community is local political capital and buy-in, because the collaboration of communities is centrally important – one person suggested that it is the voice of the older person and people with dementia that resonates within communities.

Related to this issue of buy-in, it was pointed out that we need to ensure that we get the funding model right – we don’t want an Irish Water situation where we miss the mark on gauging our social values, including peoples’ willingness to cost-share and make some contribution to the overall cost of care.

Finally, a number of people pointed out that what had not been discussed in detail in the morning is the role of leadership in creating and implementing change at a systems level – who is going to lead the collaborative effort to create change?
Mid-morning session

Prof Eamon O’Shea and Dr Sharon Walsh presented the results from a discrete choice experiment (DCE) undertaken to examine what the public want from a home care system. There is consensus that home care is important and Ireland is about to legislate for change. However, little is known about people’s preferences for home care, what they value and by how much. Nor do we know much about factors that the public find important in the design and delivery of home care for people with dementia. A DCE was carried out to answer these questions and elicit people’s preferences for home care for people with moderate dementia.

A DCE is a quantitative technique for eliciting people’s preferences. It is based on the principle that (1) any good or service can be described by its characteristics (attributes); and (2) the extent to which an individual values a good or service depends on the nature and levels of these characteristics. In DCE, respondents are asked to make choices between hypothetical alternative goods or services. Each good or service is described by several characteristics (which are referred to as attributes). For each choice, the individual is asked to choose their preference. The inclusion of a proxy price, known as a cost attribute, allows for the monetary value of each attribute to be estimated. This is its marginal willingness-to-pay or implicit price.

Analysing DCE data makes it possible to determine whether particular attributes are important, the relative importance of attributes, how much people are willing to trade off between attributes, and willingness to pay for different attributes. Choosing an airline provides a simple example to illustrate how DCE works. Airline flights may differ according to the following attributes: check-in service (yes/no), entertainment (charge/free), food and drink (charge/free), legroom (standard/extra), and ticket price (€100/€150). Given an option of airline A and airline B, which differ according to these attributes, individuals are asked to choose one option based on the attributes.

This approach had been used in studies of care services in Australia and several European countries (Nieboer et al. 2010; Lehnert et al. 2018; Gomes et al., 2017; Hall et al., 2013), including studies to elicit the preferences of people with dementia and/or their family carers on home support services (Chester et al., 2018; Kampanellou et al., 2017).

The first step in designing the DCE was to develop the attributes and their levels. These were informed by a literature review and review of policy as well as interviews and engagement with a range of stakeholders including carers and people with dementia.

In this DCE, four attributes were chosen, each with between two and three levels:

- communication, the way in which care staff interact with person with dementia (standardised, personalised)
- flexibility of service provision, refers to the extent to which care is tailored and responds to the needs identified by the person with dementia (low, high)
- number of care hours is the number of publicly funded home care hours provided to the person per week (10, 15 or 20 hours per week)
- co-payment, whether or not the person with dementia makes a co-payment towards the cost of care (no co-payment, means-tested co-payment, compulsory co-payment)

Respondents were also asked their willingness to pay additional taxation per year for the bundles of care on offer, relative to the status quo. This is an acknowledgement that changes in the level of the attributes will come at a cost to the public in the form of additional tax per year (€50, €100, €150, €200, €250), which may be paid through either direct or indirect tax.

Respondents were shown choice cards, which included a status quo option and two alternatives, from which to choose. The experiment was administered online, through iReach, a research company, to 551 members of the public. Data was collected on gender, age, marital status, education level, employment status and household income, informal caring, views on who should be primarily responsible for care and preferences for funding models. The results from statistical analysis indicate that the public has a preference for a home care system that offers personalised communication and high flexibility relative to standardised communication and low flexibility. There was a strong preference for more hours (15 and 20 hours) relative to low hours (10 hours). Citizens were against a compulsory co-payment, but were unconcerned about the introduction of a
means tested co-payment relative to a no co-payment. There was significant heterogeneity in people’s attributes of home care system.

The main conclusions from the study are that flexibility in home care matters to people, personalised communication is highly valued, citizens are willing to pay additional tax for more home care hours, but are opposed to compulsory means-test co-payment, and indifferent to means-test co-payment. Importantly, moving from the status quo provision to alternative home care services results in a significant welfare impact for individuals in the sample.

**Mid-morning Q&A session**

For the discussion which followed the presenters emphasised that the findings could be most usefully considered in terms of the overall trends in people’s preferences and choices and how these can be used to inform policy rather than treating the numbers as ‘exact’ and speculating about different values for the attributes.

A good part of the discussion focused on the experience of co-payments in the Irish system. Participants were reminded that a co-payment was not completely new in the Irish context and that voluntary contribution had been made historically by home care users, until it was found to be illegal and charges could no longer be requested. Further context for the DCE study was provided by one participant who explained what 10 hours of care gives people and how much 10 hours costs (approx. €25 per hour) and compared this favourably with the cost of the residential care bill. He commented on the difficulties of employing staff to deliver primary care and community care and asked where were staff to come from if primary and community care services are to expand. The issue of training for the workforce was also raised, and specifically providing person-centred training for health and social care workers engaging with people with dementia. Generally, respondents felt that there was strong public support for personalised home care and it is important to ensure that this was delivered in any new system.

**Panel discussion**

**Helen Rochford Brennan (HR-B)** highlighted the lack of post-diagnostic supports for people with dementia, and argued that there was a need for much more services and supports. She has long complained about the lack of services for people under 65 based on her own experience, but was surprised to find that services and supports were not much better for people over 65 when she herself reached that age. Her experience of services is that they are provided on a ‘one size fits all basis, deficits focused, and not designed to keep me well’. Services in her experience are still very medicalised, and not informed by Kitwood’s model of personhood and person-centred care. There is not much in the form of a rehabilitative approach. She would like to see social prescribing, and supports and services for people with dementia developed and delivered according to a social model. She stressed that caring for people with dementia is much more than about health. There is a lack of choice for people with dementia in terms of supports offered. Ring-fenced funding is needed and supports should not be dependent on piecemeal funding such as the Dormant Accounts Fund. She also asked everyone including policy makers and services providers ‘don’t talk about me, talk together with me’. She questioned the notion of multi-disciplinary working where health professionals referred from one service to the next, and stated a preference instead for inter-disciplinary working where health professional actually worked together. She asked for a value-based health care system that is personalised, measured and cost effective. She said that care recipients had much more to contribute than simply making a financial contribution to care. In this vein, she asked for more partnership at community level, and decisions to be devolved to a more local level, with significant input from people with dementia.

**Christy O’Connor (CO’C)** stressed the importance and primacy of primary and community care services. He argued that older people have a right to remain at home and would like to see more models of supportive housing and long-term care that go beyond the traditional ‘home or nursing home’ option. Christy stressed the importance of choice and independence for older people, especially for those who may not be able to live in their own homes, but do not need nursing home care.
**Aisling Harmon (AH)** pointed out that home care is still ‘medicalised’ and falls far short of a good quality system. She also highlighted that the health and social care system is over-reliant on the good will of families and that family carers need much greater support than currently provided. She agreed with presenters that family make a large contribution to caring for older people and people with dementia, but wanted acknowledgement that care most often falls to women. She supported personalised care that respected the wishes and will of the person, but not at all costs, and only as long as it is safe. She argued that there is a phenomenal waste in the health and social care system, a view that was supported by other participants.

