



## THE POST

<b>College:</b>	<a href="#">University of Exeter Medical School</a> <a href="#">College of Life and Environmental Sciences</a>
<b>Post:</b>	<b>3 x Alzheimers Society Clinical Training Fellows</b>  <b>2 x at Graduate Research Assistant level (Grade E) and</b> <b>1 x at Graduate Research Assistant / Postdoctoral Research Fellow level</b> <b>(Grade E or F depending upon experience)</b>
<b>Grade:</b>	<b>E/F depending upon relevant skills and experience</b>
<b>Reporting To:</b>	<b>Professor Linda Clare</b>

The above three full-time posts are available from October 2018 for a period of three years.

The University of Exeter has been awarded a three year Clinical Training Partnership Grant by the Alzheimer's Society (Title: [Intervention development for Alzheimer's Clinical Training \(INTERACT\)](#)) to start in October 2018 under the guidance of Professor Linda Clare (Professor of Clinical Psychology of Ageing and Dementia) and Professor Clive Ballard (Pro Vice-Chancellor and Professor of Age Related Diseases).

Three research posts are now available for qualified health professionals to undertake PhDs as part of this award and applications are invited for these three posts which will focus on the following projects:

**Project 1: Identifying and addressing difficulties with awareness in early-stage dementia**

**Project 2: Adjusting to the diagnosis of dementia**

**Project 3: Engagement and feasibility of an evidence-based activity toolkit for people with severe dementia living in care homes**

The posts will be based in the [Centre for Research in Ageing and Cognitive Health \(REACH\)](#), which is a joint venture between the School of Psychology, the University of Exeter Medical School and PenCLAHRC. REACH is also linked with the University's Wellcome Centre for Cultures and Environments of Health and with the Centre of Research Excellence in Cognitive Health at the Australian National University.

The aim of REACH is to improve the lives of older people and people with dementia through research focused on three main themes: maintaining cognitive health in later life, living well with age-related cognitive disability and dementia, and supporting family care.

### **Brief description of the three projects:**

**Project 1: identifying and addressing difficulties with awareness in early-stage dementia (Lead supervisor: Professor Linda Clare)**

#### **Introduction**

It can be difficult for people with mild to moderate dementia living at home to evaluate how dementia is affecting their ability to carry out everyday activities. People with dementia usually want to be as independent as possible, but due to problems with awareness they may overestimate their abilities or underestimate the likelihood of running into trouble. This creates dilemmas for carers, who want to keep the person safe and may find they need to monitor closely what the person is doing.

Understanding the person's profile of awareness is important for care planning, but although there has been a lot of research on awareness, there are currently no accessible brief measures that health professionals can use in clinical practice. The first aim of this project is to develop a tool to help health professionals understand a person's profile of awareness and identify areas of potential difficulty where extra support may be needed.

Some types of difficulty with awareness could be improved through intervention. The most likely target for intervention is performance monitoring ability – this is where people have difficulty monitoring how well they are managing to carry out a task or activity, keeping track of what they are doing, noticing when things go wrong, and correcting mistakes. Interventions to improve this ability have been developed for other groups, but not for people with dementia. The second aim of this project is to develop an intervention to improve performance monitoring ability for people with early-stage dementia. An effective intervention could support independence and help to reduce some of the worry that carers experience.

### **Methods and techniques**

The project will consist of three stages. In Stage One the Clinical Fellow will review available measures of awareness and use existing data from our earlier MIDAS study of awareness to identify what should be included in a short, straightforward assessment tool.

In Stage Two the Clinical Fellow will review interventions developed for other groups. The Clinical Fellow will then use data from our recently-completed GREAT trial of an intervention to improve everyday functioning to see what activities people wanted help with, how performance monitoring difficulties affected progress and what strategies therapists used to try to overcome these difficulties. Based on these two sources, the Clinical Fellow will outline the protocol for an intervention to improve performance monitoring ability.

In Stage Three the Clinical Fellow will conduct a larger study using the new measure to make sure that it offers a reliable way of assessing difficulties with awareness. The number of people the Clinical Fellow needs to assess will depend on the features of the new measure (e.g. number of items) but we have estimated for 200. The Clinical Fellow will identify 9 participants who have difficulties with performance monitoring and test the intervention approach in a series of detailed individual studies; researchers consider 9 to be an appropriate number to show whether the intervention holds promise and is worthy of further development.

### **Dissemination and implementation**

The measure and intervention will have strong potential for implementation in clinical practice. Results will be disseminated through journal articles, articles in professional publications, social media and presentations to professional networks, and via Alzheimer's Society. Following completion of the thesis, the next stage in taking this work forward would be to conduct a pilot randomised controlled trial of the performance monitoring intervention. The Clinical Fellow could use this as an avenue to postdoctoral research.

