Throughout 2014, enquiries were received by DSIDC staff from all parts of the country with significantly higher rates in the Leinster region. The majority of enquiries came from private individuals and the private nursing home sector. The DSIDC website continues to be a valuable information source for health service professionals and the general public. During 2014, a new web-site page was designed to assist GPs in the challenges often confronted when assessing and diagnosing a person with suspected memory and/or cognition problems and communicating the diagnosis to the person and their next of kin.

A number of design consultancies were also carried out by staff from the Centre throughout the year, which enabled organisations to enhance the lived experience of their clients who have dementia by improving their environment. The majority of these requests came from the residential sector. In November the DSIDC were visited by a group of Estonian developers interested in designing dementia specific units who sought staff’s expertise in design for dementia.

DSIDC staff participated in a number of national and international networks, steering committees and projects during 2014 including:

- National Steering Group for Dementia Friendly Communities
- Scientific and Advisory Panel Alzheimer’s Society
- Trinity Haus and National Disability Design Project
- Dementia Elevator Project
- InterDën
- South Tipperary Dementia Project (Genio)
- Living Well with Dementia (LWwD) South Dublin (Genio)
- The Social Workers Special Interest group on Ageing
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- DemPath Project
- National Referral System for Memory Clinics
- National Council for the Blind Ireland
- Dáil Éireann
- ALONE
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- The Social Workers Special Interest group on Ageing

Governance Structure

The DSIDC employs five staff, two of whom work part-time. It occasionally co-opts in the expertise of Associate Trainers.

During 2014, Steering Committee meetings were held in February, June and October and the Annual Advisory Group Meeting took place in February.

In September, Dr. Siobhán Ni Bhriain stepped down as Chair of the Committee and we would like to thank Siobhan for her professional guidance.

We would also like to welcome Dr. Declan Byrne as the new Chairperson of the Steering Committee.
Introduction

A key aim of the Dementia Services Information and Development Centre is to make Ireland one of the best places in the world for people to age well and to die in dignity cared for by family members and by service providers with a thorough understanding of Alzheimer’s disease and the related dementias.

The year 2014 was significant as it culminated in the launch of the Irish National Dementia Strategy on 17th December. The launch was presided over by the Taoiseach, Enda Kenny, the Tánaiste, Joan Burton and the Minister for Social & Primary Care, Kathleen Lynch. The Strategy, which contains the blueprint for government policy over the next five years, is intended to improve the quality of life of people with dementia and their families. The Strategy was co-authored with the Mercer’s Institute for Successful Ageing (MISA) and took place at the Trinity College Dublin Derville Murphy Seminar Room.

Conferences & Seminars

During 2014 the DSIDC hosted four large conference seminars, which attracted audiences of between 800 to 100 health service professionals and family members. The first, a Memory Clinic conference titled “Dementia: More Than Memory”, was co-hosted with the Mercer’s Institute for Successful Ageing (MISA) and took place at the Trinity College Dublin. The MC was Alistair McDonald and the keynote speaker was Dr. Angela O’Donovan, Consultant Geriatrician at the Mater Misericordiae University Hospital.

The second event, which was a Mini-Symposium on Dementia, was held in May and was opened by the Provost of Trinity College, Dr Patrick Patrick. The keynote speaker was Dr. Patric Stewart and guest speakers included Professors Eamon O’Sullivan, Professor Charles Norman and Dr Caroline O’Toole.

The occasion was also used to showcase the recently completed PhD of Dr Ana Diaz Price which investigated quality of life and loneliness/Isolation among a sample of Memory Clinic patients.

The final event was our winter conference, which took place in Dublin City University in late November. It attracted an audience of over 150 health service professionals and focused on the much-neglected topic of Young Onset Dementia. It involved local and national experts including Dr. Paul MacFhionn and Mr Per Kristian Haugen all of whom are practitioners and researchers with a keen interest in the topic. The powerful opening address was given by Helen Rochford-Brennan, Chair of the Irish Dementia Working Group, at the launch of “A Guide for Family Carers and Health Service Professionals” which she have developed.