**Sean Moynihan (SM)** in preparation for the panel discussion had phoned a range of people using and providing ALONE services and asked for their views on home care in Ireland. Those he consulted gave examples of good practice especially with regard to clinical issues. While some spoke about being treated with dignity by service providers, others recounted how much unmet need existed in the system. The need for psychosocial supports was raised by a number of people. Sean praised the National Dementia Strategy, especially its role in increasing awareness of dementia. He highlighted the geographical lottery/inequity that characterised the system, with some areas and regions better served than others in terms of services and supports. He stressed the importance of leadership in such a complex system. He pointed out that family care was not just about care provision, but often about decision-making, which could be extremely difficult for families. Families are caring and making decisions in sometimes very complex circumstances and need a lot more support than currently available. The current funding model is not geared to provide that level of support and he noted that members of primary care teams especially seem to be constantly stressed.

Summing up the panel discussion, **Suzanne Cahill**, who chaired the discussion, commented that experiences of home care appeared to be mixed, with some very positive stories and other not so positive accounts. There seemed to be broad agreement across the panel that families continue to bear the main responsibility for the care of older relatives and people with dementia in Ireland.

Panellists were then asked to make one last comment as to what change they would like to see:

**Aisling Harmon** - wanted to see additional funding for home care, with the introduction of personalised budgets. She was concerned with the duplication and cost inefficiencies in the system at present, and believe that personalised budgets would help to avoid duplication and reduce cost inefficiencies. She stressed the importance of consistency and reliability in the delivery of home care services.

**Sean Moynihan** – would like to see tailored home care services, a proper infrastructure put in place for the community care and the implementation of the National Positive Ageing Strategy.

**Helen Rochford Brennan** – home care; normalisation of dementia and harnessing support of communities through volunteer schemes, focus on strengths -based approaches and supports and services that keep people well; transport to be included in the mix. However, a ‘change of mindset’ among practitioners and policy-makers will be necessary for change to happen.

**Christy O’Connor** - The importance of bringing all funding together, not just home care, but funding for primary and community care, which could alleviate admissions to A&E. The importance of support organisations and creating a localised social milieu to support people and keep them well, active and healthy was reiterated.

In summing up, **Suzanne Cahill** concluded that a whole system approach to care was needed, including family and community involvement. She highlighted the importance of good design for housing and nursing homes, especially for people with dementia.
Afternoon session

The focus of the presentation by Dr Sean Healy was on social justice and home care for dependent older people in Ireland. He defined justice as a harmony that comes from a fidelity to right relationships. Stressing the importance in social justice of the emphasis on ‘right relationships’, he pointed to four levels at which right relationships are seen: self (inner life); other people (social life); institutions (structural life); and environment (cosmic life). A just society is one in which these right relationships are promoted, and in such a way that human dignity is protected, human development is facilitated, human rights are respected and the environment is respected and protected. He identified five key policy outcomes that are necessary to deliver a just society – vibrant and sustainable economy, decent services and infrastructure, just taxation, good governance and sustainability. Using these outcomes, a policy framework for a just society was presented. To achieve a vibrant economy requires fiscal and financial stability and sustainable economic growth, adequate public investment, and a more just economic structure. To have decent services and infrastructure, it is necessary to have secure and well-funded public services and social infrastructure, reduced unemployment and underemployment, and social, economic and cultural rights to be respected. Just taxation includes a tax-take closer to the EU average; increased equity in taxation and reduced income inequality; and a fair share of corporate profits for the state. Good governance involves deliberative democracy and Public Participation Networks (PPNs). Sustainability refers to increased environmental protection and climate justice, balanced regional development and new indicators of progress and Satellite National Accounts.

Dr Healy pointed to Ireland’s changing demographics, and population ageing as potentially a good news story, and in agreement with previous presenters highlighted the need for urgent health care reform, given that support for people to remain in their homes is a key policy objective. He emphasised the importance of a well-developed, coordinated and integrated approach to the management of older people’s needs which would ultimately reduce the need for nursing home care.

In his comments about statutory home care, he highlighted the importance of an integrated approach, addressing infrastructure deficits, and reducing inappropriate admissions to acute hospital. Health promotion is a key element. Key issues when considering a statutory right to home care are: the definition of home care; providing consistent home care; the role of assistive technology; delivery of person-centred home care; having quality standards; integrated care, and increasing the availability and provision of funding. Social Justice Ireland recommends making a capital investment of €500 million over five years to meet growing demand. This would enable 12-15 community nursing facilities and approximately 50 beds each to be replaced or refurbished. The additional spending would lead to enhanced core community services for Home Care Packages and Home Help.

Prof Pamela Nadash provided an international perspective on financing long-term care, focusing on key issues for consideration when designing a system of financing long-term care. Her opening point was about how spending more does not necessarily guarantee better care/supports. Plenty of countries, the US included, spend far more than other countries and have poorer outcomes; “it’s not about how much is spent, so much as it is about how it’s spent”.

One of the first considerations when designing a system of financing long-term care is an understanding of the importance of aligning policy with social values. This is key to policy adoption. To get underneath this, she raised questions relating to public expectations as to the role of government versus market. Is the goal to encourage for-profit providers, or support voluntary organisations, or to directly provide services? How much intervention is expected from government and does it have the tools to effectively oversee the market? In relation to societal views on personal and family responsibility for care, key questions are: To what extent should individuals or their families be responsible for providing and/or paying for services? What do we expect from families? What constitutes ‘family’? Nadash reminded attendees that not everyone has family available to care and some people have very complex circumstances, e.g. drug addition, alcohol abuse, other caring responsibilities, etc. In considering policy and its alignment with social values, what trade-offs are acceptable?

To illustrate this, she presented findings from a US study, which explored what actions people
are willing to make to address their long-term care needs, and how this varies by household income and assets. Respondents were most willing to make modifications to their home and least likely to move to a nursing home, but there were significant differences among households with different levels of income/assets.

Professor Nadash examined housing equity as a source of finance for long-term care needs in two different countries, US and Australia, to illustrate how cultural differences matter in policy-making. In terms of political feasibility, there is strong resistance in the US to paying for care by drawing on housing equity. There are also several practical issues that need to be considered, including: the level of home ownership among older people; disparities in house prices across different geographical areas; the cost of care across different geographical areas; the existence of appropriate financial products that convert homes to money; the regulation of such products; and fluctuations in the value of homes due to the volatility of the housing market. In Australia, however, the Australian Aged Care Home Credit Scheme offers an example of a case where housing as a source of finance for long-term care is more acceptable – although, importantly, paying for the cost of care is separated out from the cost of board in a nursing home, which is what the Credit Scheme covers. This works because, in Australia, there is high home ownership, relatively consistent house prices and political acceptability for this idea. A government-run bond scheme has been created to deal with practical issues. However, Prof Nadash stressed that social values change over time and what is politically and societally acceptable also changes.

A second consideration is the models of financing that can be used to fund home care. The two main models are social insurance and taxation. Social insurance is based typically on a dedicated payroll tax, with contributions from both workers and employers. Advantages of social insurance are that it is a dedicated fund of money for home care, which cannot be used for other purposes. The fund, and its use, is transparent to the public. Disadvantages are that the amount received into the fund varies with the health of the economy and employment rates and opportunities. It can be difficult to change the tax rate, as such changes can be seen as a tax increase, especially on employers. It creates an entitlement, with a common saying being "I paid in, so I expect something back" – which can be seen as either an advantage or a disadvantage.

There are also advantages and disadvantages of the general taxation model. Advantages are that the general taxation is broader than social insurance, for example incorporating excise taxes and wealth taxes, and is not dependent on the labor market. It also places less pressure on employers. Disadvantages are that budgets must be negotiated by the legislature and spending at the micro level, for example on home care, is much less visible to public scrutiny. Resource allocation within general taxation is also vulnerable to the timing of elections and the machinations of the electoral process; programmes can be cut at any time. This is the current model in Ireland.

