

**ACADEMIC COLLABORATION AGREEMENT**

Dated: 16<sup>th</sup> November 2016

- (1) **University of Nottingham**
- (2) **University College London**
- (3) **The University of Sheffield**
- (4) **University of East Anglia**
- (5) **University of Hull**
- (6) **Loughborough University**
- (7) **The University of Manchester**
- (8) **University of Bradford**
- (9) **Maastricht University**
- (10) **Universidade Federal de Santa Catarina**

## CONTENTS

---

### CLAUSE

1.	Interpretation .....	2
2.	Purpose and Scope .....	4
3.	Meetings.....	4
4.	Project Management.....	4
5.	Financial Management.....	5
6.	Confidentiality and Publication.....	6
7.	Intellectual Property and Exploitation .....	8
8.	Term .....	10
9.	Addition of New Parties.....	10
10.	Withdrawal .....	11
11.	Termination .....	11
12.	Consequences of Termination .....	12
13.	Dispute Resolution .....	12
14.	Third Parties.....	13
15.	Notices .....	13
16.	Liability .....	13
17.	Liability Limitations.....	14
18.	Responsibilities to Each Other.....	14
19.	No Partnership or Agency.....	14
20.	No Implied Licence .....	15
21.	Enforcement of Intellectual Property Rights .....	15
22.	Assignment .....	15
23.	Governing Law.....	15
24.	Counterparts .....	15
25.	Miscellaneous .....	16
26.	Continuing Obligations.....	16

### SCHEDULE

SCHEDULE 1	: PROJECT .....	20
SCHEDULE 2	: OFFER LETTER.....	21
SCHEDULE 3	: FINANCIAL BREAKDOWN .....	22
SCHEDULE 4	: TEMPLATE EXPENDITURE RETURN .....	27

## ACADEMIC COLLABORATION AGREEMENT BETWEEN:

- (1) **The University of Nottingham** of University Park, Nottingham NG7 2RD, United Kingdom ("**Nottingham**"); and
- (2) **University College London** of Gower Street, London WC1E 6BT ("**UCL**"); and
- (3) **The University of Sheffield** of Western Bank, Sheffield, S10 2GW ("**Sheffield**"); and
- (4) **University of East Anglia** of Norwich Research Park, Norwich, Norfolk NR2 7TJ ("**UEA**"); and
- (5) **University of Hull** of Cottingham Road, Hull, HU6 7RX ("**Hull**"); and
- (6) **Loughborough University** of Loughborough, Leicestershire LE11 3TY ("**Loughborough**"); and
- (7) **The University of Manchester** of Oxford Road, Manchester M13 9PL ("**Manchester**"); and
- (8) **University of Bradford** of Richmond Road, Bradford BD7 1DP ("**Bradford**"); and
- (9) **Maastricht University** of Postbus 616, 6200 MD Maastricht, The Netherlands ("**Maastricht**"); and
- (10) **Universidade Federal de Santa Catarina** of Campus Universitário Reitor João David Ferreira Lima, - Florianópolis – Santa Catarina – Brazil ZIP CODE: 88040-900 ("**UFSC**")

Hereinafter, each a "**Party**" and collectively the "**Parties**".

### BACKGROUND

- (A) On 4 November 2013 the Economic and Social Research Council ("**ESRC**") made an award to UCL in respect of the project entitled "**PRIDE – Promoting Independence in Dementia**" (the "**Project**") under reference ES/L001802/1.
- (B) On 1 March 2015 the Principal Investigator transferred from UCL to Nottingham.
- (C) On 7 August 2015 ESRC made an award to Nottingham for the Project under reference: ES/L001802/2. The funding awarded was in respect of the remaining funding following the transfer of the Principal Investigator and the funding split set out at Schedule 3 in in respect of the remaining funding following transfer only.
- (D) On 1 September 2015 Gail Mountain transferred from Sheffield to Bradford.
- (E) This Agreement sets out the parties respective rights and obligations with respect to their collaborative activities under the Project and supersedes any and all previous agreements that may have been entered into between UCL and any Party, save in respect of payments made previously by UCL.

**Now, therefore**, in consideration of agreed commitments to the Project by the Parties attached at Schedule 1, the Sponsor's offer letter at Schedule 2 (the "**Offer**") and the financial breakdown at Schedule 3, the receipt and sufficiency of which are hereby acknowledged, the parties agree as follows:

RGS117367

## AGREED TERMS

### 1. INTERPRETATION

1.1 The definitions and rules of interpretation in this clause apply in this agreement.

- "Background Intellectual Property" means Intellectual Property already owned by a Party prior to the commencement of the Project or developed or acquired outside the scope of the Project by a Party and introduced into the Project by such Party.
- "Co-Investigators" means Paul Higgs at UCL; Gail Mountain at Bradford; Fiona Poland at UEA; Esmé Moniz-Cook at Hull; Eef Hogervorst at Loughborough; David Challis at Manchester; Andre Xavier at UFSC; Eleonora Dorsi at UFSC; Frans Verhey at Maastricht.
- "Confidential Information" means all information of whatever nature or form that is disclosed by a Party ("**the Disclosing Party**") to another Party ("**the Receiving Party**") and which is either clearly marked as confidential or if disclosed orally or visually, but was, at the time of disclosure indicated to be confidential.
- "Foreground Intellectual Property" means such intellectual property that is created, devised, developed or made in the course of work on the Project excluding any Background Intellectual Property.
- "Intellectual Property" means all inventions, patents, copyrights, work of authorship, design rights, trade names, trade marks, service marks, slogans (whether any of the same are registered or unregistered), know-how, data base rights (including the copyright of software in any code), and any other industrial or intellectual property and related rights anywhere in the world including applications for the foregoing.
- "Joint Intellectual Property" means individually and collectively all Foreground Intellectual Property which is generated collaboratively by two or more

	Parties in performance of the Project under this Agreement.
"Participating Associates"	means any contractor, subcontractor or service provider of a Party.
"Principal Investigator"	means Martin Orrell at University of Nottingham
"Research Contributions"	means the research activities of the Parties allocated to each Party in Schedule 1 or as may be agreed between each Party and the Project Board (as defined below) from time to time
"Results"	means any data recorded in any form resulting from experimental research, reports, statistical or mathematical tools, computer programs and algorithms developed in the course of work on the Project
"Sponsor"	means the ESRC

1.2 In this Agreement, unless otherwise expressly provided or unless the context otherwise requires:-

- (a) References to the singular include the plural and vice versa.
- (b) References to words denoting any gender shall include all genders.
- (c) References to persons include companies, government departments and agencies and all other forms of body corporate or unincorporated.
- (d) References to Clauses and Schedules are to Clauses of, and Schedules to, this Agreement.
- (e) References to laws and statutory provisions shall include reference to any subordinate legislation made pursuant thereto and shall be construed as referring to those laws, provisions and subordinate legislation as respectively amended or re-enacted from time to time.
- (f) The headings of this Agreement are for ease of reference only and are not part of this Agreement for the purposes of construction.
- (g) Any undertaking by a Party not to do an act or thing shall be deemed to include an undertaking not to permit or suffer such act or thing to be done by another person.
- (h) References to the Parties include their respective successors in title, permitted assigns and authorised legal representatives.

1.3 The Schedules form part of this Agreement and shall have effect as if set out in full in the body of this Agreement and accordingly any reference to this Agreement includes the Schedules.

1.4 In the event of any conflict between the terms of this Agreement and the terms of the Offer then the terms of the Offer will prevail. Subject to the foregoing, this Agreement shall take precedence over any other agreement signed between the parties relating to the subject matter hereof and over any other documents referred to herein.

## **2. PURPOSE AND SCOPE**

2.1 Sheffield agrees to perform this Agreement for the period 1 March 2014 to 31 August 2015 only, save that following this period it agrees to comply with its continuing obligations in accordance with clause 26 of this Agreement. All other Parties agree to release Sheffield from all future claims and demands in respect of this Agreement and from performing this Agreement after 31 August 2015, save in respect of its continuing obligations in accordance with clause 26 of this Agreement or for any claim or demand relating to matters arising under or in connection with this Agreement on or before 31 August 2015.

2.2 The Project shall be undertaken at all times by the Parties in accordance with the terms of the Offer. Subject to this Clause 2.1, the terms of this Agreement shall govern the rights and obligations of the Parties.

2.3 These obligations include their respective contributions, the management structure and all other terms of collaboration to be complied with in connection with the Project.

## **3. MEETINGS**

3.1 The Parties undertake to have regular discussions (the timings of which to be mutually agreed) on the Project's progress and to meet at least twice per year over the Project's duration to discuss all matters pertaining to the research work and Results of the Project.

## **4. PROJECT MANAGEMENT**

4.1 The overall management of the Project shall be the responsibility of Nottingham through the Principal Investigator who shall be the primary contact for and with the Sponsor and whose principal duties are listed in this Clause 4

(a) Nottingham shall manage the Project in accordance with the terms of this Agreement and the Offer.