People with dementia and carers, as well as awareness experts and clinicians, will be consulted and involved throughout all stages of the work to help guide the development and testing of the assessment measure and intervention and disseminate the findings.

## **Project 2: Adjusting to the Diagnosis of Dementia (Lead supervisor: Dr Siobhan O'Dwyer)**

### **Introduction**

Diagnosis can be a difficult time for people with dementia and their families. It often raises more questions than it answers and can lead to anger, sadness, fear, and confusion. Although coming to terms with the diagnosis is not easy, research suggests that people who are able to 'adjust' to their situation have better health outcomes. The best strategies for adjusting to a diagnosis of dementia, however, are not clear. Activism and advocacy may be one pathway to adjustment and, in the UK, the Dementia Engagement and Empowerment Project (DEEP) has been established to help people with dementia have a say on the policies and practices that affect their lives. Through DEEP more than 1,000 people with dementia are working together in small groups to change the way they are included, consulted, represented, and supported in their communities. The DEEP model, and the experiences of DEEP members, may provide important insights into the process of adjusting to a diagnosis of dementia, but there has been no previous research on DEEP.

This project has three aims: (1) to review the existing research on adjustment to a diagnosis of dementia; (2) to explore the adjustment experiences of DEEP members; and (3) to use lessons from DEEP to develop a brief, clinician-led intervention to facilitate adjustment in people with dementia who are unable to participate in DEEP.

## **Methods and techniques**

The project will consist of three studies. In Study One the Clinical Fellow will systematically review all previous research on programs, therapies, and other interventions designed to help people with dementia adjust to their diagnosis.

In Study Two, a survey will be distributed to all DEEP members. The survey will assess their physical and mental health, the support they receive, any stigma they have experienced, and how they have adjusted to the diagnosis of dementia. To explore how DEEP membership contributes to adjustment, the survey results will be compared across three groups: new members (those participating in DEEP for less than 6 months), recent members (those participating for between 6 and 18 months), and established members (those participating for more than 18 months). Twelve DEEP members will participate in follow-up interviews designed to explore the strengths and limitations of DEEP, and the factors that make it easier or harder to be involved.

Although engaging in advocacy and activism may help people come to terms with their diagnosis, DEEP groups do not operate in all areas and may not suit very person with dementia. In Study Three, the Clinical Fellow will work with DEEP members and clinicians to develop an intervention that is consistent with the ethos of DEEP but can be delivered in a one-to-one setting by a health or social care professional. Once it is developed, the intervention will be tested with a small group of people.

## **Dissemination and implementation**

This project fills a significant gap in the academic literature on adjustment to diagnosis and the role of activism and advocacy for people with dementia. The findings will be published in academic journals and presented at academic conferences. Plain language summaries will be provided to all DEEP members and shared with key dementia and care organisations such as Alzheimer's Society and Age UK. A user-friendly resource will also be created to help DEEP groups use the findings to improve their work. People with dementia and clinicians will be consulted throughout the project to ensure that the research and its outcomes reflect their lived experience and lead to practical outcomes.

### **Project 3: Engagement and feasibility of an evidence-based activity toolkit for people with severe dementia living in care homes (Lead supervisor: Dr Anne Corbett)**

#### **Introduction**

This project aims to address serious unmet need in day-to-day care for people with severe dementia living in care homes. The severe impairment in cognition, independence and communication in these residents means they are seen as extremely challenging, and as a result are often not included in regular activities or social interactions. This is somewhat counterintuitive since research clearly shows that simple approaches, such as engaging people in activities and conversation, lead to improvements in behavioural symptoms, mood, wellbeing and quality of life, all of which are major issues in people with severe dementia.

Despite good evidence supporting the use of 'pleasant activities' that are tailored to individuals, this work has not been translated into changes in care. This is usually due to a combination of care staff burden, limited time and lack of understanding, training and support in the home. Studies have highlighted the importance of providing training and helping care staff to make decisions in day-to-day care. Increasingly researchers are looking to technology for ways of making this process quick, interesting and effective for staff.

The aim of this project is to build on the best evidence, and the experience of the research team, to develop a simple way to support care staff in engaging people with severe dementia in personalised activities.

## **Methods and techniques**

The project will consist of four stages. In Stage One, the Clinical Fellow will coordinate an expert group to identify the best types of activities for people with severe dementia. This list will be used to consult with care staff and family carers as to the best way of personalising activities and deciding which will be most suitable for individual residents. The Clinical Fellow will then explore how a simple online system, called KareInn ([www.kareinn.com](http://www.kareinn.com)), which can be accessed through smartphones and tablets, can be used to provide a user-friendly tool for care staff.

In Stage Two, the Clinical Fellow will work with the expert steering group, lay advisors and a technology partner to develop and build a dedicated toolkit for activities and decision-making. The toolkit will guide care staff to use existing information about each resident, supported with prompts and questions, to decide on the best activity for that person.

