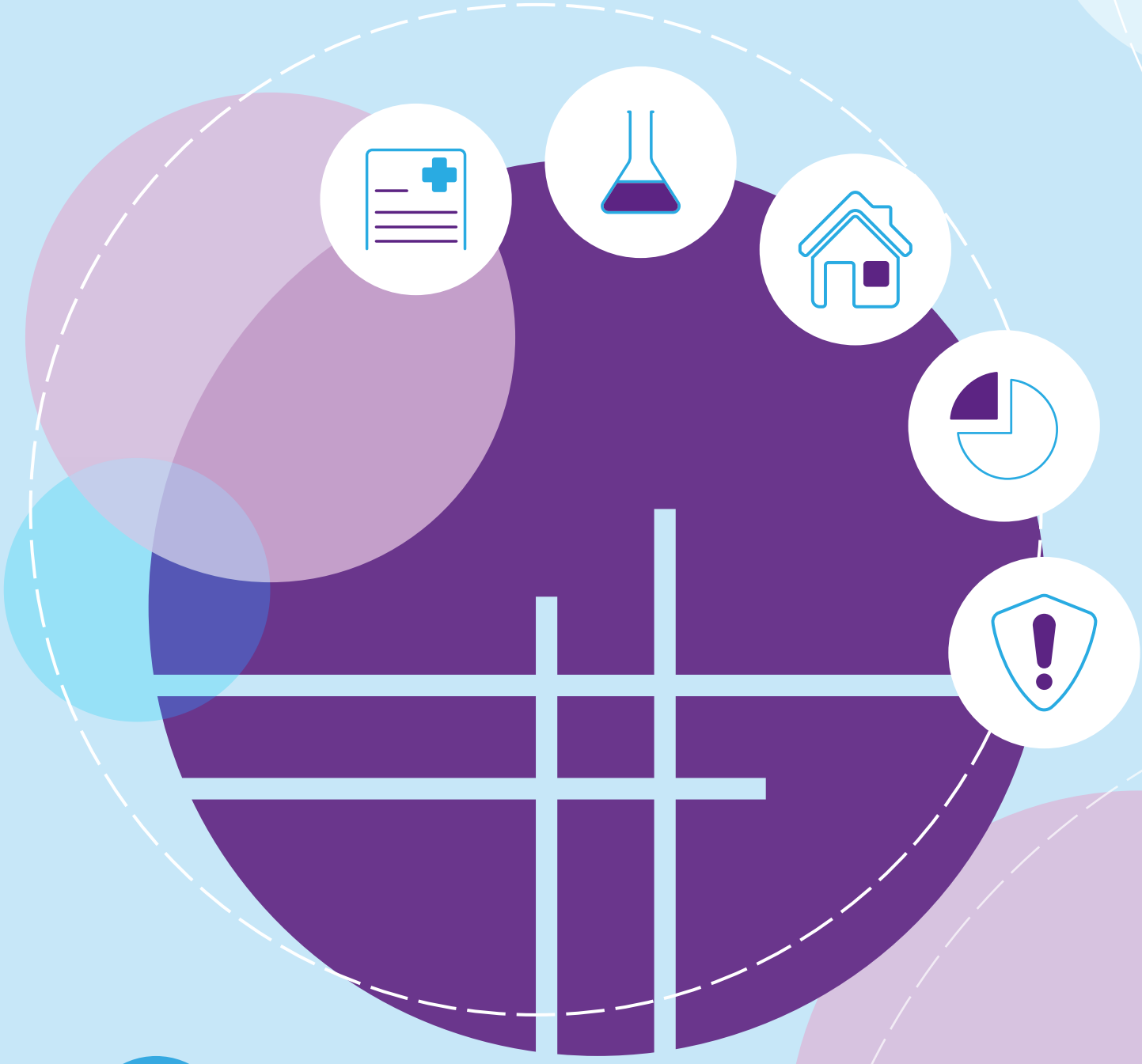
Scottish Dementia Research Consortium

Annual Report 2020/21



Scottish Dementia Research Consortium

Alzheimer Scotland
Action on Dementia

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Foreword

National Dementia Carers Action Network (NDCAN)

Marion Ritchie

The National Dementia Carers Action Network (NDCAN) was established in 2011 and exists to make the voices of carers heard, and to raise awareness of the issues that impact on their lives. Our members are all carers or former carers of people living with a diagnosis of dementia in Scotland. We understand and value the importance of the Scottish Dementia Research Consortium's work and appreciate the opportunity for carers to be involved in this and have our voices heard. NDCAN has a research subgroup that has given our members the chance to not only learn about different research approaches, research theories and ethics, but to become researchers themselves and develop their own research projects in collaboration with professionals from the University of the West of Scotland (UWS). The value of this cannot be underestimated. On behalf of NDCAN I would like to congratulate the SDRC on yet another successful year and we look forward to working together in the future.

ndcan
National Dementia Carers Action Network

Scottish Dementia Working Group (SDWG)

Archie Noone

The Scottish Dementia Working Group (SDWG) is a member led, national campaigning and awareness raising group, for people living with a diagnosis of dementia in Scotland. We have always viewed research as a priority and fully support dementia research in Scotland, and indeed internationally. The SDWG has their own Research subgroup that meets regularly to keep members informed of the latest developments in research, and also to give members the opportunity to participate in research projects. We believe that it is vital to have the voices of people with dementia included in the conversations around dementia research. As people who have a diagnosis of dementia, we are the ones with the invaluable lived experience. On behalf of the SDWG, I would like to congratulate the Scottish Dementia Research Consortium on their annual report and yet another year of great work.

the scottish dementia working group
run by people with dementia

Welcome

Prof Craig Ritchie– Chair, Scottish Dementia Research Consortium

The 2020 Annual Report of SDRC covers a year like no other and hopefully one that we never have to go through again. The impact of COVID-19 on people living with dementia was undoubtedly more severe than any other clinical population and the challenges faced by people living with dementia in care homes and their loved ones was tragic. The repercussions of this will play out for many years and must lead to changes that mean this won't happen again. I read somewhere that the COVID pandemic 'amplified' many aspects of life and society. The impact on dementia relative to other diseases was one such 'amplification', others being the huge disparity of harm from the virus on people living at different ends of the socioeconomic spectrum and between different ethnicities.

In Spring 2020, the SDRC Executive and Principal Investigators across the country in labs as well as clinical and social care settings witnessed another disproportionate impact, this time on our Early Career Researchers. Tenured, senior academics were more likely to 'weather the storm' but the so highly valued next generation were foreseeing delays to their studies that could scar their future careers. An SDRC Survey in spring 2020 allowed the SDRC Executive to have 'data' to present to the Scottish Government and Chief Scientists Office to help support this group. It also helped the Executive to form a response that led to a series of initiatives that were packaged into an SDRC Early Career Researcher Programme: Webinars, Mentorship Programme, Rapid Response Funding (thanks to a donation from Brain Health Scotland) and the offer of Internships. More will be done on this programme in the years ahead.

It was clear that grant funding was going to be hard to come by as charitable funders found their financial power massively compromised. But, to compensate for the time away from the lab or recruitment, our researchers busied themselves publishing. To see a roughly 50% increase in academic outputs in 2020 compared to 2019 is perhaps the strongest marker of any in this report of the determination and resilience of our research community.

