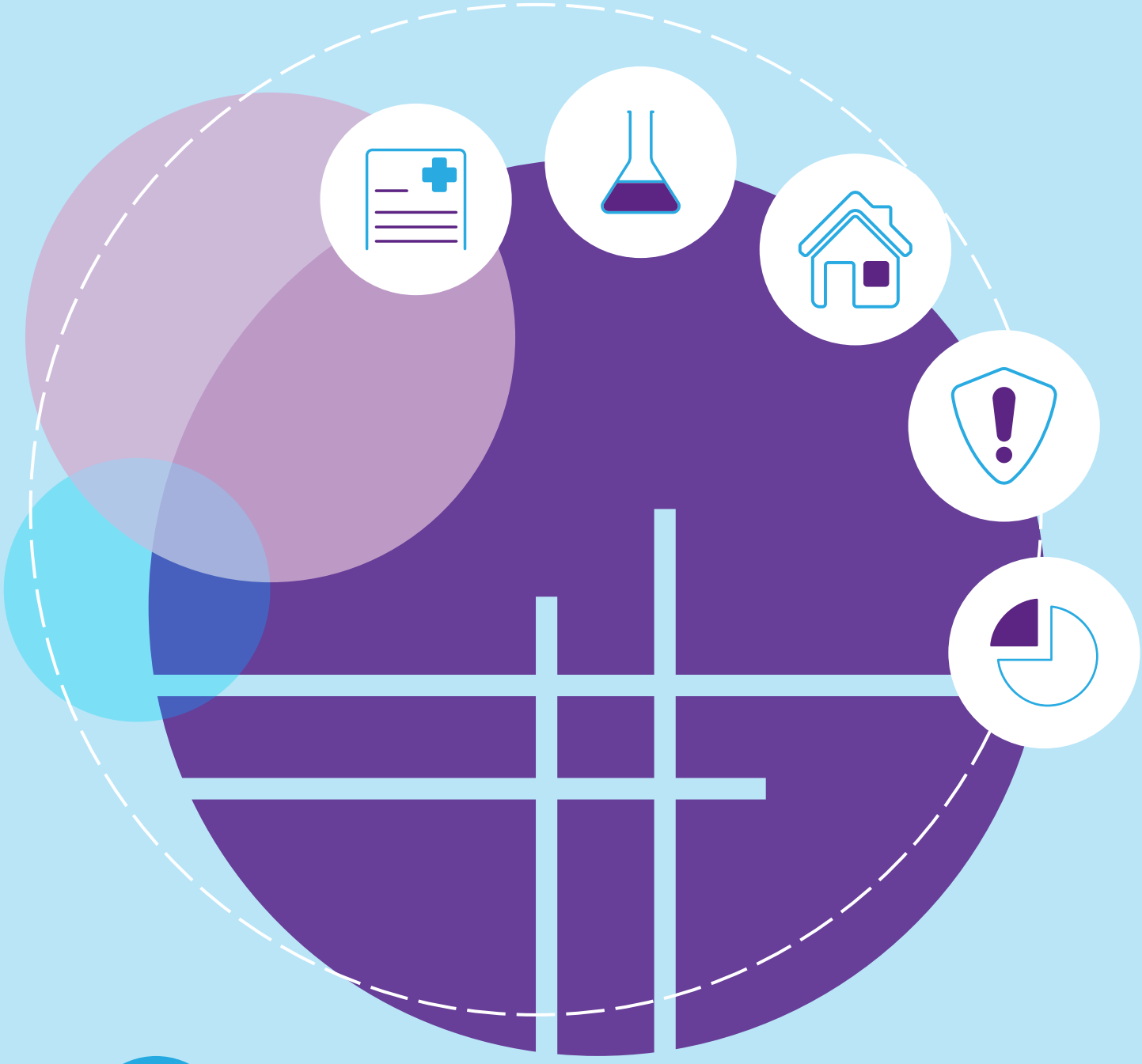
Scottish Dementia Research Consortium

Annual Report 2019/20



Scottish Dementia Research Consortium

Alzheimer Scotland
Action on Dementia

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Foreword

National Dementia Carers Action Network (NDCAN)

The amount of research being done in the field of dementia is gaining momentum. This work is vital to our understanding of this group of diseases and also to the formulation of a cure. In terms of the difference this research can make to the lives of those affected by dementia, it has the very real potential to be a game changer.

Those of us in the NDCAN fully support the SDRC's aims of championing and promoting the research being done across Scotland, whilst making sure that the opinions of those living with dementia and their families and friends are taken into account.

By intrinsically linking the research being done to the experiences and voices of folk living with dementia and their carers, the SDRC ensures that the work and studies done are of the highest value and quality. Its work will take us much closer to a world without dementia and in the meantime by spreading the word of the amazing work being done, we can open up more conversations about dementia and thus reduce the stigma that can still be attached. After all – it is easier to take away the power of something that scares us by talking about it openly and honestly – and most importantly by giving hope founded on reality.

This year has seen some exciting developments in our work with the SDRC. We are working with the Living with Dementia theme to take forward our research priorities and I also represent the NDCAN on the governance group for the Scottish Dementia Informatics Partnership.

Ann Yourston
National Dementia Carers Action Network

Scottish Dementia Working Group (SDWG)

The Scottish Dementia Working Group (SDWG) has always had an active interest in research, from looking at ways to help live well with dementia for those currently with a diagnosis, to the possibility of prevention for our future generations.

The SDWG are a member led, national campaigning and awareness raising group, who understand the importance of, and fully support the need for dementia research in Scotland. We have our own research subgroup where we keep up to date with the latest research developments from the SDRC, participate in research projects and review research requests that come to the group. I also represent the working group on the Scottish Dementia Informatics Partnership (SDIP) Executive Committee. It is wonderful that we can have a person with dementia on a committee like this as we are the people with the lived experience and our voice is so important.

On behalf of the SDWG, I would like to congratulate the SDRC on this report and all the work that has been done over the last year. We look forward to continuing to support the work of the SDRC in the future.

Geoff Orry
Scottish Dementia Working Group

Welcome

Prof Craig Ritchie– Chair, Scottish Dementia Research Consortium

I am delighted to welcome you to the second report of the Scottish Dementia Research Consortium (SDRC). Our Annual Report 2019/20 provides a review from each of our theme leads and presents an updated mapping of Scottish dementia and brain health research for 2019.

The mapping data highlights the growing importance of Prevention as a research theme across our Scottish Universities. It also demonstrates a significant increase in grant funding for the Living with Dementia theme, a pattern we hope continues over the coming years.

There have been many exciting developments over the past year, not least the launch of Brain Health Scotland which will bring together research evidence, informatics and clinical practice in developing prevention strategies and promoting brain health. The SDRC is a cornerstone of Brain Health Scotland and we look forward to the impact this work will have on public health going forward.

Working with multiple partners across the country – the SDRC will be publishing The Scottish Brain Health and Dementia Research Strategy. This strategy will be one of the first national strategies anywhere in the world and will map out objectives for the SDRC to coordinate over the 2-year period to 2022.

The SDRC has grown significantly since its formation in 2013 and we currently have 535 members. Our increasing engagement with our membership over 2019 has been facilitated by Carleen Smith, our highly valued SDRC staff member. The largest increase in membership has been witnessed in early career researchers. The creation of an environment for their work and their careers to flourish is the primary objective of SDRC.

The membership also includes others from across our research community, practitioners and people living with dementia. The annual report highlights the ways we are developing our work to ensure the voices of people with dementia and their supporters are listened to and valued in all of our research.

As noted already, our early career research community is a key priority for the SDRC. The second day of our annual conference is a dedicated early career researcher workshop which has been added to our conference programme for the first time this year as a direct result of the feedback from our membership.