Research Studies

Towards the end of the 2014 the DSIDC received an award from Dublin City University for the research project Dementia and Home Design from a Universal Design Approach. This project was funded and commissioned by the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken for the National Disability Authority by Professor Suzanne Lathrop (PhD), Dr Mary Tómas, Tom Grey and Professor Mark Dyer.

The study was commissioned to inform the development of design guidelines, to be used by built environment professionals and relevant stakeholders to design new and retrofit existing dwellings for people with dementia, their families and carers through a Universal Design Approach. The research involved several different phases, including engaging with people with dementia and their families, their carers and professional staff on how they interact with their homes. This was done through a collaborative, inter-sectoral approach.

During the 2014, the UD Programme graduated two PhDs, Dr Ana Diaz Price, and Dr Dr. Mary Tómas and Professor Mark Dyer.

In May five staff from the DSIDC’s Living with Dementia (LiD) research programme attended and delivered a Symposium at the 22nd Nordic Congress of Gerontology, the central theme of this Symposium was the subjective experience of dementia and psychological distress and intervention services.

Speakers included: Dr Maria Pereira, Dr Emer Begley, Vanessa Moore and Dr Andrea Baberley.

In May the DSIDC collaborated with the DSIDC’s Living with Dementia (LiD) research programme attended and delivered a Symposium at the 22nd Nordic Congress of Gerontology, the central theme of this Symposium was the subjective experience of dementia and psychological distress and intervention services.

Speakers included: Dr Maria Pereira, Dr Emer Begley, Vanessa Moore and Dr Andrea Baberley.

Toward the end of the year a very detailed study involving a Systematic Literature on the Public’s Knowledge and Understanding of Dementia was accepted for publication in the journal Alzheimer’s Disease and Associated Disorders. In association with other collaborators, a large grant application was also submitted to the HSE for an ICE award which if successful will support qualitative and quantitative research on Young Onset Dementia.

Education & Information Services

Throughout 2014, in house workshops continued and were well attended. These included the Foundation in Dementia Care Workshop, Alzheimer’s Disease, Activity, Life Story and Leadership in Dementia Care. A new workshop titled ‘Partnerships in Care’ was successfully piloted during the middle of the year in one nursing home. The Centre also offered LLD training in conjunction with the South Tipperary (Stillorgan/Blackrock) for the whole year.

In May the DSIDC began to contribute to the formal work of the St James’s Hospital led dementia project - Demmap. The main objectives of Demmap is to improve partnerships between community and acute care services, reduce the need for hospitalisation and length of time in hospital, provide early intervention and educate the hospital workforce about dementia.

Ultimately DementiaCare is designed to improve the experience of the person with dementia and their family across the general hospital. Two staff members from the DSIDC are leading the implementation of the project in this aspect of the project. The Centre also worked with the South Dublin ‘Living with Dementia’ Care project.

Other highlights during 2014 include the introduction of our new two-week interactive programme for secondary school students titled “Will Grandram Remember Me? A Dementia Awareness Programme for Schools”. The course teaches students about risk factors for dementia including the adverse effects of poor nutrition, cigarette smoking and excessive alcohol consumption and about cognitive reserve and protective factors for dementia.

Several of these students have grandparents who have dementia and with whom they have very close contact.

During 2014 the DSIDC continued to play a major role in the European Union’s largest neuroscience initiative – the European Union’s flagship research programme in the area of Alzheimer’s disease, Parkinson’s disease and Huntington’s disease. This is an initiative which represents an investment of €1 billion, delivered through a programme of 24 consortia led by the world’s top research institutions.