In Stage Three, the Clinical Fellow will conduct a small study to test the feasibility of the toolkit in six care homes. The Clinical Fellow will recruit staff and people with severe dementia, and will use the toolkit for six weeks. The aim will be to provide at least 10 minutes of pleasant activity for each resident each day. Data collected will include recordings of the activities, engagement and use of the toolkit, in addition to scales to quantify behavioural symptoms in residents and stress and burden in staff. Care staff experiences will be collected through interviews at the end of the study. Stage Four will consist of dissemination activity, as detailed below.

## **Dissemination and implementation**

This study has the potential to result in real improvements to the lives of people with severe dementia in a very short time. Following writing of the thesis and publication of the findings, the research team will reach out to the UK care sector through events and reports to promote the toolkit. The Clinical Fellow will also develop a funding application for a full trial of the toolkit in UK care homes.

## **FOR MORE DETAILED DESCRIPTIONS OF THE PROJECTS PLEASE SEE THE APPENDIX**

### **Application information:**

Applicants are requested in their letter of application to state which project they would wish to undertake and if interested in more than one then to indicate an order of preference.

Salary offered will be commensurate with prior qualifications, skills and experience.

### **For the Grade E posts: Main duties and accountabilities:**

1. To support research activity under the direction of the lead supervisor as appropriate to the research project. Responsibilities may include:
  - Undertaking a broad range of basic research activity according to the nature of the research project. For example preparing, setting up, conducting and recording the outcome of experiments and field work, developing questionnaires and conducting surveys, using straightforward mathematical modelling, statistical techniques or scientific computation;
  - Maintaining databases, keeping accurate written and computerised records and ensuring data is stored securely and managed in accordance with the Data Protection Act;
  - Conducting literature and database searches as required;
  - Writing up the results of own research;
  - Contributing to the production of research reports and publications;
  - Presenting information on research progress and outcomes to bodies supervising research, e.g. steering groups, sponsors or members of research groups, postgraduate research seminars and groups;
  - Assisting in the preparation of papers or reports for steering groups and other bodies;
  - Making use of standard research techniques and methods;
  - Analysing and interpreting the results of own research and generating original ideas based on outcomes;
  - Contributing to the planning of future research projects.

2. To liaise with members of the research team and other colleagues as appropriate to the research project.
3. To establish internal and external contacts to develop knowledge and understanding and form networks for future collaboration.
4. To plan own day-to-day research activity within the framework of the agreed programme of research and co-ordinate own work with that of others in the group to avoid conflict or duplication of effort.
5. To use research resources, laboratories and workshops as appropriate and to adhere to safety procedures as appropriate. This may include wearing personal protective equipment, conducting risk assessments, reducing hazards and being responsible for the health and safety of others.
6. To engage in continuous professional development and to be responsible for continually updating own knowledge and understanding in field of study or specialism and for developing own skills.
7. To update and maintain appropriate postgraduate research records (for example MyPGR)

This job description summarises the main duties and accountabilities of the post and is not comprehensive: the post-holder may be required to undertake other duties of similar level and responsibility.

**For the Grade F post: Main duties and accountabilities:**

1. To undertake research as appropriate to the field of study. The responsibilities may include all or some of the following:
  - Acting as principal investigator on research projects;
  - Developing research objectives, projects and proposals;
  - Conducting individual or collaborative research projects;
  - Identifying sources of funding and contributing to the process of securing funds;
  - Extending, transforming and applying knowledge acquired from scholarship to research and appropriate external activities;
  - Writing or contributing to publications or disseminating research findings using media appropriate to the discipline;
  - Making presentations at conferences or exhibiting work in other appropriate events;
  - Assessing, interpreting and evaluating outcomes of research;
  - Developing new concepts and ideas to extend intellectual understanding;
  - Resolving problems of meeting research objectives and deadlines;
  - Developing ideas for generating income and promoting research area;
  - Developing ideas for application of research outcomes;
  - Deciding on /following research programmes and methodologies, often in collaboration with colleagues and sometimes subject to the approval of the head of the research programme on fundamental issues.
2. To assist within the direction of the research team including some of the following:
  - Mentoring colleagues with less experience and advising on their professional development;
  - Coaching and supporting colleagues in developing their research techniques;
  - Supervising the work of others, for example in research teams or projects;
  - Developing productive working relationships with other members of staff;
  - Co-ordinating the work of colleagues to ensure equitable access to resources and facilities;
  - Dealing with standard problems and help colleagues to resolve their concerns about progress in research.