There are many new major programmes ongoing and in the pipeline, so whilst we have had a strong and productive last 12 months, we envisage even greater research success in the coming year during which, through Brain Health Scotland, we expect the research we do to rapidly translate into better practice for people with dementia and those at risk of developing it in the years ahead.

SDRC Executive Committee

Prof Craig Ritchie

Craig is the Professor of Psychiatry of Ageing at the University of Edinburgh, Director of Edinburgh Centre for Dementia Prevention and Director of Brain Health Scotland.

His primary research interest is the maintenance of brain health in mid-life to mitigate the risks of initiation and progression of degenerative brain disease that may lead to dementia. He is Chief Investigator on the PREVENT Dementia and European Prevention of Alzheimer's Dementia Research Programmes.

Prof Alison Murray

Alison is the Roland Sutton Professor of Radiology at the University of Aberdeen. Until recently, she was Director of the Scottish Imaging Network: A Platform for Scientific Excellence.

She leads NHS molecular brain imaging in people with neurodegenerative diseases and dementia and has a track record of brain magnetic resonance imaging research in the Aberdeen Birth Cohorts.

Dr Maggie Ellis

Maggie is a Senior Lecturer in Psychology and develops teaching, training and consultancy in dementia care at the University of St Andrews.

Her main research focus is on identifying and utilising the spared communication skills in people at very advanced stages of dementia to support meaningful communication.

Prof Peter Connelly

Peter is fellow of the Royal College of Physicians of Edinburgh and Honorary Professor at University of Stirling.

He was an Old Age Psychiatry Consultant until his retirement in 2016. He led a successful bid, with his colleagues, to establish the Scottish Dementia Clinical Research Network (now the Neuroprogressive and Dementia Network).

Prof Debbie Tolson

Debbie is the Alzheimer Scotland Professor of Dementia and Director of the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland.

She is a registered nurse with an international reputation and nurse leader and educator. She has led and been involved in practice based research studies to advance dementia care in Scotland, Europe and beyond.

Prof Frank Gunn-Moore

Frank is Head of the School of Biology at University of St Andrews and Deputy Director of the Scottish Universities Life Sciences Alliance.

He combines all three science disciplines in leading a research group that has made major discoveries in understanding the early stages of Alzheimer's disease, pioneering new models and identifying potential therapeutic targets.

Prof Richard Simpson

Richard is an Honorary Professor at University of Stirling and Honorary Visiting Professor at University of St Andrews.

He founded and chaired the Forth Valley Primary Care Research Group and was previously a GP, consultant psychiatrist and member of the Scottish Parliament. His interest is in the politics of dementia.

Dr Karen Watchman

Karen is Senior Lecturer in Ageing, Dementia and Frailty and co-leads the Enhancing Self-Care research group in the Faculty of Health Sciences and Sport at the University of Stirling.

She has a focus on post-diagnostic support, intellectual disability and equality issues. She is secretary of the Down Syndrome Research Group at the International Association for the Scientific Study of Intellectual and Development Disability.

Dr Louise Ritchie

Louise is a Reader in Dementia Research in the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland.

She is a psychologist with a focus on applied psychological research that aims to improve the lives of people living with dementia, their families and people who care for them.

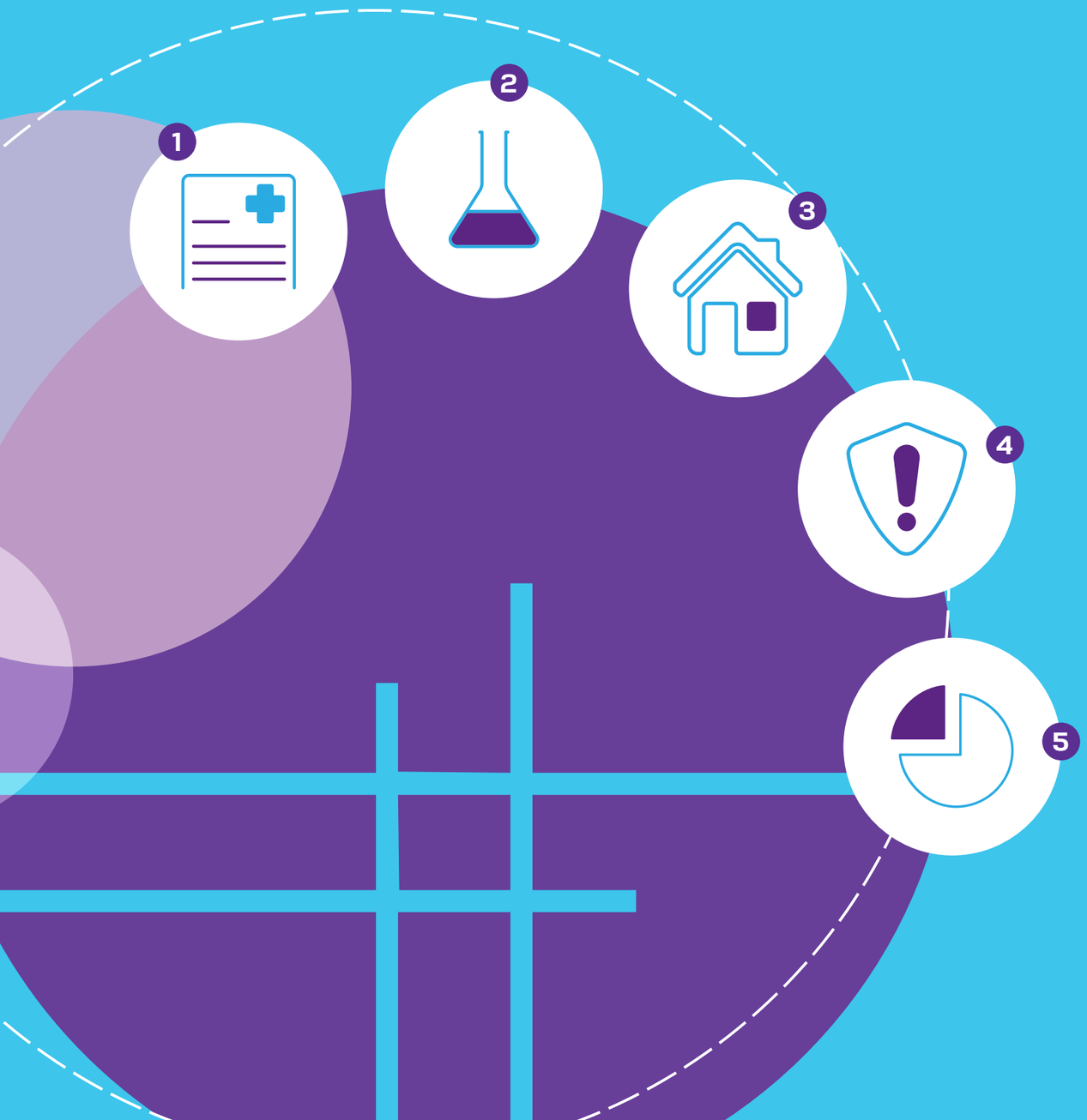
Report introduction

Our Annual Report 2019/20 provides an update on work from each of our research theme leads. In our last report we presented the results of an extensive mapping exercise of Scottish research across all dementia disciplines over the past five years. This report includes an update on this mapping data for 2019. We also provide an early career researcher spotlight, feedback from the SDRC 2019 conference and message to our members from SDRC Officer, Carleen Smith.

The SDRC was formed in 2013 as a membership-based organisation with the key aims of bringing together Scottish-based dementia researchers from all disciplines and promoting Scottish dementia and brain health research interests at a national, UK, European and International level.

The SDRC currently has 535 members, representing a network of researchers, policy makers and people living with dementia from across Scotland. Our key aims for the coming year are to continue to grow our membership, increase engagement with our membership, develop our key focus on early career researchers and ensure the voice and experience of people with dementia and their families are central to research policy and development.