In spring 2021, society, our clinics, labs and research centres opened again and already we are seeing a return in our activity to pre-COVID levels. Scotland remains a Centre of Excellence for Brain Health and Dementia Research, our SDRC membership has increased, we have reinvigorated the executive, we are working very closely with Brain Health Scotland and continue to grow our strengths in fundamental sciences, social science, applied research and informatics and technology. Our prevention research (the theme of the 2020 conference) dovetails with the 'research into practice' in Brain Health Services, Public Health Campaigns and Policy being driven forward by Brain Health Scotland. Between these two organisations we have written what we believe is one of the first, if not the first, Brain Health and Dementia Research Strategies in the world. The light at the end of the tunnel is shining very bright.

2020 was a truly horrible year with so much pain for so many across the world – a lot of it wholly unnecessary in the UK. Our responsibility though lies with people with dementia, their loved ones and those professionals who provide care for them. Our responsibility as researchers is to make sure that what happened never happens again. "Follow the science"... We need to create that science for others to follow: advocacy, better treatments, early and accurate diagnosis, better care, prevention and using data for surveillance are all critical scientific endeavours to ensure we have the credible evidence to amplify our voices for those who maybe couldn't or wouldn't hear us last time.

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 the 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.

Dr Mario Parra Rodriguez

Mario graduated as a Medical Doctor in 1993 and as a Clinical Neurophysiologist in 1997. He worked at the Cuban Neuroscience Centre and at different University Hospitals in Cuba and in Colombia.

Mario was as an Assistant Professor in Psychology at Heriot-Watt University, Edinburgh from 2015 until 2018. He is currently a Lecturer in Psychology at the University of Strathclyde, Glasgow.

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 a 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.

Dr Tom Russ

Tom trained in medicine and psychiatry in Edinburgh, the Highlands, and London and completed a PhD in dementia epidemiology at the University of Edinburgh.

He is a Consultant Psychiatrist in NHS Lothian, Network Champion of the NRS Neuroprogressive and Dementia Network, and Director of the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh

Stina Saunders

Stina is a PhD student at the University of Edinburgh carrying out a longitudinal cohort study looking at risk disclosure in the mild cognitive impairment population. This work stemmed from the European Prevention of Alzheimer's Dementia (EPAD) programme. In addition to this, she works in clinical trials for Alzheimer's disease at the University's Centre for Clinical Brain Sciences.

Dr Terry Quinn

Terry holds the post of Senior Clinical Lecturer and Honorary Consultant Stroke Physician in the Institute of Cardiovascular and Medical Sciences, University of Glasgow. He is passionate about evidence-based practice and raising standards in clinical research.

Terry has a broad research portfolio, which he combines with active teaching and clinical commitments.

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.

Dr Sophie Bradley

Sophie is the newly appointed Senior Lecturer based at the University of Glasgow. Sophie's research group is focused on determining the impact of pharmacologically targeting members of the G protein-coupled receptor (GPCR) superfamily in neurodegenerative diseases.

In 2021, Sophie was awarded the Alzheimer's Research UK David Hague Early Career Investigator of the year award for her work in this area.

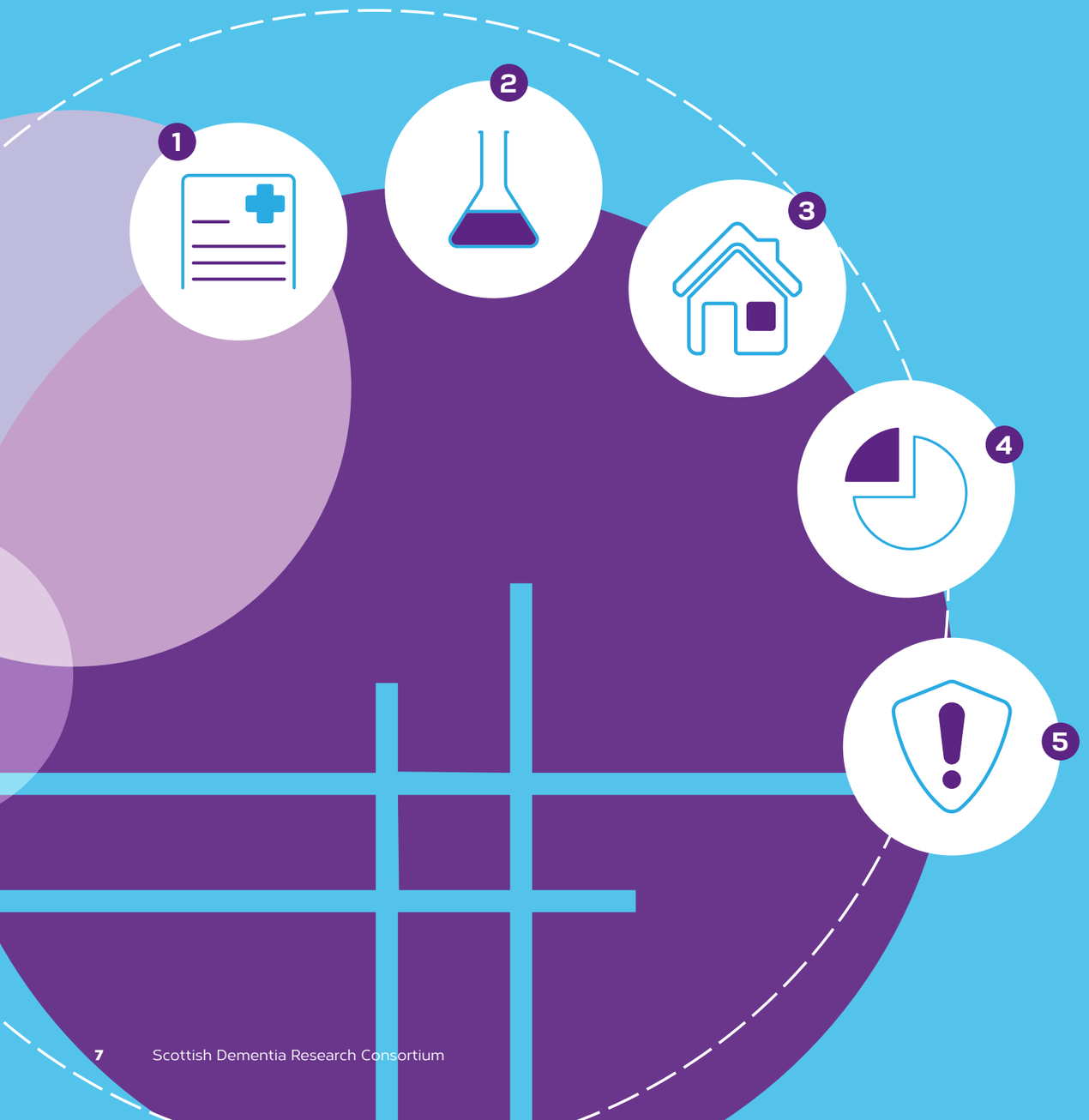
Report introduction

Our Annual Report 2020/21 provides an update of SDRC Activity from each of our research themes. We also present the results from our mapping of all dementia and brain health research in Scotland from 2020, including grants awarded, papers published, and extent of collaboration with researchers outside of Scotland. In addition, we feature profiles of a number of early career researchers, feedback from the SDRC 2020 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 631 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, support early career researchers, and, as always, ensure the voice 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. Informatics
5. Prevention

1

Diagnosis

Theme leads
Dr Terry Quinn and Prof Alison Murray

This theme is focused on the evaluation of new tests and improving our use of established tests. Early and accurate diagnosis is a crucial first step in managing dementia. If diagnosis is done well, it can help people make sense of symptoms, select the right treatments and plan for the future.