3. To routinely communicate complex and conceptual ideas to those with limited knowledge as well as to peers using high level skills and a range of media and to present the results of scientific research to sponsors and at conferences.
4. As determined by the nature of the project and at the direction of the PI, to plan, co-ordinate and implement research programme activity including:
  - Managing the use of research resources and ensuring that effective use is made of them;
  - Monitoring and reporting on the use of research budgets;
  - Helping to plan and implement commercial and consultancy activities;
  - Where appropriate, to plan and manage own consultancy assignments.
5. Maintain and complete appropriate postgraduate research records (eg MyPGR).

This job description summarises the main duties and accountabilities of the post and is not comprehensive: the post-holder may be required to undertake other duties of similar level and responsibility. Please visit the Human Resources website to view the Research Fellow role profiles.

**Person Specification (Graduate Research Assistant level (Grade E))**

<b>Competency</b>	<b>Essential</b>	<b>Desirable</b>
Attainments / Qualifications	Educated to first degree level in a related field of study or equivalent qualification/experience.  Professional clinical qualification in a relevant field of study or equivalent experience.	Relevant Masters level qualification.
Skills and Understanding	Possess sufficient breadth or depth of knowledge in the discipline and of research methods and techniques to work within own area.	
Prior Experience	Understanding of health and safety legislation.	
Behavioural Characteristics	Ability to maintain accurate records.  Ability to organise and prioritise own research work within the project framework.  Good written and verbal communication skills.  Computer literate.  Good analytical skills.  Able to liaise with colleagues and students.  Able to build contacts and participate in internal and external networks for the exchange of information and collaboration.  Actively participate as a member of a research team.  Engage in continuous professional development. Understand equal opportunity issues as they may impact on areas of research content	
Circumstances	Willing to work flexibly to achieve project demands.	

### **Person Specification (Postgraduate Research Fellow level (Grade F))**

<b>Competency</b>	<b>Essential</b>	<b>Desirable</b>
Attainments / Qualifications	PhD or equivalent qualification/experience in a related field of study.  Professional clinical qualification in a relevant field of study or equivalent experience.	Be a nationally recognised authority in the subject area.
Skills and Understanding	Possess sufficient specialist knowledge in the discipline to develop/follow research programmes and methodologies.  Record of research output in high quality publications.	
Prior Experience	Experience of managing research projects and/or research teams.	Experience of undergraduate /postgraduate teaching and supervision.  Experience of acting as principal investigator on research projects.
Behavioural Characteristics	Excellent written and verbal communication skills.  Able to communicate complex and conceptual ideas to a range of groups.  Evidence of the ability to collaborate actively within the Institution and externally to complete research projects and advance thinking.  Able to participate in and develop external networks.  Able to balance the pressures of research, administrative demands and competing deadlines.	Able to identify sources of funding, generate income, obtain consultancy projects, or build relationships for future activities.
Circumstances	Willing to work flexibly to achieve project demands.	

#### **Salary**

For appointments at Graduate Research Assistant level, the starting salary will be from £26,495 up to £33,518 on Grade E, depending on qualifications and experience.

For appointments at Postdoctoral Research Fellow, the starting salary will be from £34,520 up to £36,613 on Grade F, depending on qualifications and experience.

#### **Terms & Conditions**

Our Terms and Conditions of Employment can be viewed [here](#).

#### **Further Information**

Please see our [website](#) for further information on working at the University of Exeter.

## APPENDIX: DETAILED DESCRIPTIONS OF PROJECTS 1, 2 and 3

**Project 1: Identifying and addressing difficulties with awareness in early-stage dementia** (Lead supervisor: Clare; Co-supervisor: Savage; Back-up: Ballard)

### Aims of the project and significance of the research

People living at home with mild to moderate dementia often experience disabling difficulties with awareness. This has significant implications for individuals, carers and those providing support, and can create a tension between the dual needs of supporting independence and ensuring safety. Understanding a person's level of awareness is essential for determining the degree of support needed to enable maximum independence in daily tasks such as cooking, driving, managing finances, and participating in activities outside the home, and a key factor in many major decisions.

Awareness can be defined as a reasonable or realistic perception or appraisal of a given aspect of one's situation, functioning or performance, or of the resulting implications.<sup>1</sup> It operates at several different levels: (a) sensory registration - registering sensory information from internal (e.g. pain) or external (e.g. noise) sources; (b) performance monitoring – monitoring what we are doing and noticing and correcting errors (e.g. when making a drink or cooking a meal); (c) evaluative judgements – making general judgements about functioning or ability (e.g. about having a good or a poor memory); and (d) metacognitive reflection – reflecting on our situation and experience (e.g. talking about living with dementia, or considering how memory problems impact upon family members). People in the mild to moderate stages of dementia differ in accuracy of awareness at each of these levels, and within each level they may show better awareness for some things than for others.<sup>2</sup>

Understanding the person's awareness profile is important in establishing a care plan, identifying needs, and selecting the most suitable forms of support and intervention. Clinicians often make an informal assessment of awareness, but this is typically done in an *ad hoc* manner, and may not encompass all the necessary information or acknowledge the extent of retained awareness. Availability of a brief clinical assessment tool would enable practitioners to gain a clearer picture, support care planning, and indicate where interventions could help to address practical difficulties resulting from problems with awareness. There is currently no suitable assessment tool available.<sup>3</sup> The first aim of the project is to develop a brief but comprehensive clinical assessment of awareness in people with early-stage dementia, and provide evidence of its reliability, validity and clinical utility.