SDRC dementia research themes



What we know, where we are now and future ambitions within each of the key areas of dementia and brain health research.

1. Diagnosis
2. Fundamental Science
3. Living with Dementia
4. Prevention
5. Scottish Dementia Informatics Partnership

1

Diagnosis

Professor Alison Murray
Theme Lead

This theme is focused on evaluating new tests and making the optimal use of existing tests for accurate and early detection of illness. By detection, we mean identifying the earliest changes in the brain that occur well before the symptoms of the illness develop. In order to achieve this, we need access to the right data from people of all ages and all stages of neurodegenerative disease. To this end Scotland has extensive resources in the Scottish Birth Cohorts.

The Scottish Birth Cohorts are longitudinal studies[1] of a large group of people who undertook a test to measure their cognitive ability at age 11 through the Scottish Mental Surveys. These tests were carried out in Aberdeen and Lothian for all school children aged 11 years in 1921 and 1936. Scotland is the only country in the world to have tested the intelligence of the entire population at the same time and to have repeated this large scale exercise 15 years later.

Work happening in theme

The Scottish Birth Cohorts provided a baseline for a whole population who could then be followed up in later life. This has been carried out by a number of studies including the Aberdeen Child Development Survey[2], Lothian Birth Cohorts[3] and Walker Cohort Dundee. Subsets from some of these studies, incorporating their first degree relatives, have been recruited into other longitudinal studies. For example, GS STRADL[4], providing a rich source of information that includes cognition, genetics and brain imaging.

More recently, these longitudinal studies have been complemented by the European Prevention of Alzheimer's Dementia (EPAD) and PREVENT longitudinal studies. EPAD and PREVENT are carrying out detailed ongoing testing of people from 40 years of age upwards.

The large population group being studied by EPAD[5] and PREVENT[6] did not have a diagnosis of dementia at the time of being recruited to take part in the study. They will go on to undergo a range of observational tests at regular intervals over time to measure changes. The aim of this work is to discover the earliest changes in the brains of people who are at increased risk of developing dementia.

Many Scottish researchers are also utilising data from national databases including the UK BioBank and international initiatives such as the Alzheimer's Disease Neuroimaging Initiative.[7] One specific study utilising these data resources at University of Aberdeen is being carried out in collaboration with studies in Taiwan and India. The study is investigating brain iron, the effect of photoperiod on hippocampal volume, brain hyperintensities and imaging correlates of cognitive reserve.

At University of Edinburgh and University of Glasgow work is ongoing to develop machine learning algorithms that can take data and identify optimised diagnostic test batteries as well as prediction tools. This aim is for these algorithms to be tested and then applied in clinical practice facilitated by Brain Health Scotland.

The development of early detection and diagnosis tools will also benefit the design of and recruitment to clinical trials. For example, the TauRx sponsored LUCIDITY clinical trial[8] which follows individuals to establish how individual-level pharmacodynamics influence drug availability and efficacy.

One of the most exciting recent developments is a large scale data linkage project making NHS data available to researchers and industry. In Scotland we have the £15million centre, funded by Innovate UK, Canon and Philips, for artificial intelligence research in digital diagnosis (iCAIRD)[9] and PICTURES[10]. Whilst these are not specific to dementia research, they will create infrastructure, governance and expertise that will support dementia and brain health research programmes in the future.

The work outlined above illustrates the highly impressive level and quality of data access and development in Scotland. Our researchers are also integral to the new world of global data interoperability programmes. It is clear that early detection and diagnosis will continue to be a crucial and cross-cutting theme within SDRC. Our challenge will be to ensure research findings are translated from the laboratory into clinical practice. This challenge is a key objective of Brain Health Scotland.

[1] Study that involves repeated observations of the same research participants over a long period of time
[2] https://www.abdn.ac.uk/birth-cohorts/
[3] https://www.lothianbirthcohort.ed.ac.uk
[4] http://bit.ly/2VX46K1
[5] EPAD http://ep-ad.org/erap/
[6] PREVENT https://preventdementia.co.uk/
[7] Biobank https://www.ukbiobank.ac.uk/, ADNI http://adni.loni.usc.edu
[8] LUCIDITY https://taurx.com/clinical-trials/
[9] iCAIRD https://icaird.com/
[10] PICTURES http://bit.ly/PSCNP11

2

Fundamental Science

Professor Frank Gunn-Moore
Theme Lead

This area of research is the foundation for the development of treatments for dementia. Scotland has a strong community of fundamental scientists working in the field of neurodegenerative disease with 184 post-doctorate researchers, including independent principal investigators, and an additional 48 PhD students.

The fundamental sciences research theme can also draw on advancements across the spectrum of the life sciences, but also make use of world class physical sciences. As such Scotland also benefits from world leading facilities, with a major concentration of drug discovery research facilities that are unparalleled in Europe.

Work happening in theme

This year has seen breakthroughs from Scotland's researchers in understanding the causes of damage to brain connections in Alzheimer's disease. Research at the University of Edinburgh identified the clumping of a damaging protein "clusterin"[11] , which builds up in vital parts of neurons that connect cells, and which may lead to damage to these connections.

The study focussed on synapses, shared connection points between brain cells that allow chemical and electrical signals to flow between cells. These signals are vital for forming memories, which are key to brain health. This discovery of "clusterin" in brain tissue of people who died with Alzheimer's disease used powerful technology that allowed scientists to view individual synapses that are around 5,000 times smaller than the thickness of a sheet of paper.

The same research team also discovered how two pathological proteins (amyloid and tau) interact and work together to damage the brain in Alzheimer's disease[12]. Whilst synapse loss in Alzheimer's disease had been described previously, this clumping of damaging proteins together in synapses was previously unknown due to difficulties in studying them because of their tiny size. Using a mouse model, they demonstrated that when both amyloid and tau are present in the brain, genes that control the function of these synapses were turned down and some genes that control the immune system in the brain were turned up. Promisingly, when the tau protein was reduced in mice, the behaviour and gene expression recovered.

These discoveries in neurodegeneration are helping to identify the causes of Alzheimer's disease and crucially they are also leading the way in the search for treatments. The prevention of damage to synapses and reduction of tau present potential routes for future therapeutic intervention in Alzheimer's disease.

Researchers in Scotland have also been leading the way in highlighting the importance of vascular contributors to dementia. A series of recent workshops and discussion forums in the field were hosted by Scottish universities, culminating in key strategic papers and review articles[13].

There are also several active research programmes in the area of vascular health. Four major Stroke Association Priority Programmes are held by researchers at University of Edinburgh, in addition to major European grants at the Universities of Dundee and Edinburgh. Cerebrovascular and metabolic dysfunction is also a core theme within the newly established UK Dementia Research Institute and British Heart Foundation Centre of Research Excellence at University of Edinburgh.

An Alzheimer Society Doctoral Training Centre (Centre) was established in Scotland in 2012, combining the expertise of University of Edinburgh, University of Dundee, University of St Andrews and University of Aberdeen, with additional support from the host Universities, Alzheimer Scotland and the RS Macdonald Trust. A total of nine PhD students were funded to study interlinked projects, focussing on metabolic and vascular contributors to dementia. The Centre sought to address the major concern that modern lifestyle factors, such as high fat, high calorie intake and obesity, contribute to increased risk of dementia. It is also known that poor diet and obesity can lead to diabetes and hypertension, which in turn may also increase the risk of dementia. The Centre's research focussed on the question of how these different factors may influence brain metabolism and vascular alterations, leading to impaired memory.

The Centre has been hugely successful in providing a forum to develop collaborative studies. The PhD students have travelled the globe sharing their research findings at key dementia conferences and participated in public events communicating the importance of dementia research. All students completing their PhD are now post-doctoral researchers across various universities, the newly formed UK Dementia Research Institute and in industry.