(b) Nottingham shall use all reasonable efforts to ensure that the Parties do everything that is requisite to enable the terms of the Offer to be fulfilled

- 4.2 A project board will be set up and will consist of a representative of each Party chosen from amongst the Co-Investigators and chaired by the Principal Investigator (the "Project Board"). Each representative shall be responsible for managing that Party's responsibilities in the Project and liaison with the Principal Investigator.
- 4.3 The Project Board will meet at least twice per year over the duration of the Project either in person or via teleconference facilities. If necessary, a Party may delegate their attendance at meetings to an appropriately qualified member of their Co-Investigator's research group. The Project Board will be responsible for managing the Project in accordance with the requirements of this Agreement and the regulations of the Sponsor.
- 4.4 The quorum for a meeting of the Project Board shall be no less 80% of its members or their proxies. Each Party shall through its representative on the Project Board have one vote in Project Board decisions. All decisions shall be taken on a majority basis (of those members in attendance) save where no clear decision is reached in which case the Chairperson shall have the casting vote.

## **5. FINANCIAL MANAGEMENT**

- 5.1 The financial arrangements for the Project shall be overseen by Nottingham, details of which are set out in Schedule 3.
- 5.2 Nottingham will act as the financial hub of the Project and will receive all monies from the Sponsor and distribute them according to Schedule 3 in response to invoices sent quarterly in arrears by a Party, based on 80% of actual expenditure (with the exception of Maastricht and UFSC which shall be paid at 100%) for all items to:

Post Award Team

The University of Nottingham

Research & Graduate Services

King's Meadow Campus

Lenton Lane

Nottingham

NG7 2NR.

Each invoice should be accompanied by a completed spreadsheet in the form outlined in Schedule 4 which will be e-mailed to each Party claiming funds on signature of this Agreement. Each Party claiming funds must ensure that for all claims made against

directly incurred costs an auditable record supports the claim. A claiming Party's final invoice should be submitted to Nottingham within two months of the end of the Project.

- 5.3 UFSC will submit invoices in respect of the funding allocated both to itself and UNISUL.
- 5.4 Each Party shall ensure that Nottingham is provided, in a timely fashion, with such information, data, documentation and supporting evidence as may be reasonably required by Nottingham from time to time to enable Nottingham to comply with the financial requirements set out in the Offer and regarding the payment of such grant or funding. Nottingham shall, on request from any Party provide (within 7 days of any such request) to such requesting Party copies of all correspondence with and from the Sponsor in relation to the Offer or the Project as such Party may request.
- 5.5 The Sponsor funding will be committed to the support of the Project as set out in Schedule 1. Subject to Clause 5.6, all funding granted under the Offer will be used only by the receiving Parties in accordance with this Agreement.
- 5.6 The Principal Investigator, on behalf of Nottingham, will be responsible for submission of accounts to the Sponsor, in accordance with the Offer.
- 5.7 Nottingham shall permit an independent chartered or certified public accountant appointed by any Party, at the inspecting Party's expense to examine all books and records of Nottingham relating to this Agreement provided:
  - (a) reasonable prior written notice is given to the Principal Investigator for Nottingham;
  - (b) access is required only during normal working hours
  - (c) the inspecting Party and their auditor shall keep and shall use reasonable endeavours to procure that any of its representatives shall keep confidential information that it may acquire in the exercise of its rights under this Clause.

## **6. CONFIDENTIALITY AND PUBLICATION**

- 6.1 Subject to the provisions of Clause 6.2 and 6.3 regarding publication, all Confidential Information exchanged between the Parties or learned during the course of this Agreement shall, for a period of five (5) years from the date of receipt of such Confidential Information, be treated by the Receiving Party and its Participating Associates as confidential and shall not be disclosed to third parties by the receiving Party without express prior authorization from the Disclosing Party. Confidential Information of a Disclosing Party shall not be used by the Receiving Party except for the purpose of fulfilling its obligations of this Agreement unless otherwise agreed in writing by the Disclosing Party.
- 6.2 In accordance with normal academic freedom and the regulations of the Sponsor, the Results should be published for the general public and other relevant beneficiaries with



an acknowledgement of the support received from the Sponsor. Such publication shall not include any of the Parties' Confidential Information. For the avoidance of doubt, publication shall include but not be limited to publication in scientific journals, conferences and poster presentations.

- 6.3 In recognition of the Parties' mutual contributions to the Project each shall be given the opportunity to review any proposed publications arising from the Results prior to publication to comment and if necessary require amendment to protect their Confidential Information (that is not Results) and/or require a delay to enable protection of Foreground Intellectual Property. The Party intending to publish (the "**Proposing Party**") shall inform the Principal Investigator and the Project Board of any such intended publication in writing with a copy of the proposed publication arising from the Project at least 30 days prior to the intended submission or publication date. In the event that a representative on the Project Board identifies any Confidential Information and/or Foreground Intellectual Property it wishes to be protected it shall inform the Proposing Party in writing accordingly. If no written reply is received within 30 days of receipt of the proposed publication then the proposing Party shall deem that the Project Board has not identified any such Confidential Information and/or Foreground Intellectual Property and publication will proceed in the form disclosed to the Project Board. In no event shall permission for publication be unreasonably withheld. The Parties agree that delay in publication for the purpose of protection of Confidential Information and/or Foreground Intellectual Property shall not exceed 6 months.
- 6.4 The Parties agreed that any publication shall carry the following statement "This work was funded by the ESRC and was carried out as part of a collaborative project of the University of Nottingham, University College London, University of Sheffield, University of East Anglia, University of Hull, Loughborough University, University of Manchester, University of Bradford, Maastricht University and Federal University of Santa Catarina".
- 6.5 The obligations of non-use and confidentiality in this Clause 6 shall not apply to information which:
- (a) is known to the receiving Party before the commencement date of the Project, and not impressed already with any obligation of confidentiality to the disclosing Party; or
  - (b) is or becomes publicly known without fault on the part of the receiving Party; or
  - (c) is obtained by the receiving Party from a third party in circumstances where the receiving Party has no reason to believe that there has been a breach of an obligation of confidentiality owed to the disclosing Party; or
  - (d) is independently developed by the receiving Party, or
  - (e) is approved for release in writing by an authorised representative of disclosing Party, or

- (f) the receiving Party is specifically required to disclose pursuant to an order of any Court of competent jurisdiction in order to fulfil the Court Order; or
- (g) is required to be disclosed by law or regulation (including any requests under the Freedom of Information Act 2000 or Environmental Information Regulations 2004) or by order of a competent authority (including any regulatory or governmental body or securities exchange), provided that the Disclosing Party is given as much as possible advance notice of the intended disclosure by the Receiving Party intending to make such disclosure and the Receiving Party consults with the Disclosing Party and gives due consideration to the Disclosing Party's comments.

6.6 Nothing in this agreement shall prevent any student enrolled at a Party to undertake a higher degree based on the work undertaken by them in the Project from using a Party's Background Intellectual Property, Foreground Intellectual Property, Results and/or Confidential Information in any thesis or examination undertaken by the student at in accordance with the procedures for examination and/or admission to postgraduate status at the Party they are enrolled with provided that:

- (h) any reviewers of the thesis or examination are subject to an obligation of confidentiality no less onerous than that set out in this Agreement; and
- (i) a final draft of the thesis shall be submitted to the Project Board at least thirty (30) days prior to the date for submission for examination. If the thesis contains a Party's Confidential Information, upon the reasonable written request of that Party the thesis shall be placed on restricted access (in accordance with the relevant Party's standard procedures) for a period of three (3) years from the date of such request. Such request must be provided within fourteen (14) days of receipt of the thesis by the Project Board.

## **7. INTELLECTUAL PROPERTY AND EXPLOITATION**

7.1 The ownership of Background Intellectual Property will not be affected by this Agreement and ownership will remain vested in the Party to which it belongs. No transfer of such Background Intellectual Property to any other Party shall occur hereunder and none of the provisions of this Agreement shall be construed as such a transfer. However, where legally free to do so, the Parties shall grant to the other Parties a non-exclusive, royalty free licence of their Background Intellectual Property for the term of this Agreement and only to the extent that such a licence is required to enable a Party to fulfil its obligations hereunder.

7.2 Each Party grants to the other Parties an irrevocable, non-exclusive, non-transferable, royalty-free licence to use all Foreground Intellectual Property generated in the course of the Project for the purpose of fulfilling their obligations under this Agreement and for academic and research purposes, including research involving projects funded by third

parties provided that those parties gain or claim no rights to such Foreground Intellectual Property. Nothing in this Agreement grants any Party any right to use any of the trade marks, service marks or trade names of any other Party, directly or indirectly, in conjunction with any product, service, promotion, publication or publicity without the prior written approval of such other Party or of the appropriate trade mark or trade name owner.