The theme is not only concerned with the diagnosis of dementia syndromes. Tests and assessment are important at all stages of the dementia journey, from biomarkers to look for the earliest signs of brain health problems, through to assessments that help us treat and monitor people living with advanced dementia.

One of the real strengths of Scottish dementia research is our track record of bringing together experts from very different areas to work in collaboration. This is especially true in diagnosis research, and the theme is proudly multi-disciplinary. Within our remit is everything from technical development of new brain scan protocols through to studies of how to share a potential dementia diagnosis with a person and their family.

Work happening in theme

There is so much activity around diagnosis and assessment that there simply isn't enough space to highlight all the recent excellent, Scottish research. In the section below are some exemplars of the diverse nature of the diagnosis theme.

The digital and informatics revolution brings major opportunities for early diagnosis and assessment. However, as with all new technologies, digital assessments should be assessed with the same scrutiny and rigour that we would apply to any other intervention. We have excellent examples of this in Scotland, for example the Industrial Centre for Artificial Intelligence in Digital Diagnosis (ICAIRD) is a collaborative funded by Innovate UK that looks to improve radiology and pathology. Scottish ICAIRD is one of five UK Artificial Intelligence centres and dementia is one of the main research priorities.[1]

In the diagnosis theme we are equally interested in cutting edge new technologies and better use of existing assessments. Again, Scotland is leading in both fields. The establishment of a high field (7 Tesla) MRI scanner in a busy NHS hospital has been a major achievement for University of Glasgow and NHS Greater Glasgow and Clyde. The scanner gives an unprecedented level of detail in brain imaging and will support precision diagnostics.[2] A new approach to MRI brain scanning is also being developed in University of Aberdeen with their fast field cycling MRI work.[3] For more traditional diagnostics, the PICTURES project is a partnership between University of Dundee, University of Abertay and NHS Scotland that takes NHS clinical scans and makes them research ready as a resource for future scientific projects.[4]

We continue to learn about brain health and dementia through large cohorts of volunteers who have allowed repeat brain scans and cognitive assessment. Projects such as the Lothian Birth Cohort offer unique insights into brain ageing, while new projects such as the multi-centre R4VaD study (Rates, Risks & Routes to Reduce Vascular Dementia) led by University of Edinburgh allow for creation of new cohorts in specific disease areas.[5]

We can't have an annual report that doesn't mention COVID-19. The global pandemic has changed every aspect of dementia care, and diagnosis is no exception. Research projects have had to adapt, sometimes in a very short space of time. For some projects, we had to change our cognitive assessments almost overnight when lockdown was announced. One of the major changes we have seen is a move away from face to face assessment and much greater use of postal questionnaires, telephone and video calls. Here, clinical and research practice has moved faster than the evidence and there are still many unanswered questions over the best ways to remotely assess memory and thinking. The Cochrane Dementia group are collating and reviewing all the scientific studies looking at remote assessment and worked with SDRC members to find enthusiastic early career researchers to help them complete this project.[6] We will see the resulting publications in 2021 and hope that SDRC can work with Cochrane on other future projects.

Another victim of the global pandemic has been in-person meetings, however, our increasing familiarity with video conferencing has been an opportunity for our members to meet virtually. The SDRC educational webinar series has been a real success story. Within the diagnosis theme, we had a great webinar from Dana Wong and colleagues in Australia who shared their research data and clinical experience of working remotely with people living with dementia. The webinars are all archived on the SDRC website and we recommend Dana's webinar to any dementia researcher or clinician who at the end of a telephone or zoom consultation has thought – "could I have done that better?"

In SDRC we collect data on grant income from Scottish dementia projects, and then categorise by themes. In 2020, projects related to the diagnosis theme generated over six million pounds of grant funding. This would be a substantial amount at any time, but in the context of the disruption caused by the global pandemic this is an incredibly impressive achievement. Of course, we can't be complacent. It seems likely that the research effects of the pandemic will be felt for some time yet and we need to ensure that evidence-based, and person-centred diagnosis of dementia remains a research priority. So, for 2021 and beyond, we need to continue the tradition of innovative, high-quality, collaborative diagnosis research in Scotland.

1 https://icaird.com/
2 https://www.gla.ac.uk/research/beacons/precisionmedicine/imaging/
3 https://www.abdn.ac.uk/research/ffc-mri/
4 https://www.dundee.ac.uk/stories/pictures-study-create-new-platform-help-tackle-major-health-issues
5 https://www.stroke.org.uk/research/national-collaborative-study-improve-our-understanding-longer-term-memory-and-thinking
6 https://dementia.cochrane.org/

2

Fundamental Science

Theme leads
Prof Frank Gunn-Moore and Dr Sophie Bradley

The fundamental science theme is focused on understanding the mechanisms underlying neurodegeneration in order to develop drugs for the treatment of dementia. Across Scotland, we have a diverse range of world-class scientists conducting fundamental research into neurodegenerative diseases, including 35 PhD students in 2020..

Work happening in theme

Over the past year, we have all experienced significant disruptions to our research due to the COVID-19 pandemic. Despite this, dementia researchers across Scotland have continued to conduct ground-breaking fundamental research into neurodegenerative disease which include the following examples:

Research into pathological mechanisms in dementia

Recently, researchers at the UK Dementia Research Institute (UK DRI) in Edinburgh identified key signals within the brain's microenvironment that are necessary to maintain healthy microglia, which are primary immune cells of the central nervous system.[7] Their discovery offers novel insight into the mechanisms underlying the transformation of healthy to disease-associated microglia and highlights potential strategies to counteract these changes. Furthermore, work conducted in collaboration with the (UK DRI) in Edinburgh and published earlier this year, identifies a new mechanism by which dysfunctional brain connections may be rescued in neurodegenerative diseases.[8]

In the past year, researchers at the University of Strathclyde have also published an article demonstrating that optogenetic stimulation of basal forebrain parvalbumin-positive neurons could induce gamma oscillations and modify (increase) amyloid load in an Alzheimer's mouse model.[9] This project was funded by the Alzheimer's Research UK (ARUK) Pilot Grant scheme.

Drug discovery for Alzheimer's disease

Researchers at the University of Glasgow, in collaboration with the University of Strathclyde, have recently published a study focussed on overcoming the issues associated with targeting the M1 muscarinic acetylcholine receptor by dissecting the signalling pathways that lead to toxic/adverse responses from those which drive clinically relevant responses.[10] The M1 muscarinic acetylcholine receptor has attracted significant interest as a promising therapeutic target for the treatment of cognitive impairment in Alzheimer's disease, and drugs targeting this G protein-coupled receptor have demonstrated efficacy in clinical trials. However, despite several decades of research and clinical trials, M1 receptor drugs have thus far failed in development due to adverse cholinergic side effects. Elucidation of the distinct signalling responses downstream of M1 receptor activation may lead to next generation M1 receptor targeted therapies for Alzheimer's disease with a safer side-effect profile.

European Quality in Preclinical Data (EQIPD) project

The (EQIPD) project funded under the IMI-2 (Innovative Medicines Initiative) for Horizon 2020, united more than 20 research groups from both academia as well as industry (including the Riedel/ Platt lab at the University of Aberdeen) to combat the shortcomings in the planning, conduct and reporting of preclinical animal research with a focus on preclinical neuroscience and drug safety.

Significant outputs of this project have resulted in several systematic reviews for: guidelines for the conduct and analysis of preclinical animal research, open field test for transgenic models of Alzheimer's disease (in preparation), synaptic dysfunction and memory impairment in transgenic models of AD (in preparation). It has also resulted in the EQIPD-QS (EQIPD-Quality System) which is the first quality assurance system that puts forward 18 core requirements in categories such as research processes and data integrity.