The developments highlighted above provide a flavour of the work that is happening in fundamental science at this time. The strength of our research community and world leading facilities demonstrate Scotland's strong global contribution to the field of dementia research.

[11] Jackson RJ, Rose J, Tulloch J, Henstridge C, Smith C, Spires-Jones TL (2019) Clusterin accumulates in synapses in Alzheimer's disease and is increased in apolipoprotein E4 carriers. Brain Commun 1: fcz003 Doi 10.1093/braincomms/fcz003

[12] Pickett EK, Herrmann AG, McQueen J, Abt K, Dando O, Tulloch J, Jain P, Dunnett S, Sohrabi S, Fjeldstad MP, Calkin W, Murison L, Jackson RJ, Tzioras M, Stevenson A, d'Orange M, Hooley M, Davies C, Colom-Cadena M, Anton-Fernandez A, King D, Oren I, Rose J, McKenzie CA, Allison E, Smith C, Hardt O, Henstridge CM, Hardingham GE, Spires-Jones TL (2019) Amyloid Beta and Tau Cooperate to Cause Reversible Behavioral and Transcriptional Deficits in a Model of Alzheimer's Disease. Cell Rep 29: 3592-3604 e3595 Doi 10.1016/j.celrep.2019.11.044;

[13] Horsburgh K et al Small vessels, dementia and chronic diseases - molecular mechanisms and pathophysiology. Clin Sci (Lond). 2018 132(8):851-868. doi: 10.1042/CS20171620. McFall A et al. UK consensus on pre-clinical vascular cognitive impairment functional outcomes assessment: questionnaire and workshop proceedings J Cerebral Blood flow Metabolism in press Wardlaw JM, et al. Small vessel disease: mechanisms and clinical implications. Lancet Neurol. 2019 Jul;18(7):684-696. doi: 10.1016/S1474-4422(19)30079-1

3

Living with Dementia

Professor Debbie Tolson
Theme Lead

The experience of living with dementia will be different for each person and their family. As the condition progresses, the needs of the person and carer evolve, change and intensify. If we are to respond effectively to the World Health Organisation Global Dementia Action Plan, that is, to provide high quality care and support that people living with dementia deserve, it is important that we understand what it means to live with dementia over the course of the illness.

This research theme includes all aspects of living with dementia and encompasses dementia care and caring. Research extends across studies that focus on any aspect of life and living, practice-based research, improvement science, health and integrated care services research, caring sciences including family caring, therapeutic and caring interventions and dementia education.

Living with Dementia research is on a positive and upward trajectory, as demonstrated by the data in this report. Studies within this theme generate new knowledge that has potential for immediate impact on improving lives, services and the experiences of care. We are also focussed on finding evidence informed ways to deliver on our National Dementia Strategies. Our aim is to keep Scotland at the forefront of innovations in dementia care, policy initiatives and dementia education.

Work happening in theme

This year has seen important developments in how the SDRC is working with people with dementia and family carers.

The SDRC Executive Committee is supporting the Scottish Dementia Working Group (SDWG) to develop their research group. This group will help to shape the SDWG's own priorities for research and support the sharing of findings from all SDRC research themes. National Dementia Carers Action Network (NDCAN) have also formed a research group, supported by the SDRC and are exploring the concerns and research priorities of family carers in working towards funding applications for collaborative research studies.

The brief highlights that follow are indicative of impact from programmes of research undertaken by SDRC members:

Collaborative research on dementia in employment has informed new guidance on dementia friendly workplaces[14] and trade union approaches to supporting employees[15].

A collaborative research team at the University of Stirling, including co-researchers with a learning disability, have conducted research into the implementation on non-pharmacological interventions that informed training and development on post-diagnostic support for people with a learning disability and dementia[16].

The University of St Andrews is leading on an ongoing research programme focussed on communication with people with advanced dementia. Research is studying the impact of Adaptive Interaction – a non-verbal technique that facilitates connection between people with advanced dementia and their families and caregivers. Recent findings indicate that Adaptive Interaction increases behavioural interactions and further demonstrates that participants with advanced dementia not only reciprocate social exchanges but also initiate them.

Recommendations from the University of the West of Scotland advanced dementia care research, the Palliare programme, underpins core arguments within The Fair Dementia Care Report (2019), which calls for advanced dementia to be recognised as a continuum of living moving beyond the current focus on death and dying.

Researchers from the University of the Highlands and Islands are working on an academic and industry collaboration to enhance the development of a symptom monitoring and tracking feature within a digital application (CogniCare). The aim of the programme is to support family carers' ability and confidence in the early identification of symptoms that would help facilitate meaningful hospital and social care consultations.

The University of West of Scotland is developing work in multi-species therapeutic approaches to dementia support. This will see a multi-disciplinary network of researchers from across humanities, social sciences, nursing studies, veterinary medicine and zoology, collaborating to inform research, policy and practice[17].

Looking to the Future

The year ahead will see important research developments relating to public health policy priorities in Scotland, UK and globally. Our ambitions include interdisciplinary research to promote brain health in targeted areas, including rural remote and secure communities.

We will continue to collaborate with National Dementia Carers Action Network to develop a programme of inclusive research focussed on advanced dementia that will provide a more nuanced understanding of the advanced dementia experience, keeping safe and communication. Family carers, with the support of the SDRC, will also be leading evaluative studies within the new Alzheimer Scotland Centre for Policy and Practice Carer's Academy.

We will continue to engage with and grow our membership across Scotland. It is crucial as a Living with Dementia research community that we communicate our research findings and take advantage of collaborative opportunities to strengthen future research. We invite our members to share their funding successes through the SDRC communication channels, get in touch to explore opportunities to collaborate and encourage your colleagues to join the SDRC.

[14] http://bit.ly/WWDinfo
[15] http://bit.ly/TUEqual
[16] http://bit.ly/2P6hlqP
[17] https://multispeciesdementia.org

4

Prevention

Professor Craig Ritchie
Theme Lead

This theme is focussed on the prevention of neurodegenerative diseases and their progression to develop symptoms as observed in dementia. This theme covers all types of prevention, which is also considered in three stages. Stage 1 is Primary Prevention where we try and stop the disease starting in the first instance. Stage 2 is Secondary Prevention where we try and stop symptoms developing when disease has already started and Stage 3 which is Tertiary Prevention when we try and help people with symptoms not to progress to more advanced stages of dementia.

To achieve this we need to understand how the diseases start and progress relative to risk factors and what features in the brain (biomarkers) and symptoms (for example, memory) emerge, and in what order, to indicate the disease is progressing. With this knowledge we can identify people at high risk of disease and plan interventions to reduce the likelihood of progression and hence prevent decline.

Work happening in theme

This theme benefits from access to some of the most complete datasets anywhere in the world to create what we refer to as disease models. These include the Lothian Birth Cohort, Aberdeen Children of the 1950's Cohort, European Prevention of Alzheimer's Disease (EPAD) and PREVENT Dementia. We are also planning to complement these research cohorts with real world data collected in the Scottish Brain Health Register (see SDIP theme) which can link to medical records.

As well as developing disease models, this theme is seeking mechanisms to make it easier to use risk prediction tools in clinical practice, which will be facilitated in Scotland by the establishment of Brain Health Clinics.

As well as the technical application of the research output, this theme is developing work to look at the impact and ethics of risk disclosure to people who may be many years from being diagnosed with dementia. At the same time modelling, application and ethical considerations are key to achieving the successful use of this new knowledge to benefit all communities.

This theme also undertakes work to ensure that the results and application of our findings can feasibly be implemented by all communities globally. We have a special interest in working with Low and Middle Income countries through our association with Alzheimer's Disease International.