- 7.3 Notwithstanding any other provisions of this Agreement, ownership of any Foreground Intellectual Property shall be vested in the Party or Parties generating such Foreground Intellectual Property who shall be responsible for securing ownership of such Foreground Intellectual Property from their employees, students and other Participating Associates. Subject to the terms of this Agreement, the Party owning any Foreground Intellectual Property shall be entitled to use and exploit such Foreground Intellectual Property as that Party sees fit, and subject always to Clauses 7.6 and 7.7.
- 7.4 The Parties shall make reasonable endeavours to keep each other fully informed on a confidential basis of all Foreground Intellectual Property generated by the Project and shall be responsible for protecting and exploiting any such Foreground Intellectual Property at the owning Party's, or Parties', expense. In the event the owning Party or Parties are unable or unwilling to comply with its obligation to protect and exploit Foreground Intellectual Property, the Project Board shall consider how best to deal with such Foreground Intellectual Property and shall have the option to require an assignment of such Foreground Intellectual Property to another Party to enable prosecution and maintenance of such Foreground Intellectual Property by that other Party at its own cost. In the event that any Party wishes to exploit commercially any Foreground Intellectual Property assigned pursuant to this Clause 7.4, that Party shall pay to the assigning Party a royalty and/or other appropriate form of remuneration which is fair and reasonable taking into consideration the factors set out under Clause 7.7.
- 7.5 All Joint Intellectual Property will be jointly owned by the relevant Parties who jointly developed it and shall be apportioned according to respective inventive contribution. The detailed arrangements for handling the protection and exploitation arrangements for Joint Intellectual Property shall be made by the relevant owning Parties ("Joint Owners") under separate written agreement between them, which shall include cost sharing in relation to the external costs (official fees) for the drafting, filing, prosecuting and maintenance of such Joint Intellectual Property; and which Party shall be best placed to take the responsibility for the filing and prosecution on behalf of the Joint Owners and in their joint names of applications for registration, and the maintenance and renewal of any registrations, in such countries as the Joint Owners agree to obtain protection of such Joint Intellectual Property, subject to the other Joint Owner(s) cooperating in the provision of all necessary assistance, information and instructions, with respect to the same. Each such Joint Owner or applicant shall have the right to use Joint Intellectual Property by itself solely for non-commercial internal research and development purposes only without recourse to the other Joint Owners.

- 7.6 Any non-owning Party may request to non-exclusively exploit commercially any Foreground Intellectual Property or Joint Intellectual Property vested in another Party or Parties where such Intellectual Property is specifically applicable to their commercial area of interest (the “**Option**”) within 3 months of such Foreground Intellectual Property or Joint Intellectual Property being notified to and coming to the attention of the non-owning Party (the “**Option Period**”). The Option Period shall be extendable only by written agreement and the exercise of such Option shall be subject to Clause 7.7. However should the non-owning Party decide not to exercise such Option and/or not successfully conclude negotiations within the Option Period, the Option shall lapse and the owning Party shall be free to dispose of their Intellectual Property as they may so decide with no further recourse to the non-owning Party.
- 7.7 Should any Party require access rights to any Foreground Intellectual Property vested solely in another Party for commercial exploitation of its own Foreground Intellectual Property arising from the Project then reasonable endeavours shall be employed in negotiating terms of a separate specific bilateral written Agreement between the applicable negotiating Parties which shall include reasonable commercial terms (to include the payment of royalties or other forms of revenue) for the type of rights involved taking into account the respective Party's financial and non-financial contributions under this Agreement also taking into account the respective contributions of the Parties to such exploitation determined on a case-by-case basis. Any access rights to a Party's Background Intellectual Property shall be restricted to the extent to which such access may be legally permitted and shall be subject to negotiated fair and reasonable commercial terms.
- 7.8 Each Party shall, except as provided by Clause 16 herein, use reasonable endeavours to ensure the accuracy of any information or materials that it supplies to any of the other Parties for use in the Project.

## **8. TERM**

- 8.1 This Agreement shall come into effect on 1 March 2014 and terminate on 28 February 2019 unless an extension to this term is agreed in writing by all the Parties.

## **9. ADDITION OF NEW PARTIES**

- 9.1 New parties may join the Project subject to the unanimous agreement of the Project Board and the Sponsor, and subject to Clause 9.2.
- 9.2 New parties shall be bound by the terms of this Agreement and such other conditions as the Project Board may specify.

## **10. WITHDRAWAL**

- 10.1** Any Party (the "**Withdrawing Party**") may withdraw from the Project upon 3 months' written notice to the Project Board and subject to such conditions as the Project Board and/or Sponsor may decide.
- 10.2** In the event of withdrawal of a Party the remaining Parties will make reasonable attempts to reallocate the obligations of the Withdrawing Party under this Agreement between themselves or to a third party acceptable to the Sponsor, provided that any such third party agrees to be bound by the terms of this Agreement.
- 10.3** The Withdrawing Party shall not be entitled to recover any of its costs incurred after the date of withdrawal in connection with the Project and shall comply with all conditions imposed pursuant to Clause 10.1 which shall include (without limitation);
- (a) rights granted to the other Parties in respect of the Withdrawing Party's Background Intellectual Property shall continue for the duration of the Project subject to the restrictions contained in this Agreement;
  - (b) to the extent that exploitation of any other Party's Foreground Intellectual Property is dependent on the Withdrawing Party's Background Intellectual Property, then the Withdrawing Party shall, subject to any existing third party obligations, grant to the other Parties a non-exclusive licence to such Background Intellectual Property on fair and reasonable terms to be agreed;
  - (c) the Withdrawing Party shall grant to the other Parties a non-exclusive, royalty-free licence to use the Withdrawing Party's Foreground Intellectual Property for the purposes of carrying out the Project. For the avoidance of doubt any exploitation of such Withdrawing Party's Foreground Intellectual Property will be dealt with in accordance with Clause 7; and
  - (d) all rights acquired by the Withdrawing Party to the Background and Foreground Intellectual Property of the other Parties shall cease immediately other than in respect of the Withdrawing Party's interest in any Joint Intellectual Property.

## **11. TERMINATION**

- 11.1** In the event that any Party shall commit any material breach of or default in any terms or conditions of this Agreement, the remaining Parties via the Project Board may serve written notice of such breach or default on the defaulting Party and in the event that such Party fails to remedy such default or breach within sixty (60) days after receipt of such written notice the Project Board may, at their option and in addition to any other remedies which the Parties may have at law or equity, remove the defaulting Party and continue with the Agreement. Any removal of the defaulting Party shall be effective as of the date of the receipt of such notice whereupon the provisions of Clause 10.3 shall apply to the defaulting Party.

**11.2** If any Party ("Breaching Party") (a) materially breaches any provisions of this Agreement that are not remediable or which have failed to be remediated within sixty (60) days after notice of the breach in accordance with clause 11.1; or (b) passes a resolution for its winding-up; or if (c) a court of competent jurisdiction makes an order for that Party's winding-up or dissolution; or makes an administration order in relation to that Party; or if any Party (e) appoints a receiver over, or an encumbrancer takes possession of or sells an asset of, that Party; or (f) makes an arrangement or composition with its creditors generally; or (g) makes an application to a court of competent jurisdiction for protection from its creditors generally; a non-breaching Party may terminate its involvement on the Project on written notice to the other Parties.

**11.3** In the event that it is agreed by all the Parties that there are no longer valid reasons for continuing with the Project, the Project Board may decide by unanimous vote to terminate this Agreement by sending notice of termination in writing to all the Parties to that effect.

## **12. CONSEQUENCES OF TERMINATION**

**12.1** Options or licences granted by a Party to the Breaching Party shall terminate on the date of termination. Each Party will return of all Confidential Information and Background Intellectual Property upon demand by the owning Party.

**12.2** Rights granted to the other Parties in respect of a Party's Background Intellectual Property or Foreground Intellectual Property shall continue as set out in Clause 7.1.

**12.3** All rights acquired by the Breaching Party to Foreground Intellectual Property and Background Intellectual Property of the other Parties shall cease and be void from the date of termination of the Agreement.

**12.4** In the event of termination of the Agreement at expiration of the Term and pursuant to the provisions of Clause 11.3 where the Parties agree there are no longer valid reasons for continuing with the Project all rights to Background and Foreground Intellectual Property shall cease immediately except in the case of a Party's interest in any Joint Intellectual Property licences granted under Clause 7.2 and any agreements concluded pursuant to Clause 7.7.

## **13. DISPUTE RESOLUTION**

**13.1** The Parties shall use good faith efforts to resolve any dispute, claim or proceeding arising out of or relating to the subject matter of this Agreement via the Project Board. In the event that any disputes cannot be resolved at this level then the senior executives of the relevant Parties who have authority to settle the same shall use good faith efforts to resolve the same. The concerned Parties may instead elect unanimously to resolve by mediation any dispute or difference arising in connection with this Agreement, which cannot be settled amicably.

- 13.2 If the matter is not resolved through negotiation within twenty eight (28) days, the parties may attempt to settle it by mediation in accordance with the Centre for Effective Dispute Resolution ("CEDR") Model Mediation Procedure. Unless otherwise agreed between the disputing Parties, the mediator will be nominated by CEDR.
- 13.3 To initiate mediation a Party must give notice in writing ("ADR Notice") to the other Party to the dispute requesting mediation in accordance with Clause 13.2 above. A copy of any such request should be sent to CEDR. The mediation will start no later than 30 days after the ADR Notice.