The Platform for Exchange of Experimental Research Standards (PEERS)

PEERS is an open-access online platform which is designed to help scientists to determine which factors and variables are likely to influence the outcome of certain tests or assays, and therefore need to be considered during planning, execution, and reporting. The database has been designed for commonly utilised in-vivo and in-vitro models and will involve a comprehensive review of the literature to identify factors relevant to each method. It will have a structured, transparent, community-based system for rating the quality of evidence available about the factors that affect outcomes in these models and also draw important conclusions about the current status of evidence.

The Deep Brain Photonic Tools for Cell-Type Specific Targeting of Neural Diseases (DEEPER) project

This DEEPER project clusters technological, neuroscientific and clinical experts together with innovative start-ups and leading companies with the aim of developing photonic tools for imaging and manipulating of the neuronal activity in deep brain regions. The long-term vision of the project is to exploit photonics for meeting medical and research needs in revealing the molecular and cellular dysfunctions underlying the pathogenesis of neurological diseases. These goals will result in less invasive and more effective treatments of dramatic social impacting pathologies, such as Alzheimer's disease, depression, schizophrenia. Part of this project aims to develop a novel optical approach to monitor and modify Alzheimer's disease pathology in vivo, in which the University of Strathclyde plays a leading role.

Awards

There were also personal recognitions for some our colleagues, for example:

- Prof Tara Spires-Jones, Chair of Neurodegeneration and Deputy Director of the Centre for Discovery Brain Sciences and a group leader in the UK Dementia Research Institute at the University of Edinburgh, has been named as the new President-Elect of the British Neuroscience Association.
- Dr Sophie Bradley, Senior Lecturer at the University of Glasgow and a member of the SDRC executive committee, was awarded the ARUK David Hague Early Career Investigator of the Year award 2021.
- Dr Claire Durrant and Dr Bhuvaneish Selvaraj were named as UK DRI Emerging Leaders at the University of Edinburgh.

7 P. S. Baxter et al., Microglial identity and inflammatory responses are controlled by the combined effects of neurons and astrocytes. Cell Rep 34, 108882 (2021).
8 P. Largo-Barrientos et al., Lowering Synaptogyrin-3 expression rescues Tau-induced memory defects and synaptic loss in the presence of microglial activation. Neuron 109, 767-777 e765 (2021).
9 C. A. Wilson, S. Fouda, S. Sakata, Effects of optogenetic stimulation of basal forebrain parvalbumin neurons on Alzheimer's disease pathology. Sci Rep 10, 15456 (2020)
10 S. J. Bradley et al., Biased M1-muscarinic-receptor-mutant mice inform the design of next-generation drugs. Nat Chem Biol 16, 240-249 (2020).

3

Living with dementia

Theme lead
Prof Debbie Tolson

The Living with dementia Research theme encompasses dementia care and practice-based research. Thanks to SDRC member and former co-theme lead, Dr Karen Watchman, the 2021 Alzheimer's Disease International From Plan to Impact IV report[11], includes contributions from a number of Living with Dementia SDRC members.

In addition to existing research interests, SDRC members have studied the impact of the pandemic on people affected by dementia. Accumulating evidence of the disproportionate impact, COVID-19 mortality and excess deaths of people with dementia, confirms that individuals living with dementia are a high-risk group.

Alzheimer Scotland's COVID-19 Hidden Impact Report (2020) describes resulting levels of stress and distress, agitation and depression in people with dementia. Loss of normal family interactions, loneliness and lack of social stimulation, closure of therapeutic and social services, are amplifying their risk of COVID related harms. Estimates suggest that 50% of people with a diagnosis are deteriorating faster than expected.[12] In Scotland, this means 45,000 people are experiencing dementia-related harm and preventable cognitive and/or physical deterioration. Furthermore, there is much we don't know about the experience of surviving COVID-19 with dementia, and the impact of 'long COVID' on the lives of people with dementia.

Pre-pandemic NDCAN-SDRC research involvement activities, identified 'keeping a person with dementia safe' as a priority research topic. You can read reflections on research involvement by this group in our blog series.[13] Alas our first NDCAN-SDRC collaborative studentship funding application, submitted in March 2020, was a COVID casualty of a suspended research funding round.

Although some of our familiar and valued charitable funders have had to disappoint researchers as they adjust to reduced income, Chief Scientist Office (CSO) has funded rapid COVID Studies. SDRC member, Dr George Palattiyl, led a cross-institutional, interdisciplinary research team including several other SDRC researchers from University of Edinburgh, University of the West of Scotland, and University of Strathclyde to investigate the psychological impacts of care home lockdown on families of older care home residents. An SDRC blog[14] explores what it took to assemble a team, plan and complete an ambitious study in just six months. This mixed method study revealed that family carers exhibited higher levels of stress and loss in wellbeing than the general population, and complex emotional impacts. In depth interviews (n=36) and survey data (n=444) conveyed feelings of despair, complex grief, and fluctuations in family carers' trust of our public health policies and care systems. You can read the full scientific and short report of this study on the Creative COVID Care website.[15]

Also COVID-related, a team led by Dr Tom Russ at the University of Edinburgh has been funded by UKRI to explore patient and practitioner experiences of being given a remote diagnosis of dementia.[16] This project will be co-produced with a group of people with personal experience of dementia.

Impacts on family carers extend across health, economic and social harms identified by the Scottish Government.[17] These harms reflect an exacerbation of existing inequalities and imperfections in care systems.[18]

In reality we are just at the beginning of discovering the true impact of the pandemic on people whose lives are affected by dementia. Understanding the problem must be followed by interventional and practice-based research to find ways to help and improve lives. In the spirit of the UN Sustainable Development Goals, this is a call to action to the research community for interdisciplinary and solution focussed research to ensure that no one with dementia gets left behind.

Work happening in theme

Advances in the Field

Moving beyond pandemic considerations we are delighted to share some good news from SDRC researchers about recently funded studies.

Dr Maggie Ellis et al - University of Andrews have been funded by the Life Changes Trust to investigate Adaptive Interaction as a practical method for improving the quality of interactions between people with advanced dementia, professional caregivers and family members.

Alzheimer Society has funded Dr Louise Ritchie et al -University of the West of Scotland, to co-produce and field test an innovative career guidance and development approach to supporting people living with dementia post-diagnosis. Addressing the gap in support services for people who are diagnosed with dementia whilst still employed.

Dunhill Medical Trust has funded Dr Karen Watchman et al – University of Stirling to investigate the experience of couples with learning disabilities when one develops dementia. A key outcome being the development of evidence based support and care.

11 https://www.alzint.org/resource/from-plan-to-impact-iv/
12 The Impact of COVID-19 on People Affected by Dementia. https://www.alzheimers.org.uk/sites/default/files/2020-08/The_Impact_of_COVID-19_on_People_Affected_By_Dementia.pdf
13 https://www.sdrc.scot/news/research-involvement-blogs
14 https://www.sdrc.scot/rapid-covid-research
15 www.creativecovid.com
16 https://www.alzscotdrc.ed.ac.uk/dementia-diagnosis-post-covid
17 Alzheimer Scotland (2020) COVID-19 The Hidden Impact. A report on the impact of the COVID-19 pandemic on people with dementia and carers living at home. Alzheimer Scotland, Edinburgh.
18 https://www.alzscot.org/sites/default/files/2019-07/McLeish_Report_updated_24.01.19_Web.pdf

4

Informatics

Theme leads
Prof Craig Ritchie and Dr Mario Parra

Historically the Informatics theme has been synonymous with the Scottish Dementia Informatics Platform. However, influenced greatly by the 2020 SDRC Conference, the Informatics theme is expanding to include more than just registers. Since the COVID pandemic, we have learnt a lot about the use (and challenges of use) of technology and informatics in our day to day personal and work lives. Moreover, Scottish researchers and companies have played a leading and critical role in the design, development and delivery of the Alzheimer's Disease Data Interoperability (ADDI) platform which seeks to accommodate all data from numerous sources (cohort and real world) within a single research environment. EPAD data was the first data globally to be placed on that platform. Registries, digital technology, data sciences, informatics systems and research platforms all now fall within scope of the Informatics (and Technology) theme of SDRC.