This theme draws heavily on all the other SDRC themes. Many of the early career researchers are working across at least two themes when working on dementia prevention and maintenance of brain health.

5

Scottish Dementia Informatics Partnership

Professor Craig Ritchie
Theme Lead

The Scottish Dementia Informatics Partnership (SDIP) is a national incentive to integrate and make use of clinical and research data for people living with dementia in Scotland. Specifically, by creating an online database for research (also known as a data commons model), the SDIP project aims to increase researchers' accessibility to a high-quality, population dataset of people living with dementia, or who are at risk of dementia. Moreover, as a partnership, it is explicitly a collaboration between organisations who can use and research this dataset and those who can develop it through new technologies and informatics techniques.

The Scottish Brain Health Register (SBHR) represents the foundation database for SDIP. SBHR is designed to work within memory and brain health clinical services across Scotland to connect people who attend these services to research opportunities, and in turn provide a singular database that can hold the individuals' demographic, clinical and research information

Work happening in theme

SDIP has been established in NHS Lothian as a joint venture between the University of Edinburgh, NHS Lothian and Alzheimer Scotland, where the former two act as joint data controllers, and the latter as the governing institution, hosting the SDIP Executive Committee and Partnership Board.

The SDIP is then embedded within Brain Health Scotland, which is a new coordinating entity to be launched in April 2020 as part of the Programme for Government. The role of Brain Health Scotland is to lead, coordinate and support actions which ultimately yield a reduction in the number of people who get dementia in Scotland. This will be achieved by the coordination of activity within 3 pillars: [1] Research (SDRC), [2] Clinical (including public health) and [3] Informatics (SDIP). In practice this means that there is a meaningful connection between research studies, the data they generate, and how they are interpreted and analysed to improve clinical care. It also means that the data generated from clinical care can be used as though generated from a real-world research study.

SBHR's integration into clinical services is a critical part of SDIP's success. To ensure that the register fits within current practices, a study took place to investigate current practice with research registers within a memory service in NHS Lothian. A series of findings, recorded from clinic staff, demonstrate that there is an opportunity for the benefits of research to be better communicated to clinic staff, which in turn will encourage people to consider their options and has potential to increase recruitment onto research registers. This has led to the production of a specific approach that will be put into practice across other services in Scotland.

At a national level, the SDIP team is working with Alzheimer Scotland to canvas the Scottish public's opinion about dementia research. Following on from work by Krista Winkler (see Early Career Researcher Spotlight), we are asking the extended Alzheimer Scotland membership what their priorities for dementia research are, when they would like to hear about research, and from whom.

Together, these pieces of work will inform researchers on how to bridge the gaps between research, clinical services and the general public. This will help facilitate the flow and exchange of research activity, and therefore information, between these three sectors of the population. In this way SDIP can represent the population of people living with, or at risk of, dementia through SBHR.

The SDIP team has also begun evaluation of specialist diagnostic technology: Combinostic's cNeuro modules cMRI and cDSI. These are cloud-based programmes which automatically read magnetic resonance imaging (MRI) scans, provide the estimated probability of different types of diagnoses and produce reports that detail the sizes of different parts of the brain. cNeuro has been made available to NHS Lothian SBHR registrants and is now offered as part of their clinical care. The current evaluation work is focussed on the degree to which these approaches are feasible, acceptable and useful for clinicians, radiologists, radiographers and researchers.

Looking to the future

SDIP continues to work with the Neuroprogressive and Dementia Research Network, which is part of the NHS, so that the SBHR can be offered to as many people attending memory clinics and services as is possible. The SBHR will be extended to NHS Lanarkshire, Greater Glasgow and Clyde, Grampian and Tayside. As we roll out to wider Scotland, we also want to understand the challenges associated with collecting and integrating data in remote areas that may use different IT systems or forms of record-keeping.

SDIP continues to align with the NHS Education Scotland Digital Service (NDS), which is committed to the review and consolidation of digital healthcare services and information across Scotland. The SDIP project acts as a proof of concept for data integration for the specific population of people living with and at risk of developing dementia, and in turn can be linked to the national routine health and social care data made more accessible by NDS.

SDIP will hold biannual stakeholder forums in March and September 2020. The team will use these events to showcase the project's capabilities to members from research institutions and the pharmaceutical industry to ensure that the project can address stakeholders' questions that can only be addressed through population-level data.

Informatics is the focus of the SDRC Annual Conference "Unlocking the Mysteries of Data".

Early Career Researchers Spotlight

Angela Gregory

I joined the Alzheimer Scotland Centre for Policy and Practice (ASCPP) as a PhD student at the University of the West of Scotland in August 2019. My studentship is jointly funded by Erskine Care and Alzheimer Scotland.

After graduating with a first-class Bachelor of Arts (Hons) Three-Dimensional Crafts in 2000, I set up my own business working as a community Freelance Artist/Educator. I then completed a Post-graduate Certificate in Arts and Cultural Heritage in 2003. After the death of my mum in 2013, I decided to combine my love of creative 'doing', and passion for empowering people to live (as opposed to merely exist) by re-training as an Occupational Therapist.

I achieved a distinction in Master of Science, Health through Occupation in 2014 where my love of research was sparked. After working for five years in various settings as an Occupational Therapist, I decided to embark on a PhD.

My PhD research will explore meaning in activity with people with advanced dementia, their families and care home staff via an action research, arts-based, embodied and sensory approach.

I see myself becoming specialised in using arts-informed action research with people with advanced dementia and integrating this knowledge into clinical practice, education and care establishments.

Jennifer Waymont

I am a final-year PhD candidate at the University of Aberdeen, working towards a PhD in Medical Imaging. Prior to this, I obtained a BSc in Psychology with Clinical and Health Psychology, an MSc in Psychological Research, and a further MSc in Neuroimaging, all at Bangor University in North Wales.

My PhD title is 'Automated detection and analysis of life-course determinants of brain white matter hyperintensities in healthy ageing and in Alzheimer's Disease'. White matter hyperintensities (WMH) are a common brain magnetic resonance imaging (MRI) finding in older adults, arising from advancing age and cardiovascular risk factors, and contributing to cognitive decline, dementia, stroke, and death.

This project has included validating an open-source algorithm to detect WMH, exploring risk factors for, and outcomes of, increased WMH burden in later-life, and better understanding the association between WMH and Alzheimer's Disease (including exploring potential pharmaceutical interventions to reduce WMH burden).

I aim to complete my PhD in the coming months, after which I hope to continue to pursue a career in academia. I am interested in further exploring how life-course psychosocial and lifestyle factors influence brain health in later-life. I am especially passionate about early-intervention, risk reduction, and prevention of diseases that cause dementia.

Martha Pollard

I am currently undertaking a PhD studentship funded by the Alzheimer Scotland Dementia Research Centre at University of Edinburgh.

I have an undergraduate degree in psychology and an MSc and PhD in Public Health Sciences, focussing on the epidemiology of cardiovascular disease. From there I moved to cognitive ageing research in the Lothian Birth Cohort studies and lectured in psychology from 2001-2009. During this time, many unpaid carers of people living with dementia told me of their difficulties of finding the care they needed.

Stepping out of academia, I took up agency care work. I then moved into emotional and social support roles in the charity sector, where I developed friendship groups and creative engagement with people living with dementia and carers in programmes at the Eric Liddell Centre. I also volunteered as a befriender with Alzheimer Scotland.

Looking to deepen my emotional support work, I started training as a counsellor in 2016 and am on course to qualify this year. My current PhD studentship fits ideally with my urge to contribute to understanding of, and insights into living with dementia. My current research is in conjunction with the Edinburgh Centre for Research on the Experience of Dementia (ECRED), also at the University of Edinburgh. I am exploring dementia and freedom in psychiatric settings (specialist dementia units), from four perspectives: people living with dementia; unpaid carers/family members; medical/social care staff, and chaplains.