The second aim of the project is to develop and pilot a practical intervention targeting the performance monitoring level of awareness for those experiencing difficulty in this area. Performance monitoring is a prime target for intervention as problems with awareness at this level affect the ability to manage everyday activities independently. Overestimation of ability to carry out everyday tasks safely and effectively can expose people to risk and may require close monitoring by carers.<sup>4</sup> An intervention aimed at improving the ability to monitor performance and correct errors while carrying out daily tasks, enabling safer functioning, would help to maintain independence for the person with dementia and reduce stress and concerns about safety for the carer. Interventions addressing difficulties with awareness have been developed for other groups, such as people with brain injury<sup>5</sup> or people experiencing age-related cognitive decline<sup>6</sup> but have not hitherto been devised for people with dementia. We will develop the first evidence-based approach to improving performance monitoring ability for people with dementia.

### Work which has led up to this project

This project builds directly on a long-standing programme of research on awareness conducted by Professor Clare and colleagues, and draws on findings from Professor Clare's work on developing personalised rehabilitation interventions, in order to produce practical outcomes to benefit people with dementia and carers.

In the MIDAS study we developed the levels of awareness framework<sup>1</sup> for understanding disturbances of awareness and a multidimensional approach to assessment of awareness,<sup>6-8</sup> which utilised direct (e.g. tests, questionnaires, qualitative interviews),<sup>9-10</sup> indirect (e.g. vignettes)<sup>11</sup> and implicit (e.g. emotional Stroop)<sup>12</sup> methods. The MIDAS dataset will be used to identify the key components of a brief clinically-useful assessment measure.

Our intervention research has focused on enabling people with dementia to manage everyday activities as well as possible. In the GREAT trial<sup>13</sup> we tested the efficacy of cognitive rehabilitation (CR), a problem-solving approach to improving everyday functioning for people with early-stage dementia.<sup>14</sup> Examination of participants' goals and the logs kept by therapists will identify the key types of daily activities involving performance monitoring for which support was requested, the ways in which performance monitoring difficulties affected the progress of therapy, and the strategies that therapists used to try to overcome these difficulties. This evidence will underpin development of an intervention addressing performance monitoring difficulties.



### Detailed experimental design and methods to be used

#### *Stage 1 – developing the assessment measure (months 1 – 9)*

- The first step will be a systematic review examining properties of measures used to assess awareness in people with dementia, updating our previous review in this area.<sup>3</sup>
- Working with MIDAS data, the Clinical Fellow will identify which assessment items at each level of awareness are the most highly correlated with and predictive of the overall profile, and consult with people with dementia, carers, awareness experts and clinicians to help determine which are most feasible and useful to include in the final assessment measure.
- To assess feasibility, the Clinical Fellow will test an initial version of the measure with a small sample of people with early-stage dementia, and clinicians will be asked to try using the measure as part of their clinical assessments and provide feedback on its suitability. Any necessary refinements will be made following a further round of consultation.

#### *Stage 2 – developing the intervention targeting performance monitoring (months 10 – 18)*

- The first step will be a systematic review of interventions targeting disturbed awareness at the performance monitoring level in any condition involving cognitive impairment.
- Based on the findings of this review, consultation with people living with dementia, carers, awareness experts and clinicians, and examination of goals and therapy logs from the GREAT trial,<sup>13</sup> an intervention approach will be outlined.
- Appropriate outcome measures to assess the effectiveness of the intervention and the benefits for people living with dementia and carers will be identified.

#### *Stage 3 – establishing properties of the measure and feasibility of the intervention (months 19 – 36)*

- Reliability and validity of the assessment measure will be examined by administering the measure, together with other measures addressing specific levels and objects of awareness, to people with early-stage Alzheimer's, vascular or mixed dementia. The required sample size will need to be determined on the basis of measure characteristics,<sup>16</sup> but we have estimated for 200. A research assistant will provide limited support for data collection.
- The feasibility of the intervention will be tested in a series of at least nine n=1 studies using detailed single-case experimental designs.<sup>17</sup> Individuals who may benefit from intervention will be identified from the wider study of the properties of the assessment measure.
- If the intervention is shown to be feasible, the Clinical Fellow will work with Exeter CTU to prepare a protocol and funding application to conduct a pilot randomised controlled trial to gather more evidence about the effectiveness of the intervention.