More recently, countries are adopting a mixture of both social insurance and taxation to finance long-term care. An example of a country with a mixture is Taiwan, which has proposed a three-way split between employees, employers and a general fund. Co-payments or user contributions must also be considered. A benefit of this approach is that it creates an ideological commitment to personal contributions. It addresses the moral hazard argument. It answers the practical need for additional revenues, but it creates a need to cover costs of care for those who cannot afford co-payments. ‘Pre-funding’ is another approach, in which individuals or societies put money aside for future demands – Germany has recently taken this approach, but most are sceptical about the extent to which this will make much difference over the longer run.

The benefit structure was identified as a third area for consideration and key features were discussed. Should the benefit be universal or means-tested? How generous should the benefit amount be and should there be a safety net? How comprehensive should benefit eligibility be? Should it be continuous or consistent with other disability-related benefits? To what extent should cognitive impairment be covered? What level of need is to be assessed as eligible? Should the benefit scheme be for front-end or back-end (e.g. catastrophic care) care? Should there be

---

benefits for caregivers? Should there be a split between coverage for services vs coverage for housing/nursing home care? Will the scheme provide cash for care? Germany and France offer two very different and contrasting benefit schemes.

Prof Nadash offered several other issues for consideration when designing a new programme. A key learning from other countries is to start small and allow flexibility to deal with contingencies.

The issue of infrastructure with regard to regulation and workforce was also covered by Prof Nadash. The government infrastructure for oversight includes the establishment of regulation and procedures, development of expertise among bureaucrats, and establishment of intragovernmental understandings. There is also the regulation of individual workers as well as provider organisations. Regulation is closely tied to quality assurance. It is important to establish regulation before service expansions, as the availability of funding creates entrenched interests and will shape the market, and all provider groups seek to protect their interests.

Quality assurance is problematic and no country has been entirely successful in resolving this issue. Quality assurance leads to a tension between respecting autonomy and the need for oversight. Where person-centered care is an underlying principle, there is a need to balance the identification of individual goals and comfort with risk, and to educate care recipients and their loved ones about quality assurance. Quality assurance can lead to a “safety” culture—engagement with maintaining safety by all parties. Systems for quality assurance require standardised metrics for assessing safety and harm; information-sharing/data-sharing and transparency among key parties; support and endorsement of continuous learning; care coordination across systems of care, with the question of who is responsible for this?

There is no single definition of direct care workers and the care work that they do. But there are many issues such as: What level of training is appropriate? What incentives can be provided to attract quality workers? To what extent will this class of worker be seen as a source of jobs for hard-to-employ individuals? To what extent will Ireland rely on immigrants to do this work? What controls can be put into place to prevent the exploitation of workers and ensure that they pay taxes? What controls can be put into place to ensure that workers don’t exploit care recipients? There are negative impacts of caring on family carers, especially women, but also costs to governments. Prof Nadash stressed that caregiving, although often perceived as not costing the state anything, is not free; it has hidden but significant opportunity costs. A negative impact is that it reduces or curtails labour market participation, and consequently reduces government revenue from income tax. It reduces women’s financial security over the longer term, which means that women will have a higher dependency on government benefits in the longer term. The mental and physical health consequences of caring, for some people, may lead to increased costs for the health care system. This raises questions about the extent to which the state can play a role in mitigating care burden, and the approach that it should take—whether that be respite care, paid carers leave, pension credits, and/or caregiver training and support, all of which have budgetary implications.

Similar to some previous speakers, Prof Nadash stressed that home care is only one part of a complex ecosystem, with good housing at the centre of care. There are many different ways of thinking about housing, beginning with adaptations to own home. There is also a need to move away from traditional thinking of supported housing for older people in group homes to housing options that respect the privacy and autonomy of residents, but which also offer supports.

Dr Cindy Bergman’s presentation focused on developing resilience in older adults. She explained that in life, there are many ups and downs, major stressors such as bereavement or retirement, life changing events such as serious injury and moments of calm. As people age, these experiences affect people differently. People with good coping skills may be able to navigate and manage negative life experiences well, but for others negative life experiences may result in feelings of hopelessness. People develop resilience through their experience of negative life experiences. Social support from family and friends is significant in helping people deal with difficult situations. Bergman’s preferred definition of resilience is psychological resilience, which refers to the ability to bounce back from adversity; to resist, cope with, recover from, and succeed in the face of adverse life experiences; to see difficulties as
challenges to be overcome rather than threats to be endured. There are six ways in which older adults can be supported to develop resilience:

- Older people can develop emotional and physical reserves and increase resistance to stress by engaging in physical exercise and getting enough sleep. Eating a healthy diet is important as healthy and well-nourished bodies can better deal with adversity. Participating in activities that people enjoy is also important as part of a routine of self-care.

- Giving people a sense of control (including of thoughts and behaviours), autonomy and safety is especially important as people age, as people may begin to lose a sense of control as they age. They may become less independent if for example they can no longer drive or cook, or have difficulty caring for themselves as they become more frail. Developing resilience is about taking charge of thoughts, emotions, environment, and the way a person deal with problems. However, finding a balance between autonomy and safety is not always easy. For a plan for the care of older people to be successful, it must involve opportunities for control and autonomy, while maintaining safety.

- Stress reduction can be achieved through reframing the problem, but it is also important that home care systems support stress reduction and do not lead to increased stress.

- Helping people to adapt is another way of developing resilience and when a person can’t change the stressor (e.g. diagnosis of dementia), one way to adapt to stressful situations and regain a sense of control is by changing expectations and attitudes. This involves reinforcing the idea of optimism, promoting positive relationships and seeing opportunities not problems. It is useful in doing this to encourage older people to express feelings instead of bottling them up, be willing to compromise, and to try and reframe problems, i.e. viewing stressful situations from a more positive perspective.

- Social support and spending time with positive people who enhance a person’s life is important. A strong support system can buffer people from the negative effects of stress. Therefore, it is important to help older people connect with others. However, social support is complicated and the most beneficial support networks are those that develop organically over time. Perceptions of support networks are also important. People may have a support network but may not regard them as supportive or beneficial or may be reluctant to ask for or rely on support in times of need. Research shows that people in difficult situations are more resistant to stress and are less likely to get ill when they have a loving family and good friendships, whereas people without good social support are more vulnerable to distressing conditions. Being able to talk with friends and family helps to diminish the impact of difficulties and increases feelings of self-worth and self-confidence.

- Keeping a positive attitude is the sixth way in which to develop resilience.

**Professor Martin Orrell** presented on models of care aimed at improving the quality of dementia care in the hospital, memory services and in the community. Starting first with dementia care in the hospital, he outlined the University College London Partners (UCLP) initiative, which by fostering collaboration across UCLP, aimed to significantly improve the diagnosis, management and care of people with dementia. This was achieved by designing and implementing an agreed programme of quality improvement based on clinical evidence, national standards, and a consensus of good practice. Improving care involved collaboration between UCL and hospital trusts and mental health trusts, with input from primary care and a range of other relevant organisations. The initiative followed four steps: planning and consensus; getting commitment; progress review; and reviewing outcomes. For the first step, a one-day conference was held to agree a UCLP wide strategy for dementia. Four priority themes were agreed: involving families; managing delirium; education and training; and joined up working. The second step focused on getting commitment through: the establishment of local leadership groups with NHS Trusts; defining Trusts within the group; getting commitment from local groups to select objectives to work with; defining time lines and outcomes; and provision of data by local groups for summary outline actions. In the third step, progress on the first two steps was reviewed. This included four acute Trusts and local groups (UCLH, RFH, NMUH, BHR) making presentations
on progress made against the aims, discussion of progress in four key areas and a review of outcomes collected. The fourth step covered a review of the outcomes. This included reviewing and standardising the outcomes being measured such as: length of in-patient hospital stay; rate of dementia diagnosis; user/carer satisfaction; use of antipsychotics; number of staff trained; and adverse incidents/complaints. The use of delirium screening and care pathways was also reviewed.