My aim is for closer integration of my community-based, counselling and academic work, all focussed on ways to maximise freedom and flourishing for people living with dementia and carers: and for everyone.

Juan Varela

My academic background is a mixture of physics, nanomedicine and neuroscience. I was initially trained in experimental physics in Uruguay and did my PhD in nanomedicine in Ireland. I am now a Principal Investigator at University of St Andrews, funded by a European Research Starting Grant.

As my interest in neuroscience became stronger, I moved to France with a Marie Curie fellowship where I developed new strategies to study living brain tissue at the nanoscale. I subsequently took up another post-doctorate role in Cambridge working on optical methods to study protein aggregates involved in Alzheimer's disease and Parkinson's disease. In 2018 I started my own laboratory in St Andrews.

My lab studies the way small protein aggregates involved in neurodegeneration are cleared from the extracellular space of the brain, as well as the interactions of these aggregates with receptors in neurones. Understanding the basic physiology of the extracellular space of the brain has been very challenging due to the lack of biophysical methods able to study such a complex space shaped at the nanoscale. It is for this reason that we are developing new optical methods that are suitable to undertake these challenges.

I aim to understand how the extracellular space of the brain influences the development of neurodegenerative diseases. Once we understand the basic physiology and what goes wrong in neurodegeneration we will be able to design strategies to improve clearance of toxic protein aggregates that induce neurodegeneration.

Clarisse de Vries

I started my academic career in 2015 during my MSc in Medical Physics. During the final MSc project, I investigated the relationship between the klotho gene, brain structure and survival in the ageing brain. My interest in science was sparked, and I embarked on a four-year PhD.

I continued with my work on the klotho gene, which led to two publications. I also worked on a measure of brain complexity, extracted from brain activations. I found that motion causes artefacts in brain complexity maps. I also found that women had greater brain complexity than men in the frontal lobe, and that brain complexity decreased with age in several regions located deep in the brain. In addition, I created a user-friendly interface so that other researchers will be able to use the complexity measures I have developed.

I submitted my PhD thesis last September, and passed my viva/oral examination on the 16th of December.

I have just started my new role as an iCAIRD Radiology Imaging Research Fellow. iCAIRD stands for Industrial Centre for Artificial Intelligence Research. It is a Scotland-wide project which aims to employ artificial intelligence (AI) in healthcare to aid diagnoses and alleviate NHS shortages.

I am currently working on developing and implementing AI systems focussed on applications for the brain. My aspirations are to continue my research into brain health and the effects of brain ageing, and to improve scientists' and the public's understanding of the brain.

Luisa Parkinson

I am in my second year of my PhD in the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh, investigating environmental risk factors for dementia.

Prior to this I gained my undergraduate degree in Veterinary Medicine and Physiology at the University of Cambridge and worked both in first opinion practice and clinical research.

Dementia is a complex condition, with genetics, lifestyle and environmental factors all playing a role in whether an individual develops it. There is also a variation in your risk of developing dementia based on where you live. My project aims to explore the amount of this geographic variation that is explained by environmental factors and whether the effects of environmental factors are stronger in a specific life period, such as childhood, or are cumulative over a lifetime.

I am currently investigating how different spatio-temporal modelling methods affect the results of an analysis using data on deaths with dementia in Scotland. The aim is to better understand how arbitrary modelling decisions influence the results and how best to minimise these effects to ensure that the results are robust. There are several areas where legislators feel that the evidence linking environmental factors to dementia is currently insufficient to allow them to bring in new policies.

If my PhD project could add to the evidence and help to get legislation in place to reduce the risk of developing dementia for future generations, that would be a fantastic outcome.

Krista Winkler

I completed my MSc in Clinical Trials in November 2019. My dissertation centred on the public's current perception of dementia and dementia research. I developed an expert-validated questionnaire to gather data on the public's experience with dementia, their knowledge of dementia as a disease, their perception of dementia research, and their concerns (if any) regarding data collection during studies. I am now working on publishing my Master's thesis as an article.

A few months ago I moved to the south of Germany. This area is a hot spot for pharmaceutical companies and research companies. I hope to work with clinical trials and advance my research in the areas of dementia and cancer in particular.

I am now on maternity leave. I have most recently worked at a wholesale pharmaceutical company in Berlin, while reading in parallel for my Master's degree part-time via distance learning at the University of Edinburgh.

Prior to this, I graduated from the B.Pharm course in Malta in 2011, my Bachelor's thesis abstract was published in the journal Rheumatology.

I hope to use my time on maternity leave for academic purposes and would also be open to more academic research in the future if opportunities arise.

Suzanne Gray

I am currently a mental health nurse lecturer at the University of the West of Scotland, Paisley. My professional interests include the mental and physical well-being of older adults, professional issues and evidence-based practice.

Having had over 30 years' experience as a mental health nurse, latterly supporting younger people with dementia, I achieved an MSc in Dementia Studies from Stirling University and decided to move into an academic role and undertake further study at doctoral level regarding one of the most challenging clinical issues I had encountered whilst supporting younger people with dementia.

I am a Clinical Doctorate student in the Faulty of Health Sciences and Sport at the University of Stirling. My study aims to investigate the experiences of living with a diagnosis of frontotemporal dementia (FTD) from the perspective of the person and to identify factors which help and hinder the person living well with FTD, in order to inform clinical practice.

The data consists of 13 semi-structured interviews of 7 people with a diagnosis of FTD. Participants were recruited via third sector services across central Scotland. An interpretative phenomenological analysis (IPA) approach was adopted and themes have emerged. They are diagnosis, assessment and support; experience of support throughout the journey; the changing self; challenges of living with FTD; strategies for living; someone there. Currently, I am writing the draft thesis and hope to be able to submit by the end of 2020.

In the future, I am hoping to continue to build upon my current research and strengthen networks with others in order to collaborate in future research projects.

Mapping Scotland's key contribution to global dementia and brain health research

The SDRC has updated the extensive mapping exercise of Scottish research for 2019. This includes all dementia disciplines over the past five years and covers the key areas of number of active researchers, grant awards and publications.

The results once again demonstrate the significant contribution and key position of Scotland to global dementia and brain health research over the past five years. Scotland has been awarded 270 grants totalling £113 million of funding during this time.

We have had 721 active dementia researchers over the last five years, with an additional 148 PhD students. They are working across all disciplines of dementia and brain health research and are presented here within the SDRC themes.

We provide an analysis of the 2019 data below and comparison to the data for the past five years where appropriate.

Funding levels and sources

In 2019, there were around 50 grant awards totalling just over £20m received by Scottish-based dementia and brain health researchers. Figure 1 shows that whilst this is an increase from the previous low of 2018, it has not exceeded or returned to the level of previous years.

Figure 2 illustrates how the grants were distributed between the research themes in 2019. This shows that Prevention has overtaken Fundamental Science as the theme receiving the largest proportion of grant funding for the year.

Figure 3 shows the pattern of an increasing proportion of grant funding going to informatics research and the Scottish Dementia Informatics Partnership theme. Informatics research can often fall into other themes, but this growth in funding demonstrates that data research is becoming a more prominent field of research in its own right.

Living with Dementia has enjoyed its largest share of investment ever in 2019. We would hope this is the start of a trend towards greater investment in supporting people who are living with dementia today.

Figure 4 shows where the resources come from, with most funding from sources within the rest of the UK. However, there is also a substantial proportion of grant income coming from international sources, particularly the USA.

Figure 5 shows the patterns over the past year. Funding from the European Union has declined in 2019 compared to previous years.

Figure 6 shows the proportion of money received from the different types of funding organisation. It highlights that the largest proportion has come from charitable organisations.

Figure 7 demonstrates that whilst a significant amount of grant funding has always come from charitable organisations, the proportion in 2019 is the highest over the past five years. It was also the lowest investment from governmental organisations over the last five years.