#### **14. THIRD PARTIES**

- 14.1 The Contracts (Rights of Third Parties) Act 1999 shall not apply to this Agreement and no person or persons other than Parties to this Agreement shall have any rights under it, nor shall it be enforceable under that Act by any person other than the Parties to it.

#### **15. NOTICES**

- 15.1 Any notices should be addressed to the Parties as set out in Schedule 5.

#### **16. LIABILITY**

- 16.1 In respect of information or materials supplied by one Party to another hereunder, the supplying Party shall be under no obligation or liability (other than as stated in this Clause 16), and no warranty condition or representation of any kind is made by, given by or to be implied against any Party as to the sufficiency, accuracy or fitness for purpose of any such information or materials, or the absence of any infringement of any proprietary rights of third parties (including without limitation intellectual property rights, trade secret rights and rights over Confidential Information) by the use of such information and materials; and the recipient Party shall in any case be entirely responsible for the use to which it puts such information and materials. Each Party represents and warrants to the best of its knowledge that it has the full right and power to grant the licences granted hereunder, and that there are no outstanding agreements, assignments or encumbrances inconsistent with the provisions of any said licence or with any other provision of this Agreement. No Party makes any other representation or warranty, express or implied, neither shall any Party have any liability, in respect of any infringement of patents or other rights of third parties owing to any other Party's operation under any licence granted hereunder. Subject always to such other undertakings and warranties as are provided for in this Agreement, each Party shall be solely liable for any loss, damage or injury to third parties resulting from the carrying out by it of its parts of the Project and from its use of the Results.

**17. LIABILITY LIMITATIONS**

- 17.1 The Parties shall at all times have sufficient insurances in place to cover their obligations under this Agreement which shall be as a minimum £5,000,000 (five million pounds) and shall upon the reasonable request of any Party provide evidence that such insurance and premiums are up to date and effective.
- 17.2 The Parties undertake to make no claim in connection with this Agreement or its subject matter against any employees, students, agents or appointees of the other Parties (apart from claims based on fraud or wilful misconduct). This undertaking is intended to give protection to individual researchers: it does not prejudice any right which a Party might have to claim against any other Party.
- 17.3 The liability of any Party for any breach of this Agreement, or arising in any other way out of the subject-matter of this Agreement, will not extend to loss of business or profit, or to any indirect or consequential damages or losses.
- 17.4 Subject to clause 17.6, the maximum liability of any Party under or otherwise in connection with this Agreement or its subject matter shall not exceed the monies received by that Party under this Agreement as detailed in Schedule 3.
- 17.5 Nothing in this Collaboration Agreement limits or excludes either Party's liability for:
- (a) death or personal injury resulting from negligence; or
  - (b) any fraud or for any sort of other liability which, by law, cannot be limited or excluded.
- 17.6 The limitation at clause 17.4 shall not apply in respect of any wilful breach resulting in:
- (a) damage to real property;
  - (b) infringement of any of the Intellectual Property Rights, trade secret rights and rights over Confidential Information of any other Party or any Affiliate of any other Party

where liability shall be limited to the level of insurance as set out in clause 17.1

**18. RESPONSIBILITIES TO EACH OTHER**

- 18.1 Each Party shall use all reasonable endeavours to ensure the accuracy of any information or materials it supplies hereunder.

**19. NO PARTNERSHIP OR AGENCY**

- 19.1 Nothing in this Agreement shall create any partnership or agency between the Parties.



**20. NO IMPLIED LICENCE**

20.1 Except as explicitly granted herein, no license, immunity, or other right is granted or assigned under this Agreement, either directly or indirectly, by implication, estoppel or otherwise, to any Party with respect to any Intellectual Property Right of any other Party.

**21. ENFORCEMENT OF INTELLECTUAL PROPERTY RIGHTS**

21.1 No Party shall have any obligation under this Agreement to institute any action or suit against any third party for infringement of any Intellectual Property Rights to which it has granted a licence hereunder, or to defend any action or suit brought by any third party, which challenges or concerns the validity of any such Intellectual Property Rights. In addition, no Party to which any other Party has granted such a licence hereunder shall have any right to institute any action or suit against third parties for infringement of any such Intellectual Property Right.

**22. ASSIGNMENT**

22.1 Except as otherwise provided under this Agreement, no Party shall, without the prior written consent of the other Party assign or otherwise transfer partially or totally any of its rights and obligations under this Agreement.

**23. GOVERNING LAW**

23.1 This Agreement shall be subject to the laws of England and the Parties agree to the exclusive jurisdiction of the courts of England with regard to any dispute arising from it or its subject matter.

**24. COUNTERPARTS**

24.1 This Agreement may be executed in any number of counterparts, and by the Parties on separate counterparts, each of which so executed and delivered shall constitute one and the same instrument. Each party agrees that the delivery of this Agreement by email shall have the same force and effect as delivery of original signatures and that each Party may use such PDF/JPEG signatures as evidence of the execution and delivery of this Agreement by all parties to the same extent that an original signature could be used.

24.2 No counterpart shall be deemed as validly executed until each Party has signed a corresponding counterpart agreement.

24.3 A notice given under or in connection with this agreement is not valid if sent by e-mail.

**25. MISCELLANEOUS**

25.1 If any part or any provision of this Agreement shall to any extent prove invalid or unenforceable in law, including the laws of the European Union, the remainder of such provision and all other provisions of this Agreement shall remain valid and enforceable to the fullest extent permissible by law, and such provision shall be deemed to be omitted from this Agreement to the extent of such invalidity or unenforceability. The remainder of this Agreement shall continue in full force and effect and the Parties shall negotiate in good faith to replace the invalid or unenforceable provision with a valid, legal and enforceable provision which has an effect as close as possible to the provision or terms being replaced.

25.2 No failure to exercise or delay in the exercise of any right or remedy which any Party may have under this Agreement or in connection with this Agreement shall operate as a waiver thereof, and nor shall any single or partial exercise of any such right or remedy prevent any further or other exercise thereof or of any other such right or remedy.

**26. CONTINUING OBLIGATIONS**

26.1 The provisions of Clauses 6 (Confidentiality and Publication), 7 (Intellectual Property and Exploitation), 11 (Termination), 13 (Dispute Resolution), 16-17 (Liability), 21 (Governing Law), and 25 (Miscellaneous) shall survive termination or expiry of this Agreement (howsoever caused).

Signed by an authorised  
representative of University of  
Nottingham

  
.....  
11/11/16

Name:  
Title:  
Date:

Lee Towers MBA FCCA,  
Director of Financial Operations  
University of Nottingham

Signed by an authorised  
representative of the University  
College London

.....

Name:  
Title:  
Date:

Signed by an authorised  
representative of The University of  
Sheffield

.....

Name:  
Title:  
Date:

Signed by an authorised  
representative of the University of East  
Anglia

.....

Name:  
Title:  
Date:

Signed by an authorised  
representative of the University of Hull

.....

Name:  
Title:

Signed by an authorised  
representative of University of  
Nottingham

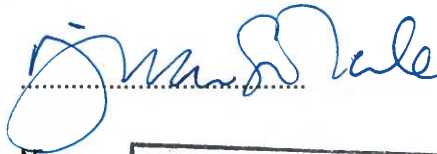
.....

Name:

Title:

Date:

Signed by an authorised  
representative of the University  
College London



Name:

Title:

Date:



Signed by an authorised  
representative of The University of  
Sheffield

.....

Name:

Title:

Date:

Signed by an authorised  
representative of the University of East  
Anglia

.....

Name:

Title:

Date:

Signed by an authorised  
representative of the University of Hull

.....

Name:

Title:

Signed by an authorised  
representative of University of  
Nottingham

.....

Name:  
Title:  
Date:

Signed by an authorised  
representative of the University  
College London

.....

Name:  
Title:  
Date:

Signed by an authorised  
representative of The University of  
Sheffield



Deborah Lodge  
Head of Operations  
Research and Innovation Services  
University of Sheffield

*Deborah Lodge*

.....

Name:  
Title:  
Date: 8/8/2016

Signed by an authorised  
representative of the University of East  
Anglia

.....

Name:  
Title:  
Date:

Signed by an authorised  
representative of the University of Hull

.....

Name:  
Title:

Signed by an authorised  
representative of University of  
Nottingham

.....

Name:

Title:

Date:

Signed by an authorised  
representative of the University  
College London

.....

Name:

Title:

Date:

Signed by an authorised  
representative of The University of  
Sheffield

.....

Name:

Title:

Date:

Signed by an authorised  
representative of the University of East  
Anglia

  
.....

Name:

Title:

Date:

**Tracy Moulton**  
Contracts Manager  
9/8/16

Signed by an authorised  
representative of the University of Hull

.....

Name:

Title:

Signed by an authorised  
representative of University of  
Nottingham

.....

Name:

Title:

Date:

Signed by an authorised  
representative of the University  
College London

.....

Name:

Title:

Date:

Signed by an authorised  
representative of The University of  
Sheffield

.....