To improve the care of people with dementia in acute hospitals, a UCL Training Initiative was created. It intended to facilitate service improvement by offering training, utilising and developing the skills of staff in the Trust; support in training and monitoring and evaluation of outcomes. A target of 1,000 hospital staff to be trained by the end of the initiative was established. To ensure sustainability, self-sustaining training plans were implemented within each Trust, and there was continued evaluation of outcomes by UCL.

The many benefits of the UCLP initiative are that: 2,000 staff have been trained; dementia identification schemes, and ‘This is me’ information sheets about the person with dementia have been introduced; carer passports have been introduced to improve access to relatives in hospital. Delirium screening scales are now being used, dementia care pathways are being implemented and there are training programmes for a wide range of staff. Innovation is spreading among Trusts and new hospitals are joining the initiative. All of this is improving the care and experience of people with dementia and easing the burden on carers.

Prof Orrell turned next to memory services, focusing on improving quality through the Memory Services National Accreditation Programme (MSNAP) that has been established in the UK. The key argument is that accreditation can improve quality of service provision at memory services. He explained the historical background, quality standards and policy context to the programme. People with dementia and family carers were involved in developing standards from the start. He explained the MSNAP standards for accreditation purposes and outlined the accreditation process and the many benefits associated with accreditation. Feedback from patient and carers is positive and it has resulted in service improvements. Key messages are that:

- Innovative practice can reduce admissions for people with dementia to acute hospital care.
- Training and education can improve the quality of care on general hospital wards.
- Memory services can work to a standard model reducing waiting times and improving patient satisfaction.

**Afternoon Q&A session**

A question was asked about the place of cognitive stimulation therapy (CST) in memory clinic services. In response, Prof Orrell explained that the provision of CST is seen as a standard everyday practice for people with dementia and that the type of psychosocial interventions offered by memory services is included in standards for accreditation. Access to CST was discussed. In the UK not all memory services offer CST, but where they don’t they will have access to CST in the community to which they can refer people with dementia post-diagnosis. Memory services are encouraged to provide CST or to have access to CST.

The role of GPs in diagnosing and managing dementia was raised, and it was argued that over the past five years GPs have become more confident in diagnosing dementia but less confident in managing dementia. The role of GPs versus Memory Clinics was discussed, particularly in relation to post-diagnostic supports and questions were raised about who should be linking people with dementia to post-diagnostic supports, GPs or memory clinics, and which was best placed to do so.

In UK GPs are often perfectly able to make diagnosis but are encouraged to refer to memory clinics for diagnosis, part of the reason being that memory clinics provide better links to post-diagnostic supports.

Prof Orrell asked why Ireland had taken a decision to invest more in primary care than in memory clinics as place for diagnosis and post-diagnostic support. Why this approach when no other country had focused so much on primary care? A discussion ensued about this, with Orrell questioning if GPs/primary care were most appropriate place for diagnosis/post-diagnostic care, given difficulties in skilling up GPs, their time availability, lack of specialist
access for GPs etc. Arguments for why GPs are well placed to make the diagnosis and manage dementia post-diagnosis, included: their long-established relationships with patients; and the poor geographical spread of memory services in Ireland, with some areas having no memory clinics and many areas having less well-developed models of memory clinics. There is only one centre of excellence in the country.

Former Prime Minister, David Cameron’s support for dementia and his Challenge on Dementia in the UK were very influential in generating engagement and support for dementia in that country, but that sense of momentum has declined in the UK recently with the distraction of other issues, such as Brexit. However, this does underline the importance of political leadership in supporting service development in dementia. The absence of political leadership in Ireland in relation to ageing issues was noted by many in the audience.

Speakers & Presentation:

President of NUI Galway, Prof Ciarán Ó hÓgartaigh, opening the symposium.
Common Themes and Reflections
New thinking

The changing population structure of Ireland leaves us in no doubt that action on care for older people is needed. The number of older people in the country is going to increase, absolutely and relatively. Therefore, we need to be creative and future-focused in order to develop cost-effective solutions to health and social needs associated with ageing. We need urgent, proactive and joined-up actions that will bring about direct improvements for older people. Significant decisions on the provision and financing of care for dependent older people will have to be made in the near future. What decisions are made and who is involved in making those decisions will shape services and supports now and into the future. A clear message from the symposium was the need to listen to what older people are saying and respect their preferences for different types of care. Methods such as co-production offer practical ways in which this can be achieved, whereby people using a service have assets and expertise that can help improve a service and can be directly involved as partners in designing and potentially transforming that service (Hunter and Ritchie 2007). People powered health is another model which is being widely used and is a central feature of future plans for the NHS (NHS, 2014; Horne et al 2013). This approach focuses on self-management and self-agency and provides support for the person to remain healthy and actively manage their health conditions along with their health professionals. Resilience is a related concept. While psychological resilience is important and needs to be nurtured throughout the life-course, necessary resources such as income and education need to be available to the person in a supportive local environment in order to maximise resilience and enable self-management (Ungar 2011).

A strong message from the symposium was that it is not enough to focus only on medical and clinical needs; the person is as important as the patient. There is also a need to see the whole person embedded within their own community and wider society. Care is one element of that, but it cannot be considered in isolation. Older people should be supported to continue doing the ordinary things and the social activities they have always done. A reablement approach to home support is a practical way to achieve this – doing chores with the person and maintaining their abilities rather than doing things for them and de-skilling them as a result. Another approach is social prescribing, whereby existing social and community resources are used as part of a menu of services to meet the psychosocial needs of the person. Both of these approaches operate on a small scale in different parts of Ireland. The full implementation of such approaches involves communities, and non-health services and organisations, playing a greater and more proactive role in supporting older people. This in turn requires integrated care and a ‘joined up’ whole system response to provision. However, this notion has almost become rhetoric - repeated often but with little action to support it - that it is increasingly seen as either meaningless or an unachievable objective.

In reality, many of the building blocks for a better system are already in place and were referred to throughout the day. For example, the Age Friendly Counties Programme, Understand Together and the community activation programme for Understand Together are all working to create inclusive, supportive communities for older people and people with dementia. The Healthy Ireland programme and the Health and Positive Ageing Initiative (HaPAI) involve a range of activities designed to support people to stay healthy and to maximise their self-care and self-management. In different ways, these programmes help to create the environment required for effective social prescribing. These are not ‘health service’ responses, but they can have a significant positive impact on health. As needs increase, social care and other health care services come in – but layered on top of all this, i.e. not replacing it but supplementing it. The Integrated Care Programme for Older People (ICPOP) is a good example of how this might work, where specialist medical input ‘sits within’ an enriched community-oriented environment, maximising the effectiveness of both. However, linking the Age Friendly counties programme, which sits within the Department of Housing Planning and Local Government, to the ICPOP programme in the HSE remains a challenge. A high level vision is needed, which incorporates a variety of ‘separate’ pieces of work, all of which contribute to creating an overall infrastructure which will support better lives for older people and better outcomes for dependent older people. Although progress is being made, this ‘joined up’ vision is some time away unless priority is given to accelerating the pace of change. For this to happen there has to be leadership within the
health and social care system itself and within the political system.

More immediately, participants in the symposium were strongly of the view that enhanced resources for home care are essential, with people eagerly awaiting new legislation in this regard. There was strong support for a radical shift away from the current narrow supply-side approach to home care towards a more person-centred, demand-led, integrated model of provision. Shifting the focus from provider to recipient will require a change in mind-set in relation to the design and delivery of home care. People want more home care, but they want it delivered in a different way that reflects the preferences of recipients. Personalised, flexible home care is the solution, provided in an integrated way that reflects the specific needs of recipients and supports family carers. There is evidence from the evaluation of Intensive Home Care Packages (Keogh et al, 2018), that personalised care allows people to remain in their own homes for longer, with a better quality of life.