The programme hosts over 500 researchers and is co-ordinated by the National Institute for Health Research, in the UK. The DSIDC is involved in two of the projects which are based in Ireland: the country’s first ever disease-oriented, translational neuroscience programme – the National Dementia Research Initiative (NDRI) and another initiative which is the largest research programme to date in the area of the genetics of Alzheimer’s disease. NDRI is led by Professor Colin McMillan of Trinity College Dublin and funded by the Health Research Board (HRB) for a total of €25 million over a period of five years. The Centre also worked with the South Dublin ‘Living with Dementia’ Care project.
The 2014 ANNUAL REPORT
THE DEMENTIA SERVICES INFORMATION AND DEVELOPMENT CENTRE 2014

Introduction

A key aim of the Dementia Services Information and Development Centre is to make Ireland one of the best places in the world for people to live with dementia. The centre aims to improve the quality of life for people with dementia and their carers by developing and disseminating innovative ideas from international sources that are widely welcomed, and to ensure that people with dementia and their carers are supported in dignity cared for by family members and by service providers with a thorough understanding of Alzheimer’s disease and the related dementias.

The year 2014 was significant as it culminated in the launch of the Irish National Dementia Strategy on 17th December. The launch was presided over by the Taoiseach, Enda Kenny, the Tánaiste, Joan Burton and the Minister for Social & Primary Care, Kathleen Lynch. The Strategy, which contains the blueprint for government policy over the next five years, is underpinned by the research review – Creating Excellence in Dementia Care for People with Dementia in Ireland: A Guide for Family Caregivers and Health Service Professionals’ have been developed.

Conferences & Seminars

During 2014, the DSIDC hosted four large conference seminars, which attracted audiences of between 60 to 150 health service professionals and family members. The first, a Memory Clinic conference titled “Dementia: More than Memory”, was co-hosted with the Mercer’s Institute for Successful Ageing (MISA) and took place at the Trinity Biomedical Sciences Institute in May. Two other seminars/events took place in May, linking in with a study tour from the world renowned, distinguished Professor Steve Zant and his wife Dr Judy Zant from Penn State University. The first was an evening seminar on the topic of Rosepark Care, held in the Royal Irish Academy in Dublin and chaired by Professor Des O’Hare.

The second event, which was a Mini-Symposium on Dementia, was held in May and was opened by the President of Trinity College, Dr Patrick Prendergast. The keynote speaker was Professor Steve Zant and guest speakers included Professor Emeran Eronk O’Sullivan, Professor Charlie Normand and Dr Caroline O’Nolan.

The occasion was also used to showcase the recently completed PhD of Dr Ana Diaz Ponce, and Dr Janet Convery, a report which was written by staff from the DSIDC and from NUI Galway and funded by the Atlantic Philanthropies.

The third conference of the year was held in June and linked in with the Dementia and Home Design Conference from a Universal Design Approach. This report was based on the research commissioned by the Centre Excellence in Universal Design at the National Disability Authority. The project was undertaken for the National Disability Authority by Professor Suzanne Labadie (PI), Dr Maria Pearse, Tom Grey and Professor Mark Dyet.

The study was commissioned to inform the development of design guidelines, to be used by built environment professionals and relevant stakeholders to design new and retrofit existing dwellings for people with dementia, their families and carers through a Universal Design Approach. The research involved several different phases, including strong engagement with built environment professionals and all relevant stakeholders to design new and retrofit existing dwellings for people with dementia, their families and carers. This was done through a collaborative, inter-sectorial approach.

The final public event was our winter conference, which took place in Dublin City University in late November. It attracted an audience of over 150 health service professionals and focused on the much-neglected topic of Dementia and Home Design from a Universal Design Approach.

Research Studies

Towards the end of 2014 the DSIDC received an award from Dublin City University for its research project on Dementia and Home Design from a Universal Design Approach. This report was based on the research commissioned by the Centre Excellence in Universal Design at the National Disability Authority. The project was undertaken for the National Disability Authority by Professor Suzanne Labadie (PI), Dr Maria Pearse, Tom Grey and Professor Mark Dyet.

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During the 2014, the U3A Programme graduated two PhD students, Dr Ana Diaz Ponce and Dr Janet Convery. The latter is an Assistant Professor in the Faculty of Health Studies at NUI Galway and her thesis was on the topic of Dementia and Housing with Care.

In May five staff from the DSIDC’s Living with Dementia (LiD) research programme attended and delivered a Symposium at the 22nd Nordic Congress of Gerontology. The central theme of this Symposium was the subjective experience of dementia and psychological and spiritual service interventions. The presentations were given both to the general audience and to a specialist psychological and spiritual care audience.