Name:

Title:

Date:

Signed by an authorised  
representative of the University of East  
Anglia

.....

Name:

Title:

Date:

Signed by an authorised  
representative of the University of Hull



..... 8/8/16

Name:

Title:

**Mr Jonathan Cant**  
Research Grants & Contracts Manager

Signed by an authorised  
representative of the Loughborough  
University

Date:

.....  
*L. Derriff*

Name: *Laise Derriff*  
Title: *Research Projects Manager*  
Date: *4/8/16.*

Signed by an authorised  
representative of The University of  
Manchester

.....

Name:  
Title:  
Date:

Signed by an authorised  
representative of the University of  
Bradford

.....

Name:  
Title:  
Date:

Signed by an authorised  
representative of Maastricht University

.....

Name:  
Title:  
Date:



Signed by an authorised  
representative of the Loughborough  
University

Date:

.....

Name:

Title:

Date:

Signed by an authorised  
representative of The University of  
Manchester



Name:

Title:

Date:



5 August 2016

Signed by an authorised  
representative of the University of  
Bradford

.....

Name:

Title:

Date:

Signed by an authorised  
representative of Maastricht University

.....

Name:

Title:

Date:

Signed by an authorised  
representative of the Loughborough  
University

Date:

.....

Name:

Title:

Date:

Signed by an authorised  
representative of The University of  
Manchester

.....

Name:

Title:

Date:

Signed by an authorised  
representative of the University of  
Bradford



Name: ANAELA PHILLIPS.

Title: Director of Finance

Date: 31/08/16.

Signed by an authorised  
representative of Maastricht University

.....

Name:

Title:

Date:

Date:

Signed by an authorised  
representative of the Loughborough  
University

.....

Name:

Title:

Date:

Signed by an authorised  
representative of The University of  
Manchester

.....

Name:

Title:

Date:

Signed by an authorised  
representative of the University of  
Bradford

.....

Name:

Title:

Date:


Signed by an authorised  
representative of Maastricht University

.....

Name:

Title:

Date:



MK de Vos  
director MHEMS  
23/8/16

Signed by an authorised  
representative of the Universidade  
Federal de Santa Catarina



.....

Name: **Luiz Carlos Cancelier de Olivo**  
Title: **Reitor**  
Date: **Universidade Federal de Santa Catarina**

03/11/2016

**Schedule 1 : Project**

**COMPLIANCE WITH THE DATA PROTECTION ACT 1998**

In accordance with the Data Protection Act 1998, the personal data provided on this form will be processed by ESRC, and may be held on computerised database and/or manual files. Further details may be found in the **guidance notes**

# Research Programmes PROPOSAL

Document Status: With Submitter

ESRC Reference: ES/L001802/1

## ESRC/NIHR Dementia 2012

### Organisation where the Grant would be held

Organisation	University College London	Research Organisation Reference:	ES/K006673/1
Division or Department	Mental Health Sciences		

### Project Title [up to 150 chars]

PRIDE - Promoting Independence in Dementia

### Start Date and Duration

a. Proposed start date	01 January 2014	b. Duration of the grant (months)	60
------------------------	-----------------	-----------------------------------	----

### Applicants

Role	Name	Organisation	Division or Department	How many hours a week will the investigator work on the project?
Principal Investigator	Professor Martin Orrell	University College London	Mental Health Sciences	3.75
Co-Investigator	Professor Gail Mountain	University of Sheffield	Health and Related Research	1.13
Co-Investigator	Dr Greta Rait	University College London	Primary Care and Population Sciences	1.5
Co-Investigator	Dr Fiona Poland	University of East Anglia	Allied Health Professions	1.5
Co-Investigator	Professor Susan Michie	University College London	Psychology	1.5
Co-Investigator	Dr Georgina Charlesworth	University College London	Psychology	0.75
Co-Investigator	Professor Esme Moniz-Cook	University of Hull	Faculty of Health and Social Care	1.13
Co-Investigator	Dr Rumana Omar	University College London	Statistical Science	2.25
Co-Investigator	Professor Eef Hogervorst	Loughborough University	Sch of Sport Exercise & Health Sciences	1.13
Co-Investigator	Professor Andrew Steptoe	University College London	Epidemiology and Public Health	1.87
Co-Investigator	Professor Paul Higgs	University College London	Mental Health Sciences	1.5
Co-Investigator	Professor Stephen Morris	University College London	Epidemiology and Public Health	1.88

Co-Investigator	Dr Aimee Spector	University College London	Clinical Health and Educational Psych	0.75
Co-Investigator	Professor David Challis	The University of Manchester	Medicine	1.13
Co-Investigator	Dr André Xavier	Uni of Southern Santa Catarina (UNISUL)	Medicine	2.36
Co-Investigator	Dr Eleonora Dorsi	Federal University of Santa Catarina	UNLISTED	2
Co-Investigator	Professor Frans RJ Verhey	Maastricht University	Psychiatry and Neuropsychology	0.84
Co-Investigator	Mr Andrew Haines	Age Concern Havering	HOPWA House	1.64

**Classification**

International in nature?

Yes

Please give details

The PI of PRIDE is Editor of the international academic journal Aging & Mental Health and is on the Board of Directors for the European Association of Geriatric Psychiatrists and the International Psychogeriatric Association. He also has close links with Alzheimer's Disease International. Many of the coapplicants have research links with other countries and/or are members of the INTERDEM Network.

The PRIDE study will use the English Longitudinal Study of Ageing (ELSA) cohort to examine the role of social and lifestyle factors in cognitive decline and comparisons will be made with the replicant cohort in Florianopolis, Brazil; and with related international datasets (SHARE-EU, HRS-USA).

This programme of work is closely aligned with INTERDEM (<http://www.interdem.org/>) both in terms of the collaborators and the aims of PRIDE and INTERDEM. The applicants Martin Orrell, Frans Verhey and Esme Moniz-Cook are on the INTERDEM Board. Myrra Vernooij-Dassen is Chair of the INTERDEM Board and also will Chair the PRIDE International Scientific Advisory Board which will meet annually and advise on the overall strategy of the PRIDE programme, management and research methods, and capacity development work. INTERDEM is a European collaborative research network with a mission to:

1. To develop pan-European research on Early, Timely and Quality Psychosocial Interventions in Dementia;
2. To actively disseminate this and enhance practice, policy and the quality of life of people with dementia and their supporters, across Europe;
3. To place people with dementia and their supporters at the centre of European research and practice, by actively involving them in developing these activities.

Each of the 20 INTERDEM countries has a named coordinator. EU funded projects include: EUROCODE - developing guidelines on psychosocial interventions in dementia; DIADEM - timely diagnosis and management of dementia; and AWARE - Awareness in early stage dementia: understanding, assessment and implications for early intervention. Since 1999 The INTERDEM collaboration has produced more than 25 peer-reviewed research papers.

INTERDEM Academy: We will collaborate with INTERDEM to develop an Academy to foster dementia research collaboration, knowledge exchange, capacity development, and provide a forum for talented researchers to fulfil their academic potential. This will provide the organisational capacity to develop the next generation of researchers in dementia care.

It will include:

(1) Travel exchange fellowships for PhD students and post doc researchers allowing them to spend 3 months in another INTERDEM research centre. INTERDEM currently has an exchange programme for PhD students to pursue research in other INTERDEM centres. Students are encouraged to: contribute to ongoing research on psychosocial interventions; and attend relevant local University courses, seminars, and workshops. Researchers and students have been keen to do this but this has been difficult to implement since there is no budget allocated for his programme to cover basic requirements such as travel and relocation costs. PRIDE includes such a budget which will be a strong added incentive for students to participate in exchange.

(2) A biannual programme for students/researchers comprising:

- a) seminars to discuss their work with peers and senior academics.
- b) expert workshops & masterclasses to develop research ideas and expertise in the methodology



of psychosocial research. INTERDEM organised such a workshop on methodology at the international conference of the International Psychogeriatric Association) in The Hague, Netherlands. This was overbooked, and judged to be a great success for all those attending.

(3) The INTERDEM Academy will organise annual international conferences to promote excellence in social science research in dementia care inviting key policymakers from EU nations.

## Objectives

List the main objectives of the proposed research [up to 4000 chars]

People with dementia lose independence because of neurological deterioration, loss of living skills, and negative social consequences such as stigma, social exclusion and disempowerment. This programme aims to promote independence by (1) investigating how social and lifestyle changes may reduce risk of dementia, and understanding the social impact of dementia, in order to (2) develop and evaluate an effective social intervention to enhance independence and quality of life for people with mild dementia and their carers.

### Objectives

(1) To determine social and lifestyle risk factors for dementia in the context of social changes. We will analyse the English Longitudinal Study of Ageing (ELSA) cohort and related international datasets. ELSA has followed up over 10,000 older people biennially over ten years collecting data about their health, wealth, lifestyle and social activities. Our initial analyses indicate that the use of email/internet may reduce cognitive decline and staying physically active can help improve people's daily living skills. Further analyses will assess the prevalence of dementia amongst older people in the community, the possible impact of changes in lifestyle (eg exercise, use of computers) on change over time in independence and cognitive abilities, model the impact of changing lifestyles on the economic consequences of dementia, and compare and contrast the impact of changing lifestyles across countries.