A major issue is our tendency to think about and talk about ‘older people’ as if they are one homogenous group of people with the main distinction being made as to whether they need care or not. We know there is lots of heterogeneity among older people, not just according to their health condition, but also in terms of their family situations, income, living conditions and personal life story. A life course approach encourages us to see the older person in front of us as the sum of a huge variety of life experiences which have shaped the person. Many are positive, such as having a full education and rewarding relationships, but many can be negative, especially those which compound each other and lead to cumulative disadvantage. This underlines the need for tailored service responses that may need to include more than health services in order to support the whole person.

The process of ageing and the role and position of older people in society was a major talking point throughout the symposium. There is sometimes a tendency to adopt a negative, almost nihilistic view of ageing as an inevitable descent into illness and frailty and older people, therefore, as a dependent group. A conscious re-framing is required in order to reflect the experience of the vast majority of older people, which is one of ageing well, remaining in good health most of the time, independently managing their lives. The HAPAI indicators show that about 76% of people aged 75 years and over rate their health as good or very good and healthy life years for women aged 65 is 13.2 and for men is 12 (HAPAI, 2018). Given the longer years of good health that the majority of older people now experience, it was suggested that we may need to change our view of ‘old age’, moving from age 65 to 70, which reflects changes that are already underway in terms of retirement age. However, given the variability among older people and differing life trajectories, issues of equity, flexibility and choice must be considered in any such change. This as an issue or suggestion merits wider discussion, perhaps at a future citizen’s assembly. If we begin to think about and plan for older people as a heterogeneous group of people with varying abilities and with an emphasis on maintaining independence and ability, our approach to the way we provide services and supports may change. One way in which the person’s independence and abilities can be maintained is through greater use of the approaches described above. However, we are limited by what we know and what we have data on, although TILDA has been very helpful in that regard. What is clear is that we need to look beyond the health care sector for improvements in the quality of life of dependent older people.

### Carers and informal care

Although most older people remain in good health for most of their later life, people do need additional support and services as they become frail. Most of this support is provided by family and friends; referred to as informal care. There is an implicit assumption in the Capacity Review and Slaintecare to lesser extent, that families will continue to provide as much care and in much the same way as they always have. However, practical changes such as an expected rise in the rate of female participation in the labour force will mitigate against this through a reduction in caretaker potential. We also know that family size has been decreasing in Ireland for some time, thereby leading to a reduction in the pool of available carers in the future. In addition, there may be changes in social and cultural expectations regarding the role of families in caring for family members in the future. The vote from the Citizen’s Assembly was that 60% believed primary care responsibility lay with the family/older person, with at least some state...
responsibility, but that may change over time. Some of the normative questions we need to consider include where the responsibility for care of older people should lie – with the person, the state, the family and in what combination? The overall view at the symposium was that the main responsibility lies with the person and the family but that the State also has a central role in supporting dependent older people, particularly those with few informal supports.

An important change in mind-set is also required in relation to how state bodies consider the costs which fall on families in relation to caring. These costs consist primarily of the opportunity cost of carers giving up working time or leisure time. While these costs have been well documented for some populations (e.g. O’Shea et al 2017 for people with dementia) they are typically not considered in service planning decisions as they are not costs that the state has to fund. However, the direct and indirect costs for carers should be of concern to the state as they can have important consequences for the wider economy, such as the lower participation of educated and skilled women in the workforce, which can have a detrimental effect on pensions. The trend towards increasing out-of-pocket payments for private care was also referenced at the symposium. There was concern that an over-reliance on private expenditure to supplement or supplant public provision will ultimately lead to two-tier system of provision, where the better-off have greater access to more services and supports.

Workforce and training

A larger workforce will be needed to provide care and support for increasing numbers of older people. The supply of formal carers is an issue and careful consideration will need to be given to pay and conditions to ensure an adequate supply of workers, including their distribution across the country. Training was discussed throughout the day, particularly in the context of providing high quality care. While training is important, we need to ensure that training is future focused and results in measurable changes in practice and in the service experienced by older people. Training can sometimes be seen as an end in itself rather than a means of improving services and improving outcomes for those using services. It was also acknowledged that while everyone in the workforce has at least some training, family carers, who provide the bulk of the care, receive little or no training. Education and training is central to the provision of more effective care. This is especially true in dementia where the principle of personhood needs to permeate all caring relationships in a more explicit way.

Funding and leadership

There are significant decisions to be made in terms of how long-term care is funded in Ireland. The current home care budget is inadequate and there is no clear view as to how additional revenue can be raised to support a meaningful expansion in home care – particularly if it is to play the role envisaged in Slaintecare. Several options were presented and discussed throughout the day, particularly in the presentation by Prof Nadash. Some combination of social insurance and taxation is used in most OECD countries to fund long-term care for dependent older people. General taxation has not succeeded in generating enough revenue to support long-term care in Ireland. Additional revenue will have to be found to support an expansion of home care either through a modified social insurance scheme or cost sharing mechanisms such as means tested co-payment. Any discussion of financing is fraught with political difficulties, but the reality is that without additional funding we will not be able to deliver the home care system that we all say we want. An all-party political consensus is required to facilitate an improved funding model for home care in Ireland. Participants in the symposium were agreed on the need for leadership, at all levels, but particularly within the political system, to ensure that commitments to improve services for older people are backed up by sufficient funds.

The health and social care system is a dynamic, interrelated and complex system. Thus, our understanding of the issues and the policy and service responses needs to be dynamic. This is a challenge when the motivation sometimes within a big bureaucracy is to concentrate on more immediate and pressing problems. But the issues surrounding ageing in Ireland will continue to grow. There will be no single, simple, ‘right’ answer or solution, but new policies will be required. Shared action and ownership and will be essential to maintain momentum and to provide support for politically challenging decisions in relation to production and financing.
Next Steps
Conversations on dementia policy

The research focus of the CESRD is on personhood within dementia, care relationships and resource allocation. An important part of the transformation to person-centred care is to ensure that the results of the work of CESRD are communicated to policymakers in a credible and impactful way that reflects the real-life experiences of people with dementia and family carers. Moreover, if personhood is to be taken seriously, it must include a strong voice for people with dementia and carers in the research and policy spheres, particularly when it comes to making recommendations for change in dementia care in relation to resource allocation and priority-setting. That means the direct involvement of people with dementia and family carers in the interpretation and narration of research results for subsequent policy action.

The CESRD have developed a series of engagements and events which involve people with dementia and carers along with other stakeholders, in identifying and shaping key messages. Each event builds on the other and the series aims to communicate the research findings of the CESRD and stimulate in-depth discussions and engagement, with the overall aim of influencing policy and service provision for people with dementia and their family carers in Ireland.

The policy symposium on Ageing Social Care and Social Justice which took place on 11 April 2019, reported on here, was the first event in this series.

The second event, a Policy Café took place on 9th July 2019. This involved a small discussion group consisting of 10 people with dementia from the Alzheimer Society of Ireland (ASI) Dementia Working Group, who met in an informal café style setting to discuss CESRD research findings and related policy issues in a way that reflects their own real life experiences. A professional film-maker and an illustrator documented the conversation and engagement of people with dementia in the Café environment and the journey of participants as they developed their views and responses to various research results and recommendations. The results of the Café discussion will be disseminated in due course.