Figure 1: Grant award funding by year

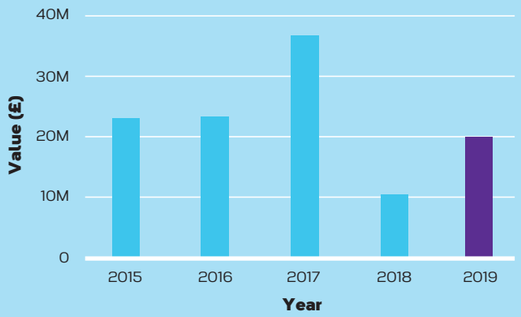


Figure 2: Proportion of grant awards by theme in 2019

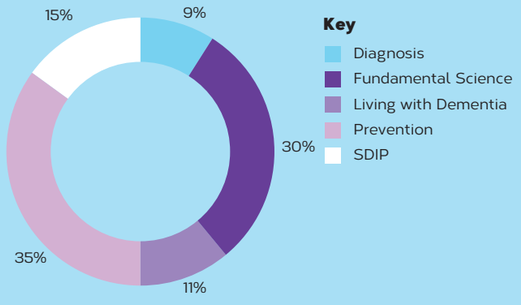


Figure 3: Grant funding by theme from 2014

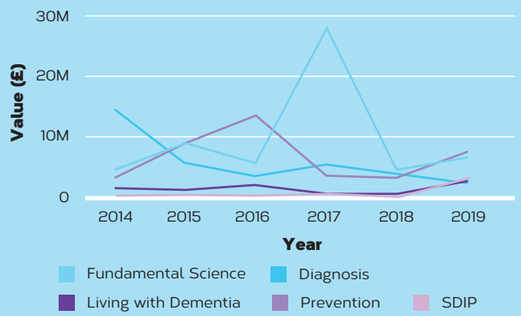


Figure 4: Proportion of grant by source country/ region in 2019

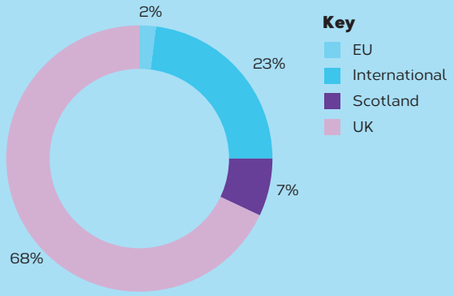


Figure 5: Funding by source country/region over five years

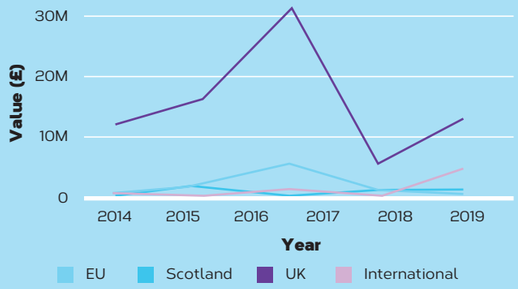


Figure 6: Funding source by type of organisation

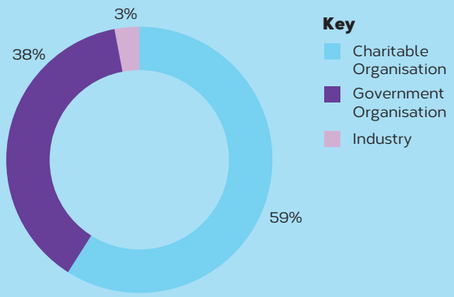
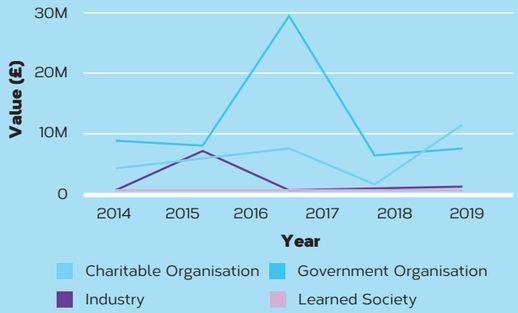


Figure 7: Funding patterns by source organisation over five years



Researchers in Scotland

In 2019 there were 296 Scottish-based researchers that have either contributed to a research paper or been part of a grant award related to dementia and brain health. Figure 8 illustrates how they are spread across the research themes. The largest proportion of researchers are within the Prevention theme, which has now overtaken Fundamental Science and highlights that it is an area of growing importance for investigation.

Figure 9 highlights the proportion of researchers at each phase of the research career pathway. This demonstrates the wealth of experienced and early career dementia and brain health researchers.

The Figure 10 shows the proportion of PhD students by theme in 2019. There were 148 students working towards their doctorate in 2019 across dementia and brain health research. Of these students, 24 have either contributed to a paper or been part of a successful grant application. This is encouraging for the future of research, particularly in Living with Dementia and Prevention themes, where there are significant numbers of students being trained in these areas of study.

Figure 8: Proportion of active researchers and PhD students by theme for 2019

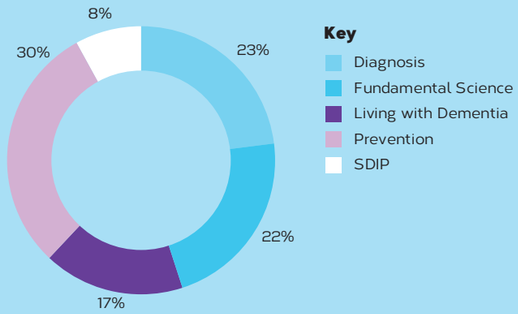


Figure 9: Researchers by stage of career for 2019

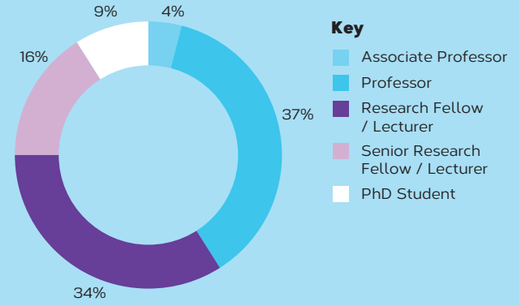
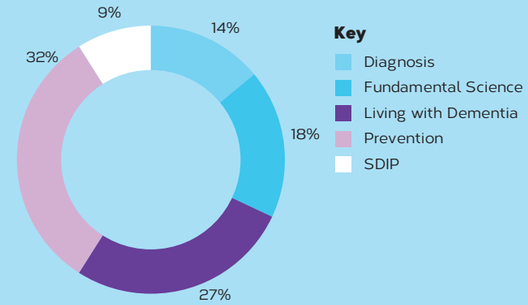


Figure 10: PhD students by research theme for 2019



Published Papers

The level of research output was analysed through the publications produced by our research community in 2019. Figure 11 shows a total of 220 papers and a breakdown by theme. Consistent with other areas of the mapping data, Prevention is making great strides across all the key indicators.

Figure 12 compares the level of 2019 output to previous years. While the number of published papers remains high, the output from 2019 is slightly lower than the previous two years. We will continue to monitor these figures in future years to establish a fuller picture and understand the pattern.