Work happening in theme

This theme is at a point of transition as a reflection of expanded scope as outlined above. A series of workshops are planned through 2021 to bring together researchers and expertise in data sciences, applied data technologies and platform engineering. This will mean close working relationships with the newly formed Research Data Scotland and eDRIS (for storing and accessing real world data) and organisations like iCAIRD and the PICTURES study. The use of technologies based on the behavioural sciences and health psychology will be pursued in concert with the developing Brain Health Services, where behavioural changes for risk factors for dementia at an individual level can be developed, implemented and tested. There are strengths across Scottish Academic Institutions with specific work developing with University of Strathclyde, Heriot Watt and Stirling Universities as well as the Digital Health and Care Innovation Centre. The continued growth of Join Dementia Research and expansion of the Scottish Brain Health Scotland beyond the pilot location in Edinburgh to the rest of Scotland will also be pursued through 2021 and beyond. Remote assessments and care using platforms like NearMe have been important in maintaining contact with patients through the pandemic but these are not new technologies and much expertise exists in the University of Highlands and Islands and NHS Highland and Islands for telemedicine which we can learn so much from for remote assessments elsewhere in Scotland.

https://www.researchdata.scot/
https://www.isdscotland.org/Products-and-Services/EDRIS/Data-for-Research/
https://www.dhi-scotland.com/

5

Prevention

Theme lead
Prof Craig Ritchie

This theme is focussed on research into the earliest stages of neurodegenerative disease; how and why disease develops and how these diseases express themselves before a dementia syndrome develops. Through this knowledge we can understand how to prevent the onset of neurodegenerative disease (primary prevention) as well as providing knowledge for clinical trials or interventions in practice that can be used in people with early disease before dementia develops (secondary prevention). This theme covers both observational studies as well as intervention studies that include drug trials. Scotland is in a privileged position to deliver knowledge for global use in dementia prevention. We have several of the most important cohort studies taking place in Scotland, a fantastic clinical trial infrastructure and (through Brain Health Scotland) a clinical and public health environment to put research into practice rapidly.

Work happening in theme

The 3 pillars of the PREVENTION theme in Scotland are cohort studies, clinical trials environment and Brain Health Scotland.

The EPAD study came to an end at a pan-European level in early 2020 but funding has been secured to follow up 500 people in Scotland who were involved in the EPAD study i.e. 'EPAD Scotland' and provide longer term clinical outcomes from the deep phenotyping done in the parent EPAD study. These data compliment the PREVENT Dementia Cohort which includes 700 people aged 40-59 at baseline. This study in 2020 was awarded funding from Alzheimer's Society to add 70 retired elite rugby and football players to the cohort to determine if there are any differences due to sport participation in terms of brain health compared to non-athletes. These two cohorts are relatively new compared to the Lothian Birth Cohort and suite of studies associated with Generation Scotland which have both yielded hundreds of papers regarding ageing and brain health. Collectively these 4 cohorts and their data have supported and continue to support scores of PhD students and post-docs. We are also supported by the second key pillar through the Trial Delivery Centre Network developed in EPAD now an 'asset' within the Neuroprogressive and Dementia Research Network that plays a critical leadership role in delivering clinical research. This network is led by Dr Tom Russ who recently was elected onto the SDRC Executive. This continues the strong bond between SDRC and the network after Prof Peter Connelly retired from the executive and leadership role, having played a pivotal role in both since their inception. This network and delivery work is being augmented and given even greater visibility globally with collaboration with the Global Alzheimer's Platform who are working with SDRC, the CSO, the network and Brain Health Scotland to establish Scotland as a 'Centre of Excellence' for clinical trials in Alzheimer's Disease. In 2020 we saw the launch of Brain Health Scotland which is the first organisation of its kind anywhere in the world and is tasked by Scottish Government to deliver a year-on-year reduction of Dementia Incidence over (at least) the next 10 years. It will achieve this through public health campaigns and policy as well as the establishment of NHS Scotland Brain Health Services across all of Scotland by 2025 within the for risk profiling, early disease detection and implementation of personalised prevention plans. Brain Health Scotland is also contracted to work with various stakeholders to increase registration of people for research through both Join Dementia Research and the (clinic based) Scottish Brain Health Register. This means close working on applied research with the Diagnostics theme (early detection) and Informatics theme (research registration and real-world data collection).

https://www.ep-ad.org
https://www.brainhealth.scot
https://www.ed.ac.uk/generation-scotland
https://www.lothianbirthcohort.ed.ac.uk
https://preventdementia.co.uk

Early Career Researchers Spotlight

Miles Welstead

I am a third year PhD student with the Lothian Birth Cohort 1936 and I also work part time as an Assistant Psychologist at Edinburgh Dementia Prevention.

The focus of my PhD has been exploring how and why frailty changes over time. This has involved conducting a systematic review into frailty trajectories, as well as working on several empirical studies with the Lothian Birth Cohort 1936, tracking frailty over time and identifying salient risk and protective factors. During my exploration of frailty, I also got somewhat side tracked and began exploring the prevalence and predictors of MCI in the cohort. With the time I have left I hope to tie these themes, perhaps by exploring the concept of 'Cognitive Frailty' which describes the simultaneous and potentially interlinked decline in frailty and cognition.

After my PhD, I hope to continue working in the field of dementia as it is an area that I have a strong interest in. However, beyond that I have not quite worked out the finer details in which career path to take.

Miriam Scarpa

I am a PhD researcher at the University of Glasgow Centre for Translational Pharmacology, funded by an MRC-iCASE studentship in collaboration with Eli Lilly and company. Before my PhD, I completed my BSc. (Hons) in Molecular and Cellular biology also at the University of Glasgow.

My PhD focuses on the M1 muscarinic acetylcholine receptor (M1R) as a drug target for the symptomatic and disease-modifying treatment of Alzheimer's disease. I have discovered that the M1R exerts inherent neuroprotective mechanisms against neurodegeneration, indicating that pharmacological activation of the M1R could not only improve memory symptoms but also slow down disease progression. With growing numbers of dementia patients, there is a need for disease-modifying therapies for Alzheimer's disease, and understanding molecular mechanisms are crucial to inform the design of clinically efficacious medicines. After my PhD, I hope to continue to investigate molecular mechanisms underpinning cell responses to disease.

Outside the laboratory, I am involved in science communication with the GIST (Glasgow Insight in Science and Technology) magazine and outreach events such as the Pint of Science. I am member of the SDRC early career researchers' group, and I am the early career pharmacologist of the British Pharmacological Society Honours and Fellows panel.

Katherine Walesby

I am currently a clinical research fellow at the Alzheimer Scotland Dementia Research Centre, University of Edinburgh. My PhD is investigating geographical variation of dementia using big data in Scotland and New Zealand. I am also a Geriatric and General Medicine Specialist Registrar.