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### How will the results from this research be used?

A brief measure of awareness could have considerable impact in clinical practice. The measure will be introduced to clinicians through journal articles, websites, articles in professional newsletters and bulletins, and importantly through presentations to professional and service networks such as the British Psychological Society Faculty of the Psychology of Older People and Division of Neuropsychology, College of Occupational Therapists, Royal College of Nursing, British Geriatrics Society, International Psychogeriatric Association, and INTERDEM, and will be publicised to the Memory Services National Accreditation Programme and via Alzheimer's Society channels.

An intervention to address disturbances of awareness at the performance monitoring level would be both novel and highly practical and would have potential for integration with cognitive rehabilitation interventions in post-diagnostic care as well as for wider implementation. As a first step, the intervention will be introduced to clinicians through journal articles, websites, articles in professional newsletters and bulletins, conference presentations and presentations to professional and service networks (as above), and via Alzheimer's Society channels.

### Involvement of people affected by dementia and other relevant stakeholders

People with dementia, carers, awareness experts and clinicians will be consulted and involved throughout all stages of the work to help guide development of the project, including identifying appropriate items for the assessment instrument, formulating and implementing the intervention approach, and disseminating the findings.

**Project 2: Adjusting to the Diagnosis of Dementia** (Lead Supervisor: O'Dwyer; Co-Supervisors: Clare, Litherland; Back-up: Ballard)

Aims of the Project and Significance of the Research

For people with dementia and their families, diagnosis can be a difficult time. For some it brings relief, but for many it brings anger, sadness, fear, and confusion.<sup>1,2</sup> Successful adjustment to a dementia diagnosis is essential for maintaining quality of life and may even help to prevent or delay further cognitive decline, but there is no consensus on the best approaches to facilitating adjustment.<sup>3</sup> Advocacy, activism, and peer support may be powerful pathways to adjustment,<sup>4,5</sup> promoting positive identities at a time when the diagnosis of dementia and accompanying social stigma threaten pre-dementia identities and self-worth.<sup>6</sup> The work of individual dementia activists such as Kate Swaffer and Christine Bryden has generated significant interest, but less attention has been paid to collective, grass-roots initiatives. In the UK, for example, the Dementia Engagement and Empowerment Project (DEEP) is a network of 50 user-led advocacy groups that support more than 1,000 people with dementia to influence the policies and practices that affect their lives.<sup>7</sup> The DEEP model may facilitate adjustment to the dementia diagnosis and DEEP members are ideally placed to inform the development of interventions to support improved adjustment. To date, however, the DEEP model has not been subject to systematic research.

As the population ages and the demand for early diagnosis grows,<sup>8</sup> it is vital that health and social care professionals understand the impact of diagnosis and how best to support people with dementia through the adjustment process. The aim of this PhD is to conduct a program of research that will examine the process of, and develop strategies to better support, adjustment to diagnosis in people with dementia. It has three main objectives:

- (1) To review the existing evidence on adjustment to diagnosis;
- (2) To examine the experiences of adjustment in people diagnosed with dementia participating in DEEP;
- (3) To use the lessons from DEEP to develop a brief intervention to facilitate adjustment to diagnosis in people with dementia.

Work which has led up to this project

For the past seven years, Dr O'Dwyer has led and collaborated on research examining the development and evaluation of psychosocial interventions for people with dementia.<sup>e.g.9,10,11</sup> Prior to that, she conducted applied research and policy development in the third sector, with a particular emphasis on the evaluation of grass-roots programs designed to empower and engage older people.<sup>e.g.12,13,14</sup> She is currently supervising a PhD on the role of social media in fostering positive identities for people with dementia.

Professor Clare has led a long and distinguished program of research on adjustment and identity in people with dementia. This research has explored the process of dyadic adjustment to the dementia diagnosis,<sup>e.g.15</sup> the maintenance of awareness at varying stages of dementia,<sup>e.g.16,17</sup> and the influence of Dementia Advocacy and Support International (DASNI) on self-concept and adjustment.<sup>4</sup> Professor Clare has also led research on psychosocial interventions for people with dementia, including the GREAT trial (a multi-centre RCT of goal-oriented cognitive rehabilitation for people with early stage dementia).<sup>18</sup>

Ms Litherland is the Co-Director of Innovations in Dementia, a community interest company that provides advice and training on dementia for organisations and individuals across the UK, including DEEP. She is national leader in facilitating involvement of people with dementia, and has previously published on the development of DEEP.<sup>19</sup>

This PhD will build on Dr O'Dwyer and Professor Clare's previous research, and draw on Ms Litherland's close involvement with DEEP.

Detailed experimental design and methods to be used

This PhD will consist of a narrative review and three empirical studies.