(2) To investigate social attitudes to lifestyle change, cognitive decline, dementia and seeking help for memory problems; and explore the social consequences of memory problems and the diagnosis of dementia in both the ELSA sample and a cohort of people referred to memory services. In the next two ELSA surveys (2014 and 2016) we will ask people about their expectations of ageing and independence including memory loss and dementia, the associated fear and stigma, and what would make it more or less likely for them to seek help if needed. We will develop a large cohort of people with early stage dementia referred to memory services to: map the changing clinical and social picture, to determine stigma, loss of role and other negative social consequences of dementia over time; evaluate the protective effects of positive factors, such as resilience, self efficacy and sense of coherence; and examine attitudes to participation in dementia research. We will develop interdisciplinary accounts of the nature of stigma in dementia and examine how these can be used to promote independence in people with early stage dementia. We will develop and evaluate the psychometrics of negative (eg stigma) and positive (eg self-efficacy) social functioning measures, and evaluate the CASP-19 quality of life measure in people with dementia.

(3) To develop and optimise a social intervention to increase independence and quality of life for people with dementia and their carers. People with dementia prefer a menu based approach with interventions tailored to individual needs and preferences. Taking the ELSA results, evidence from the literature, and a participative research process involving consultations with patients and carers, we will coproduce an evidence based social intervention to promote independence, activities of daily living, and quality of life for people with dementia and their families. We will conduct a feasibility study to assess recruitment rates, practicality of outcomes, attrition, estimate possible treatment effect with confidence intervals; how the intervention can be delivered successfully, and develop a delivery method based on best practice implementation.

(4) To conduct a randomised controlled trial of the social intervention to evaluate clinical and cost effectiveness and determine what is needed for widespread implementation.

(5) To fast track capacity development for future research in dementia care by a programme of training and development opportunities for all levels of researcher.

## Summary

Describe the proposed research in simple terms in a way that could be publicised to a general audience [up to 4000 chars]

People with dementia lose much more than just their memory and daily living skills. They can also lose their independence, their dignity and status, their confidence and morale, and their roles both within the family and beyond. They can often be seen as a burden by society, their families and even by themselves, and feel unable to contribute to society, and they lack opportunities to reciprocate by doing things for others. This adds to the stigmatisation of people even if they only have mild memory problems. The focus of this study is promoting independence in dementia which could have substantial benefits for

the people with dementia, their families, and NHS and social care. This should translate into major economic (eg reduced costs of care) and societal benefits.

Dementia is a national priority and this proposal addresses the Prime Minister's commitment to dementia research and the need to improve community support. In the UK over 800,000 older people have dementia costing the nation over £17 billion a year through the provision of health and social care services. Dementia has profound effects on family carers who through their actions save the UK economy over £6 billion a year. This means there is a need both to better understand the impact of social and lifestyle factors on the broader ageing population at risk of dementia, and to promote independence and quality of life for people with dementia.

This study aims:

- (a) to identify how social and lifestyle changes may help reduce risk of developing dementia and disability and to better understand the social consequences of dementia.
- (b) to develop and evaluate an effective social intervention to support independence and quality of life for people with early stage dementia and their carers.

The first aim will be addressed using the information from the English Longitudinal Study of Ageing (ELSA) cohort which has followed up over 10,000 older people biennially over ten years, collecting information about their health, wealth, lifestyle and social activities. Our initial analysis of the data set indicates that the use of email/internet may reduce cognitive decline and that staying physically active can help improve people's daily living skills. We will do further analyses looking at the frequency of dementia amongst older people in the community and the potential impact of changes in lifestyle (eg exercise, use of computers) on how cognitive abilities may change over time. In the next two ELSA surveys (2014 and 2016) we will ask people about their expectations of ageing, including memory loss and dementia, the associated fear and stigma and what would make it more or less likely for them to seek help if needed. We will explore the concerns and expectations people have (eg loss of identity and loss of independence) at the point of referral to memory services, at the point of diagnosis, and for the following two years. We will also investigate their experiences in terms of loss of role and quality of life.

The second aim will be investigated by using an in depth consultation with people with dementia and their carers and an appraisal of the scientific evidence to develop an evidence based social intervention designed to promote independence and support lifestyle changes most likely to benefit cognition (eg physical activity, use of computers) delivered by a dementia advice worker. In a large clinical trial of memory services across the UK, the intervention will be evaluated in comparison to usual care to evaluate potential benefits to independence and quality of life. Lastly, we will determine the best ways to implement the intervention more widely and to publicise the results. We will ensure that there are training and development opportunities for all grades of researcher from PhD students to senior academics, so that we can develop capacity for future research in gerontology and dementia care.

## Academic Beneficiaries

Describe who will benefit from the research [up to 4000 chars].

The PRIDE study has emerged from key concerns from clinicians, academics, people with dementia, and carers about the social impact of diagnosis, the importance of lifestyle factors and the need for action to improve care. The proposed research programme has been based on a strong cross-disciplinary approach where multiple disciplines will benefit and work together to develop enhanced understanding and improvement of collaboration. It also fits with two of the ESRC strategic priorities: health & wellbeing and understanding individual behaviour. The results of PRIDE plus the embedded capacity development will bring substantial benefits across a wide range of scientific, national and international communities across multiple disciplines including public health.

Direct beneficiaries

- 1) PRIDE will benefit academics and researchers within the scientific communities of medicine, epidemiology, psychology, sociology, health economics, gerontology, and dementia care. It will focus varied groups upon dementia research.
- 2) PRIDE will extend research capacity by creating a coherent critical mass of academics developing a cohort of talented ambitious researchers to advance social science in dementia care.
- 3) The INTERDEM Academy (a joint venture between PRIDE and the European INTERDEM Network) will benefit academics and researchers of all grades and from a wide range of disciplines by promoting knowledge exchange and developing research capacity.
- 4) We will assist PhD students and postdoctoral researchers in their career development by broadening their academic experiences by providing opportunities for them to spend 3 months in an INTERDEM research centre in a different country.
- 5) The PRIDE programme provides opportunities for: 6 exceptionally talented researchers to study for PhDs supported through either PRIDE (UCL-ESRC Doctoral Training Centre 3 students) or UCL (3 students); postdoc posts in statistics, sociology and psychology plus 2 new UCL funded fellowship posts to support career development; and a new UCL funded senior academic post in gerontology.
- 6) Through the INTERDEM network (which includes 20 countries) and the new INTERDEM Academy the academic benefits of PRIDE will be cascaded across the EU and beyond. Over 40 Universities are associated with INTERDEM members are based in: Leuven, Brussels, Vienna, Copenhagen, Helsinki, Paris, Hamburg, Freiburg, Munich, Berlin, Magdeburg, Dusseldorf, Stuttgart, Thessaloniki, Dublin, Genoa, Bologna, Brescia, Modena, Luxembourg (Alzheimer Europe), Malta, Amsterdam, Maastricht, Nijmegen, Oslo, Wroclaw, Poznan, Porto, Lisbon, Oviedo, Zamora (INTRAS Foundation), Salamanca, Vasteras, Hull, Bangor, Bradford, London, Manchester, Sheffield, Worcester, Bath.
- 7) The wider academic community will benefit through having access to the results of the studies presented in peer reviewed international journals and will be presented at major international conferences. We will aim to publish a range of original data and methodology papers from each of the work packages.
- 8) Our data management plan will provide a mechanism for the data generated from PRIDE to be used by other academics for further analysis and publication.

## Staff Duties

Summarise the roles and responsibilities of each post for which funding is sought [up to 2000 characters]

Full Time unless stated

- 1) Programme manager: senior post to set up/manage the programme (0-60).
- 2) Programme Administrator: senior admin post for coordination of the programme (0-60).
- 3) Postdoc: statistics (7-55) Analyses of ELSA datasets and RCT.
- 4) Postdoc: sociology (6-54) Qualitative research, data collection, analysis.
- 5) Postdoc: psychology (6-54) Development of cohort; literature review; development, evaluation and implementation of social intervention.
- 6) 3 Research Assistants: participant recruitment, data collection (14-50).
- 7) PRIMENT Staff:
  - Trial manager (20-56): Management/coordination of RCT; oversee recruitment, data collection; supervise research assistants
  - 5% Senior Trial Coordinator (20-56) supervision/support of Trial Manager
  - 20% Postdoc economics (22-58): coordination/analysis of health economic data.
  - 100% Trial administrator (20-56): admin support for Trial Manager
  - 50% Research Assistant (36-48): research support to trial manager, audit, quality monitoring.