The third event will be a Carer’s Assembly. This will bring together approximately 50 family carers to deliberate on the findings of CESRD research, with a particular focus on carer issues. The Centre is working in collaboration with ASI, Western Alzheimer’s and others, to identify and invite carers of people with dementia to the Assembly. There will be additional contributions from international experts in the dementia field. Members of the Assembly will then vote on what issues they consider most important, including an order of preference for immediate policy attention by government. A short film will be produced on the deliberations at the Assembly. The Carers assembly will take place in October 2019.

The final event – a Policy Dialogue will bring key relevant stakeholders (about 20 people) together in late 2019, to discuss resource priority-setting for dementia in Ireland with particular reference to home care and the overall continuum of care. The Dialogue will be informed by the results from the Policy Café deliberations and the Carers Assembly. In particular, film from the Policy Cafes and Carers Assembly will be used to bring the views of all who participated in these earlier events to the Policy Dialogue in an accessible way. The policy dialogue will also directly include at least one person with dementia and one family carer.

Policy Dialogue is an interactive knowledge-sharing mechanism which has been developed to support the use of research in policymaking. This innovative method is being used to bring together key national stakeholders to have a solution-focused discussion on resource priority-setting for dementia in Ireland with particular reference to home care and the overall continuum of care. This process involves establishing new and emerging priorities for services and supports for people with dementia to support the ongoing implementation of the National Dementia Strategy.
By 2031 (i.e. just over 10 years away) the number of people in Ireland aged 85+ will have doubled. There will be 1m people aged over 65 in the population and close to 1 in 5 of every person in Ireland will be aged 65+. The ubiquity of these figures can lead to a lack of engagement with what they mean and more importantly what we need to do from a policy perspective. Part of our reaction may be to postpone thinking about it and dealing with it – “it’s too far in the future ... more pressing things to do right now”. Or to feeling overwhelmed and to focus on the here and now - “our health system can’t cope now – what will we do when we have these numbers”. Taking either of these approaches would be a mistake and would constitute a dereliction of duty and responsibility for current and future generations. There is so much we can do now to effect change in the future.

The aim of the policy symposium was to create some time and space to think about the issues raised within a diverse group of stakeholders united in their interest in, and responsibility for the care of older people. Part of our thinking about ageing needs to be more creative and to move from the ‘given’ assumptions about ageing and older age which can be a constraint. For example, what constitutes older age and who should be characterised as dependent and not dependent? Is 65 years the correct entry point into older age any more? Many people now work and contribute up to age 70 and beyond, through part-time work, volunteering and caring for family members. Or perhaps there are alternative ways of conceptualising older people that is not strictly based on chronological age? Framing the typical older person as someone who is contributing, either through working or in other ways, and actively participating for any number of years beyond 65 creates a different dynamic in terms of what services and supports will be needed to support this group into the future.

We need a shared vision of what success will look like and to think creatively so that we can adapt to the possibilities that might present in the future – particularly in relation to technology. We need to move beyond the health domain and think not just about services, but about supports which are personalised, encompass all domains of life and enable people to self-manage as far as possible within their own communities. Admission to nursing homes for dependent older people should be the exception rather than the rule. It is possible to achieve this goal through different policies, supported by strong political leadership.

The presentations and discussions in the policy symposium articulated a possible action agenda for the coming years. We need to:

- Listen to older people and act on what they say using co-production and other co-design methods so that services and supports meet the needs of older people most effectively;
- Provide support that is personalised, addresses psychosocial as well as health and care needs, and in sufficient quantity to enable older people to remain living well at home. This includes home support and social prescribing so that a wide range of needs can be met;
- Acknowledge and support the contribution of family carers;
- Provide a range of new forms of housing and accommodation to address the different needs of older people at different stages of their life;
- Exploit the opportunities presented by new technologies to the full;
- Develop a new, consensus-based funding model to provide sustainable funding for these services into the future;
- Grow and sustain leadership at all levels in the system to drive action.


References


OECD (2019) Dataset: Long-Term Care Resources and Utilisation. Data extracted on 10 Apr 2019 08:59 UTC (GMT) from OECD. Stat


Appendices

Appendix 1
Symposium Programme

Ageing, Social Care and Social Justice Symposium

April 11th 2019
O’Connell House
58 Merrion Square South - Dublin

Context

The Citizen’s Assembly on Ageing (2017) has made important recommendations in relation to current and future arrangements and responsibilities for the provision and financing of long-term care in Ireland. More recently, the Department of Health has completed a review of home care services, following which plans for a new statutory scheme and system of regulation for home support services for dependent older people will be developed. The Health Service Capacity Review (2018) has also recommended a recalibrated integrated model of care that emphasises community-based provision, while expanding home care services and supports is also a core strategic objective of the Sláintecare implementation plan.

Key Questions

This one-day conference explores some of the key questions in regard to the care of dependent older people in Ireland including:

1. Who should bear primary responsibility for the care of dependent older people in Ireland?
2. Where should care be provided?
3. How should the care of dependent older people be financed?
4. What lessons can be learned from the way other countries provide and pay for care?

These and other questions will be considered in an intensive, closed
conference which brings together policymakers, practitioners and researchers to consider issues of resource allocation, priority-setting and social justice.

About CESRD

The Centre for Economic and Social Research on Dementia (CESRD), located at the National University of Ireland Galway (NUIG) provides transformative research and policy frameworks that will support personhood within dementia care through an integrated, holistic and person-centred approach to resource allocation for people with dementia. Through research, we want to bring about transformative change in the way in which we understand, prevent, intervene and care for people with dementia. We will:

- Bring together all social researchers on dementia in Ireland to examine social, economic, civic, cultural and legal aspects of dementia
- Develop and facilitate new thinking on dementia in Ireland that focuses on personhood within dementia
- Develop research capacity and facilitate collaboration and networking opportunities
- Provide the research framework for the implementation of the National Dementia Strategy in Ireland

Further details are available on www.cesrd.ie

Biographies

President Ciarán Ó hÓgartaigh

Ciarán Ó hÓgartaigh became the 13th president of NUI Galway in January 2018. Previously, he was Professor of Accounting and Dean of Business at UCD, leading its schools in Dublin (UCD Lochlann Quinn School of Business, UCD Michael Smurfit Graduate Business School and UCD Smurfit Executive Development) and its overseas programmes in Hong Kong, Singapore and Sri Lanka. Having attended Scoil Iognáid and Coláiste Iognáid, Ciarán is a first class honours, first in class graduate of NUI Galway. He trained as a Chartered Accountant with Arthur Andersen and has a PhD in Accounting from the University of Leeds. He has been published widely in the accounting field and has previously held academic positions at Dublin City University, UCD and Victoria University of Wellington, New Zealand.

A former Fulbright scholar at Northeastern University, he has served as Audit Committee Chair at the Department of Marine, Communications and Natural Resources and is a member of the Audit Committee at the Department of Finance.

Professor Kevin Whelan

Kevin Whelan, one of Ireland’s best known and widely published scholars, was named the inaugural Michael Smurfit Director of the Notre Dame Dublin Global Gateway in 1998. During his tenure, he has taught over 3,000 Notre Dame undergraduates. He has been a visiting professor at New York University, Boston College and Concordia University (Montreal). He has lectured in fourteen countries, and at the Sorbonne, Cambridge, Oxford, Torino, Berkeley, Yale, Dartmouth and Louvain. He has written or edited over twenty books and over one hundred articles on Ireland’s history, geography and culture. From 1999 to 2011 he directed the annual Irish Seminar, the leading seminar in the field of Irish Studies, whose faculty has included Edward Said, Seamus Heaney, Derek Walcott, Edna O’Brien, Homi Bhabha, Fred Jameson and Benedict Anderson.