*Literature Review*

A narrative review of the literature on how people adjust to a diagnosis of dementia will be conducted. This review will examine theoretical perspectives on adjustment as a psychological process (including its impact on identity), and explore cross-sectional research (both quantitative and qualitative) on the experience and correlates of good and poor adjustment.

*Study One (months 1 to 15)*

A systematic mixed-methods review of interventions designed to facilitate adjustment to the diagnosis of dementia will be conducted. A broad definition of adjustment will be used and interventions are likely to include, but will not be limited to, post-diagnostic support programs, self-management programs, and other psychosocial interventions. This review will synthesise the existing experimental evidence, identify gaps and limitations, and highlight directions for future research.

*Study Two (months 1 to 21)*

A cross-sectional survey of all DEEP members (n=1,000) will be conducted. The survey will include measures of adjustment, identity, physical health, mental health, social support, experiences of stigma, and wellbeing. To understand the impact of participation in DEEP, comparisons will be made between three groups of participants: (1) those involved with DEEP for less than 6 months; (2) those involved with DEEP for between 6 and 18 months; (3) those involved with DEEP for more than 18 months. Inferential statistics will be used to examine the relationships between adjustment and other variables within the sample as a whole, and between groups.

Follow-up interviews will be conducted with a sub-sample of participants to identify the strengths and limitations of the DEEP model, including barriers and facilitators to participation. Maximum variation sampling will be used to select 12 participants for interview with a mix of relevant experiences and demographic profiles. Interviews will be recorded on a digital Dictaphone and the data will be transcribed and analysed thematically.

### *Study Three (months 13 to 33)*

Although DEEP groups may offer a valuable pathway to adjustment, they may not be suited to, or accessible for, all people with dementia. Study Three will use the findings from Study Two to create a DEEP-based intervention suitable for one-on-one delivery by health and social care professionals. The intervention will be co-created with DEEP members and clinicians via a series of workshops, and tested for feasibility in a series of single case studies with people with dementia who have not been involved with DEEP.

### How will the results from this research be used?

The findings from each study, along with the narrative review, will be reported in peer-reviewed journal articles and academic conference presentation. Lay summaries will be distributed to DEEP members and other health and social care organisations that support people with dementia. A resource will also be prepared to help DEEP groups use the findings to promote their activities and identify areas for improved engagement. Media and social media will be used, as appropriate, to further share the findings. Following completion of the PhD, the candidate will be supported to apply for funding for a pilot trial of the intervention.

### Involvement of people affected by dementia and other relevant stakeholders

DEEP members will be consulted and involved through all stages of the work. Clinicians (including psychologists, social workers, nurses, and general practitioners) will also be consulted to ensure that the intervention developed in Study Three is feasible for use in their professional practice.

## **Project 3: Engagement and feasibility of an evidence-based activity toolkit for people with severe dementia living in care homes** (Lead supervisor: Corbett; Co-supervisors: Testad, Savage; Back-up: Clare)

### Aims of the project and significance of the research

This project addresses a major unmet need in the care of people with severe dementia living in care homes. These individuals have extremely complex care needs due to severe cognitive and functional impairment, which is compounded by the loss of verbal communication inherent in late-stage dementia. As a result, opportunities for engagement and involvement in activities and treatment is limited, particularly in care home settings where staff struggle with competing demands on their time, and where these individuals are often perceived as too challenging or disinterested to engage.

There is good evidence supporting the use of psychosocial approaches for people with dementia. Engagement in pleasant activities and proactive person-centred engagement approaches are known to reduce both neuropsychiatric symptoms and the need for antipsychotic medications, and to improve mood, wellbeing and quality of life<sup>1</sup> in a cost-effective way<sup>2-4</sup>. These outcomes are of particular importance in people with severe dementia since symptoms are more common and their impact more severe as dementia progresses. Recent work has also highlighted the imperative of framing activities around structured social interaction<sup>3</sup>, and the importance of care staff training in eliciting change in care practice<sup>5,6</sup>. However, implementation of this evidence has proven challenging and there is little support for care homes in ensuring they are using evidence-based approaches<sup>7</sup>. Although over 170 manuals for person-centred care and activities exist, only three have supporting evidence<sup>8</sup>.

Opportunities for people with severe dementia to engage in meaningful activities in long-term care are restricted. This is the result of limited staff resources, the challenge of tailoring activities for residents with complex needs<sup>9</sup>, cultural and attitudinal barriers in care home settings and a lack of evidence-based training and support<sup>10-11</sup>. Staff training is integral to success in implementation, but this requires a clear structure and theoretical framework in order to embed change. There is also increasing interest in the potential for use of evidence-based technological solutions to support training and care. There is a timely opportunity to build on existing literature and recent large research programmes to improve implementation of existing activity paradigms into routine care, particularly for those with severe dementia, and to explore novel means of supporting decision-making by staff.