After completing my degree in Medicine from Newcastle University in 2007 and a Masters of Research in 2006, I have worked as a doctor in Newcastle, Edinburgh, Fife and Tayside and completed my postgraduate examinations, MRCP and SCE in Geriatric Medicine. During this time, I developed a growing interest in dementia clinical care and dementia research. I am particularly interested in the use of routinely collected electronic health data and big data sets at a national level for dementia ascertainment.

I am currently investigating dementia ascertainment and geographical variation in the Scottish Mental Survey 1947 (SMS1947) linked to healthcare data. Additionally, I am undertaking a large systematic review investigating geographical variation in dementia.

In the future, I hope to work clinically at providing holistic dementia care in medicine and academically use my skills to analyse routinely collected healthcare data to improve delivery for dementia care.

Louis Dwomoh

I am a Commonwealth scholar, with an MSc and PhD in Biomedical Science (Clinical Biochemistry and Neuroscience) from the University of the West of England, Bristol. Before moving to the UK, I studied for my bachelor's degree and qualified as a biomedical scientist after further training at the 37 Military Hospital in Ghana. My interest in research peaked during my time at the hospital, having worked on a number of research projects, including a study on diarrhoeal viruses with the US Naval Medical Research Unit Three.

I am currently a Research Associate at the Centre for Translational Pharmacology, University of Glasgow. My research aims to define and validate novel G protein-coupled receptor targets for modification of neurodegenerative disorders, with a focus on Alzheimer's disease. This is an important step in the development of drugs that can slow disease progression and improve cognitive function with minimal adverse effects.

My plan is to stay in academia to teach and establish my own research group; however, I am keen to explore other areas including industry, research policy and translational medicine.

Bogna Drozdowska

I gained my first experiences of working as a researcher at the University of Birmingham towards the end of my MSc in Brain Injury Rehabilitation, where I was involved in a project investigating apraxia and action disorganisation syndrome in stroke. I then spent a year in Melbourne, Australia, assisting on a programme promoting recovery-oriented practices within community mental health services.

In 2017 I joined the Assessing Post-stroke Psychology Longitudinal Evaluation (APPLE) project at the University of Glasgow as a PhD student. My topic was the prognosis of cognitive outcomes following stroke. Working with different datasets, I developed an interest in applying structural equational modelling techniques to allow better accuracy in capturing post-stroke cognitive change and its complex relationships with various predictors.

As my PhD is nearly finished, I hope to continue working in research on vascular cognitive impairment, with a focus on understanding its course and identifying factors that could be modified to improve cognitive function and prevent decline.

Fatene Abakar Ismail

My academic background is Biomedical Science, and my PhD was investigating the accuracy of point of care lactate device in patients with Sepsis. However, in recent years I have decided to continue my research career in dementia. My journey with dementia research has started in 2019 at the University of Glasgow. I am currently working on the project "'Risks, Rates, and Routes to Reduce Vascular Dementia'(R4VaD) study. In this role, I recruit patients from the stroke wards at Glasgow Royal Infirmary and assess their cognition and mood. I perform assessments whilst they are on our stroke unit and then again at 6 weeks, 1 year, and 2 years after their stroke. I have been recently offered another research role in dementia at the University of Strathclyde. In my new role, I will be working on a collaborative project (UCL, Bangor and the University of Strathclyde) which will assess an online training and support resource for family and friends supporting people living with dementia for use in the UK. This is an exciting opportunity for me as it will help me to enhance my research skills in dementia.

In the future, I am planning to continue working in dementia research and develop research ideas to apply for a fellowship.

Emily Ball

I am currently in the final year of my PhD in Precision Medicine at the University of Edinburgh.

My interest in stroke and cognitive impairment began during my undergraduate degree in Psychology where I worked as a research assistant exploring long-term memory deficits in patients with stroke. I subsequently wanted to understand the molecular mechanisms that underlie cognitive decline and completed an MSc in Molecular Neuroscience. I am now continuing to pursue my interest in stroke and dementia during my PhD.

Cognitive decline and dementia are common following stroke. My PhD focuses on identifying clinically relevant risk factors that are associated with the development of post-stroke dementia. To address my research questions, I am undertaking systematic reviews, a survey of healthcare professionals, and setting up collaborative data linkage studies in Scotland and Sweden using electronic health records. I have particularly enjoyed learning about ethical challenges of using electronic health records in data linkage research.

In my future career I aim to use prognostic factor data linkage studies to address research questions relating to the earlier identification of dementia.

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

The SDRC has repeated our extensive mapping exercise of Scottish dementia and brain health research to include data for 2020. 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 clearly show how the pandemic has affected research activity in 2020. However, despite the challenges faced, researchers in Scotland have still been able to make a significant contribution to global dementia and brain health research. While the number of grants awarded have fallen, it is not all bad news. The number of published papers has increased to almost double that of previous years' totals.

The number of active researchers in 2020 have also increased compared to the previous five years. This includes the number with which researchers based in Scotland have collaborated internationally. 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 2020 data below and comparison to the data for the past five years where appropriate.

Funding levels and sources

Unfortunately, due the COVID-19 pandemic, both the number and amount of money invested into dementia and brain health research in Scotland has significantly reduced. In 2020, there were around 25 grant awards totalling just over £8m received by Scottish-based dementia and brain health researchers.

This is more than half of what was awarded the previous year, the figure in 2019 was over £19 million, and the lowest amount recorded since we started to analyse this data. Figure 1 shows the level of funding in 2020 compared to the previous five years.

Figure 2 illustrates how the grants were distributed between the research themes in 2020.

Figure 3 highlights how much almost all themes have been affected by the pandemic in the past year. The only exception is Diagnosis, in which a research team received one very large grant award.

Figure 4 shows where the resources come from, with most funding from sources within the rest of the UK.

Figure 1: Grant award funding by year

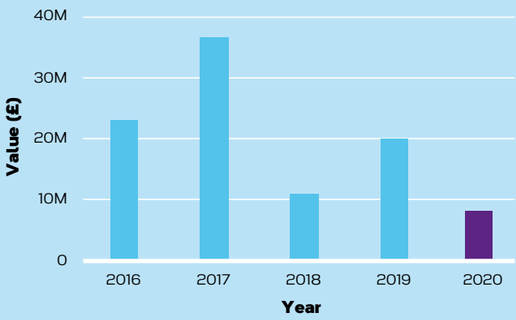


Figure 2: Grant award by theme (£)