Speakers included Dr Maria Pierce, Dr Ener Begley, Vanessa Moore and Dr Andrea Baboolally.

Towards the end of the year a very detailed study involving a Systematic Literature of the Public’s Knowledge and Understanding of Dementia was accepted for publication in the journal Alzheimer’s Disease and Associated Disorders. In association with other collaborators, a large grant application was also submitted to the HSE for an ICGC which would support qualitative and quantitative research on Young Onset Dementia.

During 2014, the DSIDC continued to deliver the extra rural course “Understanding Dementia and Promoting Family Caregivers’ Quality of Life”, an evening course designed to up skill family caregivers and promote their well being. The course was provided free of charge and was very well evaluated. Due to its success the course will be repeated in early 2015.

A one off successful seminar on sensory impairment and dementia was also hosted by the Centre in St James’s Hospital in Dublin and held in conjunction with DeafHear and National Council for the Blind in Ireland.

During the year, staff from the DSIDC continued to play a significant role in the teaching of Trinity College, Dublin which offers a course titled “Dementia and Associated Disorders”. The course develops students about risk factors for dementia including the adverse effects of poor nutrition, cigarette smoking and excessive alcohol consumption and alcohol and cognitive reserve and protective factors for dementia.

Several of these students have grandchildren who have dementia and with whom they have very close contact.

Education & Information Services

Throughout 2014, in house workshops continued and were well attended. These included the Foundation in Dementia Care Workshop, responsive Behaviour, Activity, Life Story and Leadership in Dementia Care. A new workshop titled ‘Partnerships in Care’ was successfully piloted during the middle of the year in one nursing home. The Centre also partnered with Our Lady’s Hospice, Harold’s Cross and co-facilitated a three day course for all professionals working in the area of dementia.

This was a success and was repeated in the Autumn.

In May the DSIDC began to contribute to the formal work of the St James’s Hospital led dementia project – Dempath. The main objectives of Dempath are to improve partnerships between community and acute care services, reduce the need for hospitalisation and length of time in hospital, provide early intervention and educate the hospital workforce about dementia.

Ultimately Dempath is designed to improve the experience of the person with dementia in the acute hospital general. Too staff members from the DSIDC are involved in leading on key aspects of this project. The Centre also worked with the South Dublin ‘Living with Dementia’ Genio project.

Other highlights during 2014 include the introduction of our new week-interactive programme for secondary school students titled “Will Grandman Remember Me?: A Dementia Awareness Programme for Schools”. The course teaches students about risk factors for dementia including the adverse effects of poor nutrition, cigarette smoking and excessive alcohol consumption and alcohol and cognitive reserve and protective factors for dementia.

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During 2014 staff from the Centre contributed to a number of conferences, seminars and lectures. Paper presentations were given at the Waterford Skills Chambers Conference, CARDI Colloquium, the ‘Ganfio Annual Conference, Semnas apig at the InterDem day at Alzheimer Europe in Glasgow.

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Conferences & Seminars

During 2014, the DSIDC hosted four large conference seminars, which attracted audiences of between 60 to 150 health service professionals and family members. The first, a Memory Clinic conference titled ‘Dementia: More than Memory’, was co-hosted with the Merieux Institute for Successful Ageing (MISA) and took place at the Trinity InterDem day at Alzheimer Europe. The main objectives of the second event, which was a Symposium ‘Understanding Dementia and Housing with Care’, was held in May and was opened by the Provost of Trinity College, Dr Patrick Prendergast. The opening address was given by Helen Rochford-Brennan, Professor Charles Normand and Dr Caroline O’Nolan. The study was commissioned to inform the development of design guidelines, to be used by built environment professionals and relevant stakeholders to design new and retrofit existing dwellings for people with dementia, their families and carers through a Universal Design Approach. The research involved several different phases, including strong engagement with built environment professionals and also people with dementia, their families and carers. This was done through a collaborative, inter-sectoral approach.