A native of County Wexford, he received a BA at University College Dublin (1978), a doctorate from the National University of Ireland (1981) and awarded a Travelling Studentship from the National University of Ireland (1981), held at Memorial University, Newfoundland. He is a former Newman Scholar at University College Dublin, and Bicentennial Research Fellow at the Royal Irish Academy. Between 1995 and 1998, he was historical advisor to the Irish government on the Famine and the 1798 Rebellion.
Tim O’Connor

Tim O’Connor is a former Senior Diplomat of the Irish Foreign Service and a former Secretary General to the President of Ireland. He was a member of the Irish Government Talks Team for the Good Friday Agreement in 1998 and was the inaugural Joint Secretary of the North/South Ministerial Council, based in Armagh, from 1999-2005. He was Consul General of Ireland in New York from 2005-2007. Since his retirement from the public service in 2010, he has combined running his own advisory business with several not-for-profit positions. He was Chairman of the Advisory Board of the Gathering in 2013 and is currently Chairman of the Shannon Consortium, which promotes collaboration between the three Higher Education Institutions in Limerick. He is also on the Board of GOAL, Holocaust Education Trust Ireland and Crash Ensemble. He was appointed by the Irish Government in 2017 as its Representative on the Independent Reporting Commission dealing with measures to end paramilitarism in Northern Ireland. He has also served on the Boards of the Clinton Institute at UCD and Third Age. Tim holds honorary doctorates from NUI Maynooth (2005), Quinnipiac University (Connecticut, USA) (2007), the University of Ulster (2009) and UCD (2016).

Dr. Fiona Keogh

Dr Fiona Keogh, is a Senior Research Fellow at the Centre for Economic and Social Research in Dementia in the National University of Ireland, Galway. Her work there includes research into psychosocial interventions for people with dementia, decision making on resource allocation for dementia services, and evaluating intensive home care packages for people with dementia. Fiona has over 25 years’ experience conducting health services research and policy analysis in the areas of dementia, mental health and disability. Her special interest is the development and implementation of policy in complex systems with a focus on personalising health and social care services. Fiona has written national policy in Ireland in mental health (Vision for Change) and disability (Disability Policy Review: Report of the Expert Reference Group). She is a member of the Oversight Group reviewing Vision for Change and a member of the monitoring group for the implementation of the National Dementia Strategy.

Dr. Kathleen Mac Lellan

Kathleen Mac Lellan is Assistant Secretary, Social Care, Department of Health. Previously she was Director of the National Patient Safety Office (NPSO) in the Department of Health, leading a programme of patient safety policy, legislation and the national clinical effectiveness framework. The NPSO collaborated with HIQA and the HSE to deliver the first National Patient Experience Survey which took place in May 2017. As Director of Clinical Effectiveness Kathleen supported the development, quality assurance and publication of 14 National Clinical Guidelines including the National Sepsis Guideline. Previous roles include Nurse Advisor in the Department of Health, Head of Professional Development with the National Council for the Professional Development of Nursing and Midwifery, Project Lead NMBI Scope of Practice Framework and Assistant Director of Nursing, St James’s Hospital.

Dr. Diarmuid O’Shea

Dr Diarmuid O’Shea is a Consultant Geriatrician at St Vincent’s University Hospital in Dublin, Ireland. A graduate of University College Dublin, he served as Vice-President of Education and Professional Development at the Royal College of Physicians of Ireland from 2007 to 2014, and was appointed to the role of Registrar of the RCPI in 2014. He has been the lead for the National Clinical Programme for Older People in the HSE since its inception in 2010 and is the current president of Irish Gerontological Society.
Sharon Walsh is a Postdoctoral Researcher at the Centre for Economic and Social Research in Dementia (CESRD). Sharon’s research interests are focused in the application of quantitative economic methods to explore and inform policy questions in the areas of health and education. Her research expertise includes the methodological techniques of discrete choice experiments, econometric analysis and spatial analysis. Her current projects include analysing public preferences for home care services for people with moderate dementia in Ireland, a Cochrane Review of palliative care interventions in advanced dementia, as well as modelling informal care costs of spousal caregivers in Ireland. Prior to joining the CESRD, Sharon worked as a Postdoctoral Researcher in the Health Economics and Policy Analysis Centre in NUI Galway, where her work focused on examining issues relating to youth mental health in Ireland. She completed a PhD in Economics at NUI Galway in 2017, and she also hold a Masters Degree in Economics, and Bachelor of Arts Degree in Economics and Geography from University College Cork (UCC).

Eamon O’Shea is a Personal Professor in the Department of Economics, founder Director of the Irish Centre for Social Gerontology (ICSG) and Director of the Centre for Economic & Social Research on Dementia at the National University of Ireland Galway. His research interests are focused on the economics of ageing, rural gerontology and dementia. His work has been influential in setting the agenda for reform of services and policies for older people in Ireland. Professor O’Shea is the holder of a Health Research Board Leader award in Dementia. The award provides the research framework to support the implementation of the National Dementia Strategy.

Suzanne Cahill has over thirty years experience working in aged care and dementia services. She is the former National Director of the Dementia Services Information and Development Centre in Ireland and currently Honorary Professor of Dementia Care at the CESRD in NUI Galway and Adjunct Professor of Social Work and Social Policy at Trinity College Dublin. She is recognized nationally and internationally as a commentator and advocate on dementia matters and is widely published. She currently serves on the Expert Advisory Group of Alzheimer Europe, on InterDem, on the Irish National Dementia Strategy Monitoring and Evaluation Committee and on the Editorial Board of Dementia, the International Journal of Social Research and Practice. Suzanne has recently authored a book titled Dementia and Human Rights.

Helen Rochford-Brennan is the current Chairperson of the European Working Group of People with Dementia and is the group’s nominee to the Board of Alzheimer Europe; she is former Chair of the Irish Dementia Working Group. Helen is on the Monitoring Committee of Ireland’s first National Dementia Strategy and a Global Dementia Ambassador. Throughout Helen’s time with these organisations she has campaigned to raise awareness of dementia through a Rights based approach, to the media, speaking at international conference’s, engaging with pharma, scientists, clinicians, educators, students and many research projects from developing evidence –based diagnosis to palliative care to rural isolation.

Helen was diagnosed after a five year struggle with Early Onset Alzheimer’s seven years ago at the age of 62 and has since written very personally about living with Alzheimer type of dementia. She hopes her participation in research will one day help find a cure. Throughout Helen’s life she has been a...
Rights and Social Justice Campaigner and today advocates for the Rights of People with Dementia in particular Alzheimer's disease. Helen has received awards for her advocacy work and recently has been awarded an Honorary Doctor of Laws degree from the National University of Ireland Galway. She contributed to two books last year: Dementia and Human Rights - Suzanne Cahill and Global Perspectives on Legal Capacity Reform Our Voices Our Stories -Centre for Disability and Law NUI Galway. Helen has also received recognition in her native County of Sligo for raising awareness of dementia. She received a Lifetime Achievement Award from Sligo Business Community and also received The Spirit of Sligo Award from Sligo County Council.

I am a Registered Osteopath working part time in my own private practice. I lobbied extensively for Osteopathy in the UK, Ireland and Brussels. I was a founding member and Inaugural President of the Osteopathic Council of Ireland, and Course Tutor for the Irish College of Osteopath Medicine. I have volunteered for Parkinson’s Association Ireland from 2013-2017, and the Alzheimer Society of Ireland for over 10 years, becoming a DCCN Advocate in 2018. I have a keen interest in the translation of research to policy, and in particular the Carer experience of care in the community. I am currently a participant of the IPPOSI Patient Education Program. I am regularly called upon as Expert Carer Advocate/Speaker for UCD, RCSI, NUIG, ASI Research & Advocacy Panels and Care Alliance Ireland. I sat on the Project Advisory Group of the HRB funded research study “Towards Resilience in Family Caregiving for People with Dementia (EnCaRe), resulting in the EnCaRe Workshop Programme and the “takecareofyourself.ie” resource. I’ve been a carer for over 20 years for both parents: my father with Alzheimer’s disease, my mother with leukaemia, Parkinson’s disease, and now rapidly advancing dementia. I returned home from the UK in 2006 into the primary carer role as my parents’ needs escalated. My father was at home till 2014, I oversaw his transition to nursing home where he passed in Oct 2017. My mother is still living at home, I endeavour daily to honour her wish NOT to transition to nursing home care.