This project aims to:

1. Develop and evaluate the feasibility of a quick and easy method of determining activity options for people with severe dementia in care homes
2. Explore the most effective means of implementing an activity toolkit for people with severe dementia, including the use of technology to support decision-making.
3. Examine the impact of the resulting toolkit on participation and well-being of people with dementia and staff engagement and behaviour

#### Work which has led up to this project

This project builds on a portfolio of research into person-centred care and psychosocial interventions in care home settings that has been led by the supervisory team for the last two decades, including two major programmes of research<sup>1,3,5,8,10,12-14</sup>. The FITS (Focussed Intervention Training and Support)<sup>14</sup> study, supported by Alzheimer's Society, reported benefit to reducing antipsychotic prescribing following a structured person-centred training programme (involving Prof Ballard and Dr Corbett, and collaborator Prof Fossey) and identified major organisational barriers to implementation. The subsequent NIHR WHELD (Well-being and Health for People with Dementia) programme showed that a complex intervention combining care staff training, antipsychotic review, activities and social interaction (Prof Ballard, Dr Corbett, and Prof Fossey), led to significant benefit to behavioural symptoms and quality of life in people with dementia<sup>6</sup>. Crucially, this work has highlighted key challenges to implementation, which directly inform the current project<sup>5</sup>. The project also builds on the AwareCare study (Prof Clare), where even residents with very severe dementia demonstrated signs of responsiveness that could be further increased through providing a stimulating environment<sup>15</sup>.

#### Detailed experimental design and methods to be used

##### *Stage 1: Stakeholder and expert consultation (Months 1 – 9)*

Stage 1 will involve a series of focus groups with family carers and care home staff to discuss issues around acceptability and feasibility of different activities for people with severe dementia, and to receive guidance on the most important elements for a simple tool to support decision-making by staff. This will include discussion of the potential value of a technology-based approach. An expert steering group consisting of specialists in the field, supervisors / collaborators, care staff and lay advisors will be convened to review recent systematic reviews and prioritise suitable activities for inclusion. These are expected to include sensory activities, social interaction and music therapies. Finally, the Clinical Fellow will work with technology company KareInn ([www.kareinn.com](http://www.kareinn.com)), who specialise in simple solutions for supporting care staff decision-making and improving care practice. This work will explore how to adapt an existing smartphone-based system to prompt use of activities for people with severe dementia.

##### *Stage 2 – Development of activities and decision-making toolkit (Months 10 – 16)*

The outcomes of Stage 1 will be discussed by the expert steering group and used to develop a specification for the activities and decision-making toolkit. The specification will build on a theoretical framework for behaviour change and will utilise a technological solution to prompt decision-making through a simple tablet-based system which draws on a residents' personal details to guide care staff in selecting appropriate activities. The overall aim will be to engage people with severe dementia in a personalised and meaningful activity for at least ten minutes each day, as recommended in the literature. Usability testing will be completed with care staff using simulated scenarios.

##### *Stage 3 – Feasibility study of activities and decision-making toolkit (Months 17 – 33)*

The Clinical Fellow will conduct a six-week feasibility study of the activities and decision-making toolkit to establish its use by care homes and its effectiveness in supporting care staff to engage people with dementia in meaningful activities. Six care homes will be recruited, and staff will receive a brief training session after which they will be asked to use the toolkit developed in Stage 2. All residents with severe dementia (MMSE <12) and care staff will be eligible. The primary outcome will be feasibility of the toolkit as measured through usage statistics and engagement of residents with activities. Secondary measures collected by the Clinical Fellow and Research Assistant at baseline, three and six weeks will include behavioural symptoms (Neuropsychiatric Inventory) and care staff job satisfaction and burden. Feasibility and care staff experience will be explored through semi-structured interviews.

##### *Stage 4: Dissemination (Months 34 – 36)*

The project will close with a period of dedicated dissemination. This will focus on thesis writing, but will also involve preparation of publications for peer-reviewed journals, presentation of posters at key conferences and creation of a lay report for circulation to care homes. The Clinical Fellow will work with Exeter CTU to prepare a funding application for a full RCT.

#### How will the results from this research be used?

This work has the potential to produce tangible benefit for people with dementia and staff, and could be implemented rapidly across the care sector. If successful, we will run a series of training workshops to promote the toolkit to the UK care sector and to explore how the tech-based system could be rolled out. Results will also be disseminated through academic, professional and public channels, including conferences, social media and UK networks.

#### Involvement of people affected by dementia and other relevant stakeholders

People with dementia, family carers and care home staff will be consulted and involved throughout all stages of the work to help guide development of the project through the REACH Lay Advisory Group. The group will contribute to key decisions in the project including methods of matching residents to activities, checking the acceptability and feasibility of the toolkit, providing input into the formulation and delivery of training and in the dissemination of the findings.

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