Research Studies

Towards the end of the 2014 the DSIDC received an award from Dublin City University for the research project ‘Dementia and Home Design from a Universal Approach’. This research was guided by built environment professionals and researchers and was commissioned to inform the design of new and retrofit existing dwellings for people with dementia, their families and carers through a Universal Design Approach. The research involved several different phases, including strong engagement with built environment professionals and also people with dementia, their families and carers. This was done through a collaborative, inter-sectoral approach.

During the 2014, the IDP Programmes, two workshops were held – Drs. Anne Diaz Ponce and Dr Janet Convery as Chair. The workshop session was under the theme of Dementia and Housing with Care.

During 2014 the DSIDC commissioned research involving ‘Respite Service Evaluations’ (Siva Topperayan and Stephen O’Sullivan) to determine the feasibility of a national evaluation of respite service provision and to identify key challenges and areas for improvement. The research was commissioned using a mixed methods approach: qualitative interviews and focus groups with people using respite services, and quantitative data collection from individuals using respite services. Each of the four participating locations was selected to reflect the diversity of respite services in Ireland. The research was completed in late 2014 and is currently being finalised.

In May 2015 staff from the DSIDC’s Living with Dementia (LID) research programme attended and delivered a Symposium at the 22nd Nordic Congress of Geronomologists. The common theme of this Symposium was the subjective experience of dementia and psychological and social interventions with people with dementia and their families. This was done through a collaborative, inter-sectoral approach.

The Genio commissioned research involving ‘Respite Service Evaluations’ (Siva Topperayan and Stephen O’Sullivan) to determine the feasibility of a national evaluation of respite service provision and to identify key challenges and areas for improvement. The research was commissioned using a mixed methods approach: qualitative interviews and focus groups with people using respite services, and quantitative data collection from individuals using respite services. Each of the four participating locations was selected to reflect the diversity of respite services in Ireland. The research was completed in late 2014 and is currently being finalised.

In May 2014 the DSIDC Igors Zvirgzodis led a training course ‘Dempath – Developing a Resilience Framework for Dementia Healthcare Providers’ which was a follow on from a successful training course convened by Genio, in May 2013. Dempath was a training programme designed for healthcare providers and aimed to build resilience, develop a framework for improved communication and collaboration and facilitate engagement in delivering research evidence.

In May 2014 four independent research teams from across Ireland came together for a training workshop on ‘Respite Service Evaluation’ in the DSIDC offices. The workshop was devised to assess the feasibility of a national evaluation of respite service provision and to identify key challenges and areas for improvement. The research was commissioned using a mixed methods approach: qualitative interviews and focus groups with people using respite services, and quantitative data collection from individuals using respite services. Each of the four participating locations was selected to reflect the diversity of respite services in Ireland. The research was completed in late 2014 and is currently being finalised.

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A once off successful seminar on sensory impairment and dementia was also hosted by the Centre in St James hospital in Dublin and held in conjunction with DeafHear and National Council for the Blind in Ireland.

During the year, staff from the DSIDC continued to play a significant role in the teaching of Trinity College, Dublin which delivers the National Dementia Education Programme for Schools’. The course teaches students about risk factors for dementia including the adverse effects of poor nutrition, cigarette smoking and excessive alcohol consumption and about cognitive reserve and protective factors for dementia.

Several of these students have grandparents who have dementia and with whom they have very close contact.

During 2014 from the DSIDC contributed to the formal work of the St James’s Hospital led dementia project - Dempath.  The main objectives of Dempath is to improve partnerships between community and acute care services, reduce the need for hospitalisation and long term care in hospital, provide early intervention and educate the hospital workforce about dementia.

Ultimately Dempath is designed to improve the experience of the person with dementia and their family in the general public hospital. Two staff members from the DSIDC are participating in leading the work in two key aspects of this project. The Centre also worked with the South Dublin ‘Living with Dementia’ Genio project.

Other highlights during 2014 include: the introduction of our new five-week interactive programme for secondary school students titled “Will Grandram Remember Me? A Dementia Awareness Programme for Schools’. The course teaches students about risk factors for dementia including the adverse effects of poor nutrition, cigarette smoking and excessive alcohol consumption and about cognitive reserve and protective factors for dementia.