Figure 11: Number of publications by theme in 2019

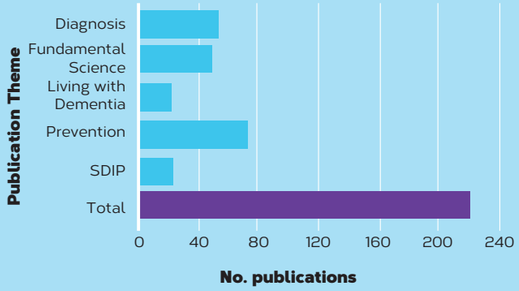
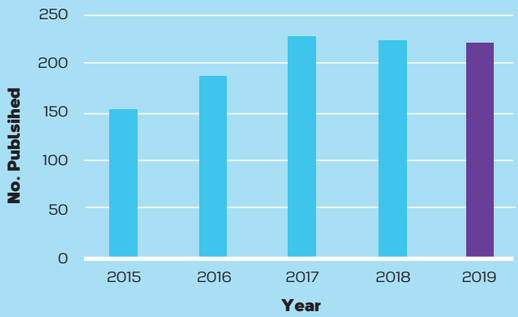


Figure 12: Number of publications by year



International Collaborations

Figure 13 highlights that Scottish based researchers value the importance of international collaborations. Much like previous years, this shows that Scottish-based researchers are building relationships and working with researchers all over the world.

In 2019, there were a total of 362 collaborations with 252 researchers across 33 countries.

Every SDRC theme collaborates with international colleagues. However, Figure 14 demonstrates that the level of international collaboration varies across themes. Over three quarters of collaboration with researchers outside of Scotland is within the Diagnosis and Prevention themes.

Figure 15 highlights that Scottish-based researchers collaborate most frequently with researchers within the UK rather than any other country. However, collectively researchers in Scotland collaborated more with researchers in the European Union and Internationally.

This highlights that our researchers are very much embedded within the global dementia and brain health research environment.

Figure 14: Proportion of international collaborations by theme

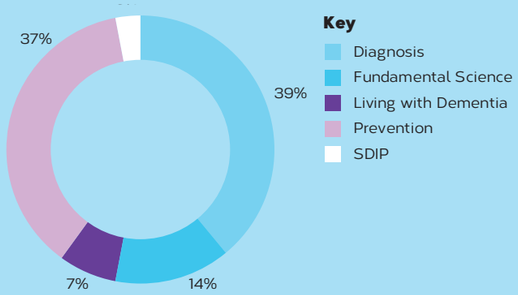


Figure 15: Proportion of collaborations by region

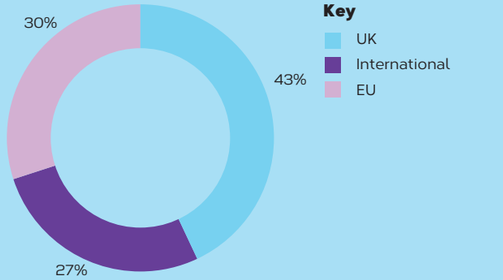


Figure 13: Number of international collaborations by country

USA	52	Netherlands	23
Canada	19	Spain	16
Australia	12	Germany	14
Brazil	4	France	8
Argentina	3	Switzerland	7
India	3	Sweden	6
Japan	3	Austria	5
Norway	3	Denmark	4
Chile	2	Italy	4
China	2	Belgium	2
Colombia	2	Ireland	2
Singapore	2	Poland	2
Botswana	1	Finland	1
Mexico	1	Portugal	1
Uruguay	1	Slovenia	1
International Total: 110		**European Union Total: 96**	

Feedback from the SDRC Conference 2019

The fourth annual Scottish Dementia Research Consortium (SDRC) conference was held at the Radisson Blu in Glasgow on Monday 15th April 2019.

The conference was focussed on the SDRC theme of Fundamental Science and was chaired by our Executive Committee member Professor Frank Gunn-Moore.

Professor Giles Hardingham, University of Edinburgh, answering audience questions

Professor Frank Gunn-Moore, SDRC Executive Committee member, was the Conference chair

The 2019 conference was the biggest yet for the SDRC. Around 200 members attended including researchers at all stages of their careers and people from a wide range of professional and personal backgrounds who all shared a common interest in dementia research. We were also delighted, and very grateful, that representatives from the two campaign groups that work very closely with the SDRC; the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) had a strong representation at the conference.

The conference aim was an exploration of the new, and often unusual, ways that researchers are learning more about dementia and working to identify potential treatments.

The programme showcased research taking place in laboratories across Scotland, featuring speakers that are world-leaders in their field. Researchers from a range of disciplines presented their work, from quantum physics, to neurodegenerative disease in cats and what that has taught us about the human brain.

In addition to presentations from established researchers, the conference provided a platform for PhD students, postdoctoral researchers and others at the earlier phase of their career. This section reflected the full range of SDRC research themes.

Outside of the main hall, delegates had plenty of opportunity to enjoy the exhibitions and posters, network, share their ideas and connect with potential future collaborators. The 2019 Conference also introduced the "Cohort Corner", where the world-famous longitudinal studies, such as EPAD, PREVENT and the Lothian Birth Cohort, had stands to showcase how Scotland is leading the way in large scale population studies.

The Conference was a fantastic success with great feedback from our delegates. We thank all the speakers, presenters and everyone who came along who made the day so memorable. We are also very grateful for all the feedback we received which was overwhelmingly positive. Not only do we hope to build on this success for the 2020 conference, but to organise more events in the year ahead to help researchers network and encourage collaboration across institutions and disciplines.

The conference provided opportunity for delegates to network and share ideas

The SDRC Conference 2019 was the biggest yet

Message to membership

Carleen Smith–SDRC Officer

I am very pleased once again to have this opportunity to give you an update of the SDRC activity throughout 2019 and what we can look forward to in the year ahead.

Much like last year, supporting the SDRC with the mapping of dementia and brain health research activity in Scotland has been a core part of my role. I am once again amazed at the quantity, quality and diversity of research happening throughout the country, as demonstrated in this report. The SDRC Executive Committee will continue to use what we have learned to identify opportunities to grow research capacity in all disciplines.

Another key ambition of the SDRC is to promote the research activity of our community of researchers. Our website visits and social media following is growing, which is helping to broaden the SDRC's reach. One of the highlights of the SDRC's online activity in 2019 was our early career researcher blog series, which had an amazing response and has been some of our most popular content so far. We want to continue to promote early career researchers through our online channels, so look out for more of these blogs in 2020.

We were also able to support our early career researchers through funding. It was a great achievement of the SDRC in 2019 to collaborate with the Scottish Neurological Research Fund (SNRF), when we administered over £130,000 in grant awards. Given this success, the SNRF are planning to roll this funding out again. Please keep a look out for the announcement of the funding cycle in the coming months!

This year will see a new addition to the conference programme, with a second day workshop to support early career researchers to write funding applications.

Like last year, I will continue to support the SDRC in their commitment to providing a platform for the voices of lesser heard groups. The SDRC wish to ensure people with dementia and their families are at the forefront of everything we do. Throughout the report there have been so many examples of this engagement. For the SDRC generally, we have established a research subgroup within the Scottish Dementia Working Group and National Dementia Carers Action Network, and we will continue to expand this engagement over the next year.

In 2019 I was also fortunate enough to help organise and attend my first SDRC conference, a summary of which is featured in this report. I was delighted that it was our biggest yet and I look forward to building on this success for 2020.

The past twelve months have seen the SDRC achieve so much. I have enjoyed the opportunity to support this success and, once again, I would like to extend my deepest gratitude for the tremendous guidance of the SDRC Executive Committee and colleagues at Alzheimer Scotland.

Finally, I would like to thank the SDRC members for being so active and engaged in the past year. The SDRC exists for our members, and we want it to be as accessible and open as possible. I encourage members to get in touch with me with ideas of how we can grow together to build the SDRC further in 2020 and beyond.

Become an SDRC member today

The SDRC is open to everyone who is taking part or is interested in dementia and brain health research.

There are many benefits to being an SDRC member. These include:

- Invitations to attend members only events to discuss dementia research
- Linking and networking with other members
- Opportunities to showcase your research and current projects to a wide audience
- Gain career advice from world leading dementia researchers

If you would like to become a member, please visit www.sdrc.scot/join

Scottish Dementia Research Consortium

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