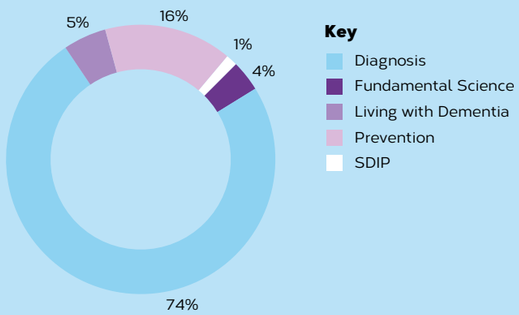


Figure 3: Grant awards over 5 years, by theme

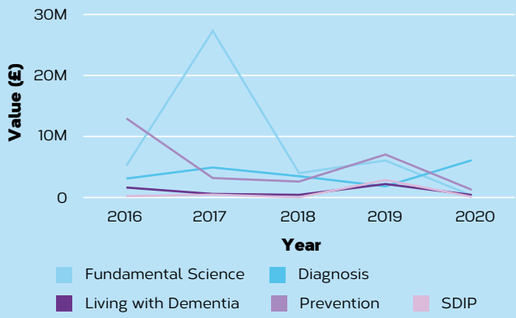


Figure 4: Grant source by region

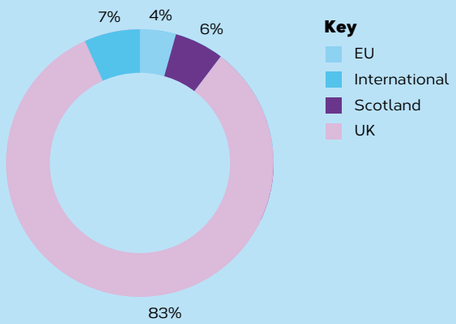


Figure 5: Funding by source/country region over 5 years

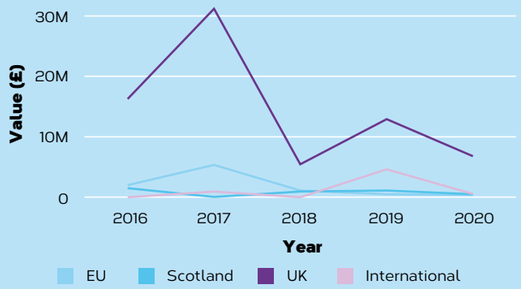


Figure 6: Proportion of grant source by organisation type

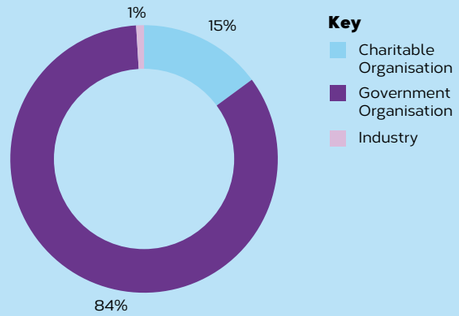


Figure 7: Funding source by organisation over 5 years

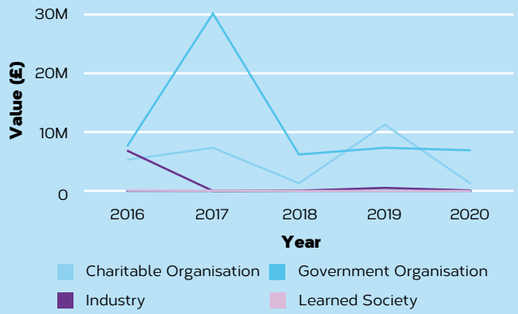


Figure 5 shows the patterns of funding sources over the past five years. It is clear to see that funding from all locations has decreased since 2019.

Figure 6 shows the proportion of money received from the different types of funding organisation. The overwhelming majority of grant income in 2020 was from governmental organisations. This is very different from previous years, where the majority source of funding comes from the charity sector. For comparison the amount of funding from the charity sector in 2019 was over £11 million, in 2020, it was just over £1 million.

Figure 7 demonstrates the source of funding by organisation and shows the impact of the reduction of funding from charities more clearly. It is clear to see the extent to which income from charitable organisations has decreased. This unsurprisingly is due to the pandemic, as a result of which many charitable organisations had to delay or cancel funding calls. However, the amount of funding from other sources, most notably governmental organisations, has remained relatively steady. This data shows how important charities are in advancing dementia research in Scotland, and we hope that they are in a position to re-establish their support in 2021 and beyond.

Researchers in Scotland

In 2020 there were 497 Scottish-based researchers that have either contributed to a research paper or been part of a grant award related to dementia and brain health. This is a far greater number of researchers than in previous years. In 2019, there were 296 active researchers. The reason for this increase is because of the greater number of publications, as will be discussed in the following Published Papers section. Figure 8 illustrates how the active researchers are spread across the research themes. The largest proportion of researchers are within the Prevention theme, which is the same as 2019. However, Diagnosis is only slightly behind. This data may highlight which researchers were able to maintain a high level of activity during the pandemic and those that found this more challenging.

Figure 9 shows the proportion of researchers at each phase of the research career pathway. In previous years, the proportion of active researchers has been heavily weighted in favour of more senior researchers. Now there is more balance in representation between more established researchers and those in an earlier stage of their career. From this we can see how well represented our community is in terms of both experienced and early career dementia and brain health researchers.

Interestingly, the percentage of PhD students who actively contributed to a grant or research paper has doubled from the previous year. Figure 10 shows the breakdown of PhD students in 2020 by research theme.

The data of active researchers in 2020 is very different from previous years. It will be interesting to see if this is an anomaly due to the pandemic, or if what we have seen here will be part of a trend.

Figure 8: Proportion of active researchers by theme

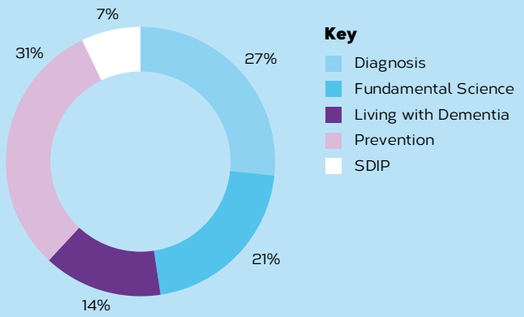


Figure 9: Researchers by career stage

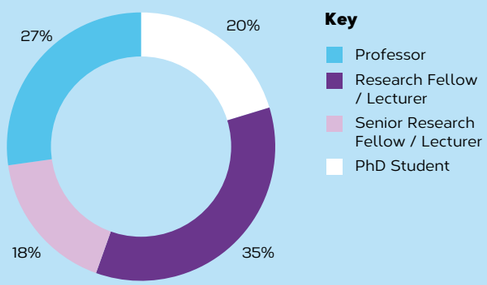
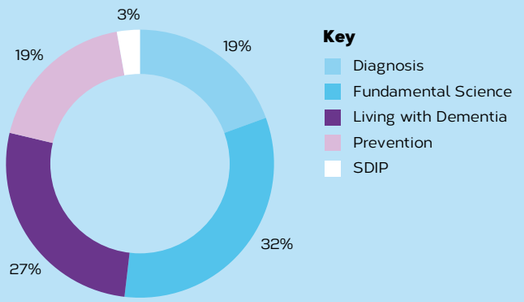


Figure 10: PhD students by theme 2020



Published Papers

We have analysed the number of publications produced as a means by which to measure the level of research output in 2020. Figure 11 shows a total of 371 papers and a breakdown by theme. This is a significant increase from previous years.

Figure 12 compares the level of 2020 output to the four previous years. Despite the challenges of 2020, our research community were able to direct activity into writing when they were unable to submit grant applications. Specifically, there were 21 publications to scientific journals which related to coronavirus and how the pandemic affected people with dementia.

Figure 11: Number of publications by theme in 2020

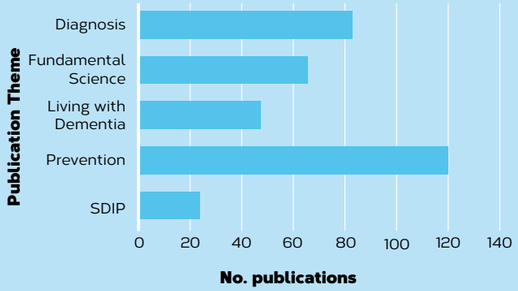
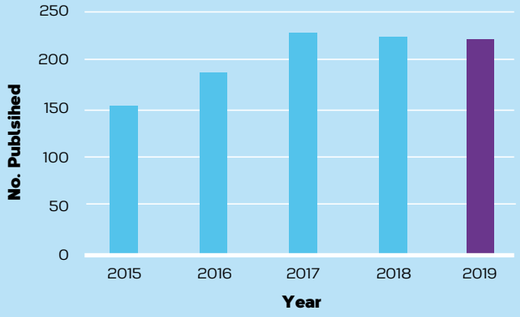


Figure 12: Number of publications by year



International Collaborations

Previous reports have shown how much Scottish-based researchers valued the importance of collaboration with colleagues across the world. Due to the increase of papers published in 2020, the extent of this collaboration has increased further still. In 2020, there were 947 international collaborations with 453 individual collaborators across 36 countries. Figure 13 shows to top countries that Scottish-based researchers have collaborated with.