Throughout 2014, in house workshops continued and were well attended. These included the Foundation in Dementia Care Workshop which was well attended and was carried out in partnership with specialist care units for People with Dementia in Ireland: A Guide for Family Caregivers and Health Service Professionals have been developed.

During 2014, the DSIDC completed the data collection and analysis of a new research study on dementia conducted across 623 Nursing Homes in Ireland. The purpose of this study was to investigate the number and location of specialist care units across the RAI and to examine in particular the extent to which these facilities complied with best practice guidelines on dementia care. Based on the key findings from this study a detailed report and a new booklet were commissioned Specialist Care Unit for People with Dementia in Ireland: A Guide for Family Caregivers and Health Service Professionals have been developed.

During 2014 the DSIDC, with partners from the National Dementia Education Programme for Schools, the National Council for the Blind and the National Disability Authority, developed a curriculum to include dementia education for all students in post-primary education. The project was undertaken for the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken for the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken for the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken for the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken for the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken for the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken for the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken for the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken for the Centre for Excellence in Universal Design at the National Disability Authority. The project was undertaken for the Centre for Excellence in Universal Design at the National Disability Authority.

During 2014, the DSIDC also undertook a number of research projects in partnership with other organisations and researchers. In particular, the Centre continued its work in collaboration with the Health Service Executive to deliver a training programme on ‘Genetics in Dementia’ and ‘Promoting Health and Wellbeing through Nutrition in Dementia Care’. This programme was delivered to the HSE Staff Health, Safety & Welfare Department.

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Throughout 2014, enquiries were received by DSIDC staff from all parts of the country with significantly higher rates in the Leinster region. The majority of enquiries came from private individuals and the private nursing home sector. The DSIDC website continues to be a valuable information source for health service professionals and the general public. During 2014, a new web-site page was designed to assist GPs in the challenges often confronted when assessing and diagnosing a person with suspected memory and/or cognition problems and communicating the diagnosis to the person and their next of kin.

A number of design consultancies were also carried out by staff from the Centre throughout the year, which enabled organisations to enhance the lived experience of their clients who have dementia by improving their environment. The majority of these requests were from the residential sector. In November the DSIDC were visited by a group of Estonian developers interested in designing dementia specific units who sought staff’s expertise in design for dementia.

DSIDC staff participated in a number of national and international networks, steering committees and projects during 2014 including:

- National Steering Group for Dementia Friendly Communities
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- Living Well with Dementia (LWaD) South Dublin (Genio)
- The Social Workers Special Interest group on Ageing
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Governance Structure

The DSIDC employs five staff, two of whom work part-time. It occasionally co-opts in the expertise of Associate Trainers.

During 2014, Steering Committee meetings were held in February, June and October and the Annual Advisory Group Meeting took place in February.

In September, Dr. Siobhan Ni Bhríain stepped down as Chair of the Committee and we would like to thank Siobhan for her professional guidance.

We would also like to welcome Dr. Declan Byrne as the new Chairperson of the Steering Committee.
Throughout 2014, enquiries were received by DSIDC staff from all parts of the country with significantly higher rates in the Leinster region. The majority of enquiries came from private individuals and the private nursing home sector. The DSIDC website continues to be a valuable information source for health service professionals and the general public. During 2014, a new web-site page was designed to assist GPs in the challenges often confronted when assessing and diagnosing a person with suspected memory and/or cognition problems and communicating the diagnosis to the person and their next of kin.

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- Siel Bleu

Governance Structure

The DSIDC employs five staff, two of whom work part-time. It occasionally co-opts in the expertise of Associate Trainers. During 2014, Steering Committee meetings were held in February, June and October and the Annual Advisory Group Meeting took place in February.

In September, Dr. Siobhán Ni Bhriain stepped down as Chair of the Committee and we would like to thank Siobhan for her professional guidance.

We would also like to welcome Dr. Declan Byrne as the new Chairperson of the Steering Committee.