Thomas Christopher O’Carroll, known as Christy hails from Crossboyne, Claremorris, Co. Mayo. He joined the Christian Brothers and trained in Marino (now MIE) and began teaching in O’Connell Schools in August 1956. Christy transferred to Rome in 1961 and taught in Istituto Marcantonio Colonna until 1980 when he returned to Ireland and was appointed Community Leader and Primary School Principal in CBS Drogheda. Again in 1988 he went back to Rome as Community Leader to Christian Brothers’ Generalate and spent a sabbatical at School of Applied Theology in Oakland. In 2004 he took up residence in Galway and was appointed Community Leader at Christian Brothers, Galway until 2017 when he was transferred Edmund Rice House, Westcourt, Callan. While in Galway, Christy joined the Knocknacarra Active Retirement Association and was elected Chair of the Western Region (Galway, Mayo & Roscommon) from 2006 – 2009. He also became Regional Development Officer for the Western Region from 2009 – 2017.

After a career within senior management and business owner, Seán moved to the NGO sector as Head of Housing and then Director of Service for the Simon Community. He went on to work as Management Consultant for a number of years before becoming Chief Executive of ALONE. During this time ALONE has increased thirty fold the amount of older people supported each year. Now national we retain our values that services must be affective and compassionate improving the quality of life of those who use them. Sean vision and drive is for Innovation services where staff, volunteers work together with all agencies to create sectoral approaches to solve problems. Our services are scalable models and we provide and share all
our knowledge and technology with others in our sector. Under Seán’s oversight, ALONE is reimagining the role of the community and of the NGO. Including technological innovation as a key tool in maintaining the wellbeing of older people, Seán has also been involved in multiple national oversight groups, and has played a key role in influencing social and health policies for older people on housing, loneliness, and ageing at home, in order to meet emerging needs.

Brendan Kennelly
Chair

Brendan Kennelly is a lecturer in economics at NUI Galway in Ireland. He was the director of the MSc (Health Economics) programme at NUI Galway between 2014 and 2018. His main research interest is health economics, particularly mental health and dementia. He has published papers on these and other topics in journals such as the Journal of Mental Health Economics and Policy, Social Science and Medicine, and Health Policy. He is currently working on several research projects in health economics including an evaluation of an integrated care programme for people with dementia, an analysis of early intervention programmes for psychosis, eliciting preferences of students for mental health services in universities, and eliciting preferences of the general public for home care services for people with dementia. He has worked closely with the public health agencies in Ireland on a number of research projects.

Pamela Nadash
Associate Professor

Pamela Nadash is an Associate Professor of Gerontology at University of Massachusetts, Boston, in the McCormack School of Policy & Global Studies. She specializes in health policy issues affecting older people. In particular, she focuses on policies that enable people with long term care needs to access the supportive services they need. This includes looking cross-nationally at long term care financing and service delivery systems, as well as studying variations in policies and practices among states in the US; it also includes evaluating policies and programs that seek to improve the lives of older people. Her work has been published in Health Affairs, Health Services Research, The Gerontologist, and The Milbank Quarterly. She teaches policy courses in the Gerontology PhD program and in the Management of Aging Services program. Prior to academia, she worked for Thomson Medstat as consultant and has extensive experience conducting research on aging and disability issues for nonprofits. Her career also includes six years as at the Policy Studies Institute and the Consumers’ Association in the UK. She earned her Ph.D. in Public Health and Political Science from Columbia University and has a master’s in political theory from Oxford University and an undergraduate degree in philosophy from Bryn Mawr College.

Dr. Séan Healy

Dr Seán Healy is CEO of Social Justice Ireland, an independent social justice think-tank. For more than 30 years he has been active on issues of socio-economic policy in Ireland. Before that he worked for more than 10 years in Africa. He has done work with the European Commission, the Council of Europe, the Economic and Social Council and the United Nations. He is a member of Ireland’s National Economic and Social Council. He chaired the Government Working Group that produced the report that first recommended the establishment of Public Participation Networks (PPNs) in every Local Authority in Ireland. He has done extensive work on the Sustainable Development Goals and Social Justice Ireland has published an analysis of how Ireland is doing on achieving these goals. With his co-director Brigid Reynolds, he has written or edited more than 40 books on public policy as well as three books on spirituality and social engagement. Their most recent book (co-authors) is: ‘Social Justice Matters 2019’, published April 2019. The most recent book they have edited is: ‘From Here to Where? – Negotiating a Better and Fairer Future’ published 13th November 2018. Seán has a PhD in sociology.
Cindy Bergeman is a Professor of Psychology and an Associate Vice President for Research in the University of Notre Dame. She received her Ph.D. from the Pennsylvania State University in Human Development and Family Studies. She has 40 years of experience working with and studying older adults. Her research investigates the interplay among stress, resilience mechanisms and health and well-being outcomes in young, middle-aged and older adults. The goal of her work is to understand why some individuals age more successfully than others. Her work is funded by multiple research grants from the National Institute of Aging.

Professor Martin Orrell is Director of the Institute of Mental Health, a partnership between the University of Nottingham and Nottinghamshire Healthcare NHS Foundation Trust and Head of the Division of Psychiatry and Applied Psychology at the University of Nottingham. He is Chair of the Memory Services National Accreditation Panel (MSNAP). He has been awarded 7 major dementia care research grants totalling £17 million. He has published 300+ academic papers. He is a Board member of INTERDEM. He is President of the European Association of Geriatric Psychiatry. He is Editor of the journal Aging & Mental Health.
8:30am Registration/Tea & Coffee.

9:00am Opening address - Professor Ciarán Ó hÓgartaigh, President, NUI Galway.

9:15am Welcome Address - Professor Kevin Whelan, University of Notre Dame.

Chair - Mr Tim O'Connor


10:00am Kathleen MacLellan, Department of Health. Reforming home care in Ireland.

10:25am Professor Diarmuid O’Shea, President, Irish Gerontological Society and St. Vincent’s University Hospital Dublin. Transforming care of older people in Ireland.

10:50am Morning Q & A

11:00-11.30am: Coffee Break

11:30am Prof Eamon O’Shea and Dr. Sharon Walsh, NUI Galway. What do the public want from a home care system? Results from a discrete choice experiment (DCE).

12:00am Panel discussion facilitated by Professor Suzanne Cahill on the lived experience of care and caring. Panel members: Helen Rochford-Brennan, Aisling Harmon, Christy O’Carroll, Sean Moynihan (ALONE).

12.45pm: Lunch

Chair – Mr. Brendan Kennelly, NUI Galway

1:30pm Dr. Sean Healy, Social Justice Ireland. Social justice and home care for dependent older people in Ireland.

2:00pm Prof. Pamela Nadash, University of Massachusetts Boston. Financing long-term care: an international perspective

3.00pm: Coffee Break

3:15pm Prof Cindy Bergeman, Notre Dame University Building Resilience in Older Adults.

3:45pm Prof. Martin Orrell, University of Nottingham Memory Services and Models of Care for people with dementia

4:30pm Afternoon Q & A

4:45pm Closing address: Prof Eamon O’Shea.