Investigators: roles/expertise (0-60)

- 1) 10% Martin Orrell: lead for programme
- 2) 5% Steve Morris: health economics
- 3) 6% Rumana Omar: statistics
- 4) 5% Andrew Steptoe: supervision of ELSA studies
- 5) 4% Paul Higgs, 4% Fiona Poland: sociology/qualitative/PPI
- 6) 2% Aimee Spector: psychosocial interventions
- 7) 2% Georgina Charlesworth: clinical psychology/carer wellbeing/PPI
- 8) 4% Susan Michie: health psychology/implementation
- 9) 4% Greta Rait: trials expertise
- 10) 3% Eef Hogervorst: psychology/exercise
- 11) 3% Gail Mountain: occupational therapy/self management
- 12) 3% Esme Moniz-Cook: psychosocial interventions
- 13) 3% David Challis: community care/social care

International Investigators: roles/expertise (0-60)

3% Frans Verhey: coordination INTERDEM Academy, PhD student exchange programme. 3% Andre Xavier & 3% Eleonora D'Orsi: Coordinate Brazil sample, link ELSA datasets, field testing social intervention locally.

PPI U Htay/D Prothero

## Impact Summary

Impact Summary (please refer to the help for guidance on what to consider when completing this section) [up to 4000 chars]

PRIDE will lead to substantial benefits across a wide range of stakeholders including the scientific and public health communities, policy makers, commissioners and service planners, the voluntary sector, carers, people with dementia, service providers, and international organisations. Initial benefits:

- (a) better public and scientific understanding of the social and cultural impact of dementia, the role of lifestyle factors, and the impact on the changes in cognition and activities of daily living across time; the associated economic and social benefits; the potential impact on the future prevalence of dementia.
- (b) improved public health guidance on lifestyle approaches to reduce risk of dementia (eg physical exercise, cognitive stimulation), and updated policy and practice (eg updated NICE guidelines, update of National Dementia Strategy, and commissioning guidance).
- (c) better public understanding of lifestyle and social factors in dementia should lead to reduced fear and stigma, and a more proactive approach to seeking help by people worried about their memory and their families.
- (d) The programme could within 5 years provide the evidence required to demonstrate to managers and policy makers that the intervention was effective, leading to changes in the way older peoples' services are organised and opportunities for national implementation. This would promote independence and quality of life, and reduce service use for people with dementia and their carers. The applicants' networks and the key drivers to influence policy means there could be extensive implementation of the social intervention by memory services across the UK.

Future benefits:

- (e) if as expected the social intervention leads to improvements in independence, activities of daily living and quality of life

this should translate into major economic benefits (eg reduced costs of care) addressing the key policy concern of improved resource use through innovation in a time of economic stringency. Societal benefits will also accrue for people with dementia (and their carers) who will be able to retain their independence for longer and experience reduced stigma about the condition.

(f) Services across the UK and Europe use information and support interventions and because of the comprehensive approach including a major trial and implementation study, the social intervention could rapidly become widely used, as a clinical/cost-effective, standardised, and feasible intervention providing effective and better targeted support and information at an early stage. We will network with other countries to encourage them to translate and evaluate the intervention aiming for 5 major languages within 3 years of completion. Countries with the capability to adopt the intervention quickly include the Netherlands and Australia. We will explore the feasibility of the intervention in Brazil, India and China in the context of different cultures and health systems.

(g) There is potential for major policy impact in Europe and elsewhere. The INTERDEM network includes 20 European Nations, has close links with the European Commission and Alzheimer Europe. This means it is in an excellent position to promote and disseminate the findings and influence EU policy.

(h) The INTERDEM Academy will have an international impact improving dementia care by fostering research collaboration, improving knowledge exchange and developing junior researchers. We will build on the successful cohort of researchers coming through major grant programmes led by the applicants (eg SHIELD, iCST, VALID - the PI also has 7 PhD students) programmes, and other major studies from the UK and the wider INTERDEM community.

### **Ethical Information**

Has consideration been given to any ethical matters raised by this proposal ?

Please explain what, if any, ethical issues you believe are relevant to the proposed research project, and which ethical approvals have been obtained, or will be sought if the project is funded? If you believe that an ethics review is not necessary, please explain your view (available: 4000 characters)

This takes into account the ESRC Framework for Research Ethics and the research ethics initial checklist. The study will be approved through the appropriate multicentre research ethics application and local research governance procedures. We will create a Programme Steering Committee (PSC) with an independent chair and a Data Monitoring and Ethics Committee (DMEC) reporting to the PSC. All researchers and sites will be up to date with best practice training in Good Clinical Practice guidance. The social intervention trial will be registered with [www.controlledtrials.com](http://www.controlledtrials.com) and allocated an ISRCTN number. As a social intervention this is not covered by the Medicines for Human Use (Clinical Trials) Regulations 2004.

### **Potential Risks**

There are unlikely to be any harmful side-effects from participating in either psychological or social interventions and no adverse reactions were apparent in the recent study CST or REMCARE studies. The interviews for participants will be limited in duration and not unduly long or stressful. Prospective participants will be fully informed of the potential risks and benefits of the projects. Moreover after the end of the study all trial participants will receive a copy of the social intervention materials to enable them to potentially benefit from the programme. Safety procedures for researchers in the UK and Brazil will follow standard guidelines and potential risks will be minimal.

### **Consent**

Trial participants will be in the mild stage of dementia, and therefore would generally be expected to be competent to give informed consent for participation, provided that appropriate care is taken in explaining the research and sufficient time is allowed for them to reach a decision. It is helpful for a family member or other supporter to be involved, and we would aim

to ensure that this is done wherever possible. It will be made clear to both participants and family carers that no disadvantage will accrue if they choose not to participate. In seeking consent, we will follow current guidance from the British Psychological Society on evaluation of capacity. In this context, consent has to be regarded as a continuing process rather than a one-off decision, and willingness to continue participating will be continually checked through discussion with participants during the assessments. Where the participant's level of impairment increases, so that they are no longer able to provide informed consent, the provisions of the Mental Capacity Act and the National Research Ethics Service guidance on consent for people lacking capacity will be followed. The initial giving of informed consent provides a clear indication of the person's likely perspective on continuing at this point, and the family carer will be consulted in this regard. At any point where a participant with dementia becomes uncomfortable with the assessments they will be discontinued.

#### Confidentiality

The research will follow the Data Protection Act 1998 guidance. Only members of the research team will have access to the original data. Participants' personal details will be stored separately from the data, and will be kept in a separate file on a password protected computer at University College London. Each participant will be assigned an identification code, which will be used in all data storage files; these will not contain names or any other means of personal identification. All personal details will be deleted on completion of the study.

#### Retention of trial documentation

In line with UCL data protection policy anonymous data and trial documentation will be kept securely for a period of 10 years following study completion.

---

## Summary of Resources Required for Project

### Financial resources

Summary fund heading	Fund heading	Full economic Cost	ESRC contribution	% ESRC contribution
Directly Incurred	Staff	1765980.00	1412784.00	80
	Travel & Subsistence	48000.00	38400.00	80
	Equipment	0.00	0.00	100
	Other Costs	154300.00	123440.00	80
	<b>Sub-total</b>	<b>1968280.00</b>	<b>1574624.00</b>	
Directly Allocated	Investigators	271295.11	217036.09	80
	Estates Costs	250778.00	200622.40	80
	Other Directly Allocated	1401.00	1120.80	80
	<b>Sub-total</b>	<b>523474.11</b>	<b>418779.29</b>	
Indirect Costs	Indirect Costs	1441565.00	1153252.00	80
Exceptions	Staff	187080.00	187080.00	100
	Other Costs	352936.00	352936.00	100
	<b>Sub-total</b>	<b>540016.00</b>	<b>540016.00</b>	
	<b>Total</b>	<b>4473335.11</b>	<b>3686671.29</b>	

### Summary of staff effort requested

	Months
Investigator	44.75
Researcher	374.50
Technician	0
Other	96
Visiting Researcher	0
Student	144
<b>Total</b>	<b>659.25</b>



## Other Support

Details of support sought or received from any other source for this or other research in the same field.  
Other support is not relevant to this application.