Figure 13: International collaboration by country in 2020

England	383	Italy	16
USA	149	Wales	13
Netherlands	64	Northern Ireland	12
Australia	49	Czech Republic	12
Germany	38	Switzerland	10
Canada	30	Spain	9
France	29	China	9
Mexico	25	Ireland	6
Sweden	21	Finland	5
Austria	20	Russia	4

There are examples of international collaboration within every SDRC theme. Figure 14 demonstrates the extent to which international collaboration varies across themes. Similar to previous years, around three quarters of collaboration with researchers outside of Scotland is within the Diagnosis and Prevention themes.

As always, and to be expected, Scottish-based researchers collaborate most frequently with researchers within the UK rather than any other country. Also, the same as all previous years we have collected this data, researchers in Scotland collaborated in total more with researchers in the European Union and Internationally than with the UK. This is shown in Figure 15.

This data highlights that, despite a global pandemic, researchers in Scotland have been taken advantage of remote working. We have leveraged the shift to increased interconnectivity to greater establish relationships within the global dementia and brain health research community.

Figure 14: Proportion of international collabortations by theme

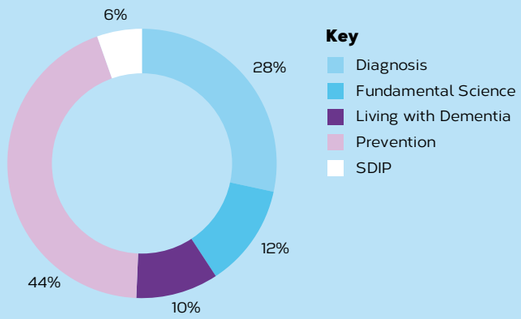
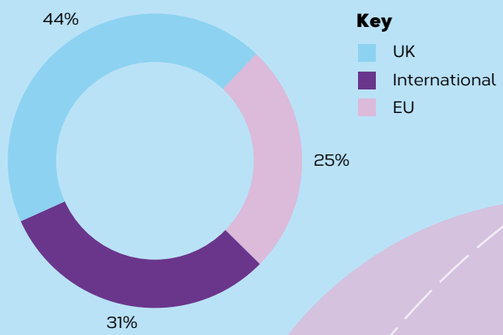


Figure 15: Proportion of collaborations by region



Feedback from the SDRC Conference 2020

On the 7th September 2020, the SDRC hosted our fifth annual conference. Due to COVID restrictions it was an entirely virtual event.

The SDRC Conference 2020 was our biggest yet. Over 240 people registered to attend, with three plenary speakers, eight early career researchers, 15 poster exhibitors and four exhibition stands.

Scottish Dementia Research Consortium

Chaired by Prof Craig Ritchie, the SDRC Conference 2020 was titled 'Unlocking the Mysteries of Data'. It focused on the world of big data and informatics in dementia and brain health research.

The Conference programme was split into three parts. The morning sessions were plenaries featuring world-leading researchers in their respective fields. The first speaker was Prof Timothy Croudace who discussed health data in research and health science in a digitally connected world. Our second and third speakers, Prof Joanna Wardlaw and Dr Graciela Muniz Terrera, were both invited to speak by the SDRC as they had jointly produced the most publications in 2019, as identified in our SDRC Annual Report 2019/20.

The second part of the day provided an opportunity for delegates to have conversations with each other. Even though it was a virtual conference, we wanted space for delegates to meet and network as we know this is such an important part of the conference experience for researchers. In the late morning, we held our breakout sessions. These sessions allowed delegates to contribute to discussions and share their own perspectives on topics such as perceptions of healthcare data in research, social media and the use of data in care homes. Following this, our formal sessions took a break and conference attendees had the opportunity to view the posters and chat with the authors, as well as visiting the interactive exhibition stands.

The afternoon session of the Conference was dedicated to our Early Career Researchers. Eight ECRs provided an overview of their research and careers. These presentations highlighted the diversity within the dementia and brain health research community and represented all SDRC research themes. It also celebrated the immense talent which exists among our next generation of researchers.

We hope that everyone who attended the Conference enjoyed the day. We also hope you learned something about the dementia and brain health research in Scotland and helped to demystify the world of informatics. A big thank you goes to all the event organisers, speakers, presenters, and everyone who attended. We are very appreciative of all the positive feedback we received, which we will build on to make our 2021 virtual conference an even bigger success.

Message to membership

Carleen Smith

Much like our previous SDRC Reports, I am delighted once more to have this opportunity to provide this update of the past 12 months, and talk about our plans for the future.

I usually start my update on my work of mapping the dementia and brain health research activity in Scotland which forms a key part of the Annual Report. While it is clear COVID-19 has had a profound impact on research activity, particularly the reduction in funding, there is a lot to be positive about. Specifically, the increase in the number of publications and extent to which Scottish-based researchers are collaborating with colleagues around the world. I will never fail to be impressed by the creativity, ingenuity, and initiative of the research community, that despite difficulties faced, they can still continue to make such an impact.

It's no surprise that many things we had planned for the past 12 months had to be put on hold or cancelled. However, we have taken a lot of new initiatives, specifically work around prioritising the needs of Early Career Researchers, which you can find out about on the SDRC website. I am also very much looking forward to working the SDRC ECR Group which has been newly established, whose purpose it is to advise the SDRC Executive Committee on potential issues or challenges the ECRs are facing and how they can be better supported.

We have also maximised the more remote ways of communicating by growing our online presence. This included launching the SDRC webinar series and increasing the number of blogs we have shared. I am delighted that this work has led to a significant rise in our website traffic, Twitter followers and number of members. We will certainly continue to build our online activity and add more resources in the year ahead.

Our most notable shift to digital was taking our Annual Conference online. This required us to change how we delivered the programme, but I was delighted we were still able to maintain the high quality that you have come to expect from SDRC events, and you can find out more about this in previous pages of this report. Our 2021 conference is also virtual, and I know this will be another successful and exciting event. However, I am sure you agree that we are looking forward to meeting in-person soon. Rest assured, when we can run in-person events once again, we have some great plans to make these better and more ambitious than ever.

And it's not just with conferences that we have grand ambitions. There is no denying that the past year has not been easy for anyone. When the COVID-19 pandemic hit, like all organisations it meant a big a change in how we have worked, requiring a great deal of re-prioritising and refocusing our efforts. I am very proud in what we have been able to do. This has not been possible without the support of the SDRC Executive Committee, our Alzheimer Scotland and Brain Health Scotland colleagues and, most importantly, continued engagement of our members. I believe all this work we have done together has created a strong foundation from which we will build and add to in the coming months and years. I feel very positive about the future!

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

The SDRC is supported by

Alzheimer Scotland
Action on Dementia

Scottish Dementia Research Consortium

A 81 Oxford Street
Glasgow G5 9EP

E SDRC@alzscot.org

@SDRC_research

www.alzscot.org

Published June 2021