## Related Proposals

Proposal is related to a previous proposal to ESRC

Reference Number	How related?
ES/K006673/1	Follow up to outline proposal

## Staff

### Directly Incurred Posts

Role	Name /Post Identifier	Start Date	EFFORT ON PROJECT		Scale	Increment Date	Basic Starting Salary	London Allowance (£)	Super-annuation and NI (£)	Total cost on grant (£)
			Period on Project (months)	% of Full Time						
Co-Investigator	Dr Greta Rait	01/01/2014	60	4	SAGP	01/08/2014	92803	2162	22877	23568
Researcher	Ms R Hunter	31/12/2015	36	20	Grade 8	01/08/2016	43312	2834	11546	35807
Researcher	Trial Manager	01/01/2016	36	100	Grade 7	01/08/2016	37382	2834	9779	154407
Researcher	Research Assistant	01/12/2016	12	50	6B	01/08/2017	25504	2834	6637	17648
Researcher	Post Doc Sociology (UEA)	01/01/2014	60	100	7	01/08/2014	33230	0	8853	232149
Researcher	Research Assistant 1	01/02/2015	36	100	6B	01/08/2015	26264	2834	6838	110285
Researcher	Research Assistant 2	01/02/2015	36	100	6B	01/08/2015	26264	2834	6838	110285
Researcher	Post Doc Psychology	01/06/2014	48	100	7	01/08/2014	33230	2834	8676	191018
Researcher	Programme manager	01/01/2014	60	100	8	01/08/2014	40834	2834	10808	292231
Researcher	Research Assistant 3	01/02/2015	36	100	6B	01/08/2015	26264	2834	6838	110285
Researcher	Post Doc Stats/Epidemiology	01/07/2014	48	100	7	01/08/2014	29541	3834	7703	171401
Researcher	Research Coordinator	01/08/2015	24	5	8	01/08/2016	40834	2834	10808	5527
Other Staff	Trial Administrator	31/12/2015	36	100	6	01/08/2016	23352	2834	5283	97013
Other Staff	Programme Administrator	01/01/2014	60	100	7	01/08/2014	29541	2834	7703	214356
Total										1765980

### Applicants

Role	Name	Post will outlast project (Y/N)	Contracted working week as a % of full time work	Total number of hours to be charged to the grant over the duration of the grant	Average number of hours per week charged to the grant	Rate of Salary pool/banding	Cost estimate
Principal Investigator	Professor Martin Orrell	Y	100	825	3.8	136009	68004
Co-Investigator	Professor Gail Mountain	Y	3	248	1.1	81561	12259
Co-Investigator	Dr Fiona Poland	Y	4	330	1.5	73497	14699

Co-Investigator	Professor Susan Michie	Y	100	330	1.5	112453	22491
Co-Investigator	Dr Georgina Charlesworth	Y	70	165	0.8	86309	8631
Co-Investigator	Professor Esme Moniz-Cook	Y	3	248	1.1	130947	19682
Co-Investigator	Dr Rumana Omar	Y	100	495	2.2	91692	27508
Co-Investigator	Professor Eef Hogervorst	Y	3	248	1.1	77232	11608
Co-Investigator	Professor Andrew Steptoe	Y	100	268	1.2	112455	18265
Co-Investigator	Professor Paul Higgs	Y	100	330	1.5	86309	17262
Co-Investigator	Professor Stephen Morris	Y	100	413	1.9	112453	28147
Co-Investigator	Dr Aimee Spector	Y	70	165	0.8	73593	7359
Co-Investigator	Professor David Challis	Y	100	248	1.1	102323	15379
Co-Investigator	Dr André Xavier	Y	52	520	2.4	0	0
Co-Investigator	Dr Eleonora Dorsi	Y	2	440	2	0	0
Co-Investigator	Professor Frans RJ Verhey	Y	3	185	0.8	0	0
Co-Investigator	Mr Andrew Haines	Y	10	360	1.6	0	0
						<b>Total</b>	<b>271294</b>

## Students

Role	Name /Post Identifier /Institution	Start Date	London Allowance (£)	Fees	Stipend
Project Student	PhD studentship no.1 / University College London	01/06/2014	Yes	15312.00	62360.00
Project Student	PhD studentship no.2 / University College London	01/06/2014	Yes	15312.00	62360.00
Project Student	PhD studentship no.3 / University College London	01/06/2014	Yes	15312.00	62360.00

## Travel and Subsistence

Destination and purpose		Total £
Within UK	Travel for assessments: Travel expenses are required for 3572 assessments/contacts costed at £8 per visit by car/public transport: £28576	28576
Within UK	Other travel expenses: travel between sites, travel to meetings: £11830	11830
Within UK	National/international conferences (Alzheimer Europe, Alzheimers Disease International, International Psychogeriatric Association): travel, subsistence: £7594	7594
Total £		48000

## Other Directly Incurred Costs

Description	Total £
Database and randomisation (PRIMENT)	39300
CARER/PPI Time: Costs of peer researchers: 8 researchers x20 hours x £20 per hour (INVOLVE rates) = £3200, PPI time: training dementia advisors 40 hours x £20 = £1600	14800
PPI coapplicant time (2 carers): 50 hours/year x 5 years x £20 x 2 = £10000	
OVERSEAS: INTERDEM Academy: researcher travelling fellowships 8 x £3500; admin support & Prof Verhey's time £55000; workshops/masterclasses, travel, room hire, conference organisation £6000 x 5 years = £30000.	113000
Costs of meetings (eg PSC/DMEC) £1600 x 5 years: room hire, travel & subsistence	8000
Production of manuals/DVDs: costs of dissemination, conference fees (Alzheimer Europe, Alzheimers Disease International, International Psychogeriatric Association)	16000
Staff training: including courses in methodology/research governance/GCP	24000
OVERSEAS - Costs for Brazil: PI time Xavier £26708 and & D'Orsi' £29040, research assistant time for epidemiology study & social intervention feasibility trial & adaptation of materials for Brazil £64526, other expenses and overheads £18726.	139000
3 X PhD student other costs £1,000/yr	12000
consumables - photocopying, office expenses, laser toner cartridges, stationery, software	31500
IT support and website development - to promote PRIDE programme and act as resource for staff (web based protocols, standard operating procedures etc).	10000
Advertising costs for staff directly employed on the project	1500
CARER/PPI expenses PPI coapplicant expenses/travel/telephone costs/consumables = £2000	5000
Conference fees, travel and subsistence for carers and people with dementia to attend & present at conferences/events: £3000	
PPI support: Funding (£4500x 5 years) to support Uniting Carers (a dementia carers organisation part of Dementia UK) for carer/person with dementia involvement/support in studies: £22250	22250
AGE CONCERN: Funding to support Andrew Haines time (£2000) and support for training dementia advisors: staff costs, room hire, subsistence: £10950	12950
computers 7 x £640 = £4480, laser printer £470 x 2. Mobile phones needed to be able to contact researchers and for personal safety £940 x 7 staff = £6580	12000
Total £	461300

## Other Directly Allocated Costs

Description	Total £
Infrastructure Technicians	1353
Other	48
Total £	1401

**Timetable** estimates of the number of months after the start of the project to reach the following stages:

Stage	Number of Months
-------	------------------

Completion of all preparation and design work	30
Commencement of fieldwork or material/information/data collection phase of study	10
Completion of fieldwork or collection phase of study	52
Commencement of analysis phase of study (substantive phase where research facilities are involved)	24
Completion of analysis phase of study	56
Commencement of writing-up of the research	22
Completion of preparation of any new datasets for archiving	56
Completion of writing-up	60

## Data Collection

If the research involves data collection or acquisition, please indicate how existing datasets have been reviewed and state why currently available datasets are inadequate for this proposed research. If you do not state to the contrary, it will be assumed that you (as principal applicant) are willing for your contact details to be shared with the affiliated data support service (Economic and Social Data Service) working with the Research Councils.	ELSA studies so far have included little in depth analysis of cognitive change in ageing in relation to social participation, chronic illness, or economic outcomes. MRC-CFAS is a longitudinal multicentre studies of health and cognitive function in older people however it does not specifically relate to memory services and so would not generate a suitable sample for the trial.
Will the research proposed in this application produce new datasets?	Yes
Will this data be:	<input checked="" type="checkbox"/> Quantitative <input checked="" type="checkbox"/> Qualitative
Please give a brief description of the datasets.	<p>ELSA cohort study follow up of 10000+ older people biennially</p> <p>Qualitative data from focus groups and interviews</p> <p>RCT of social intervention</p>
It is a requirement to offer data for archiving. Please include a statement on data sharing. If you believe that further data sharing is not possible, please present your argument here justifying your case.	Data will be prepared according to the guidelines of the Economic and Social Data Service (ESDS) and shared with the ESDS on study completion.
Who are likely to be the users (academic or non-academic) of the dataset(s)?	Researchers and academics in dementia care, gerontology, epidemiology, economics sociology and psychology of ageing from the UK and beyond.
Please outline costs of preparing and documenting the data for archiving to the standards required by the affiliated data support service (Economic and Social Data Service) working with the Research Councils.	Data will be made available through the UK Data Archive ( <a href="http://www.data-archive.ac.uk/">http://www.data-archive.ac.uk/</a> ). Costs of data archiving will be managed with PRIDE grant.

# OTHER INFORMATION

## Academic Reviewers

1	Name	Organisation	Division or Department	Email Address
	Professor Steven Zarit	Pennsylvania State University	College of Health & Human Development	z67@psu.edu

## Academic Reviewers

2	Name	Organisation	Division or Department	Email Address
	Professor Debbie Tolson	Glasgow Caledonian University	Sch of Health and Life Sciences	D.Tolson@gcal.ac.uk

## Classification of Proposal

### (a) User Involvement

The nature of any user engagement should be indicated

Design	X
Execution	X
Dissemination	X
Training	X
Not applicable	

### Proposal Classifications

#### Research Area:

Research Areas are the subject areas in which the programme of study may fall and you should select at least one of these. Once you have selected the relevant Research Area(s), please ensure that you set one as primary. To add or remove Research Areas use the relevant link below. To set a primary area, click in the corresponding checkbox and then the Set Primary Area button that will appear.

Please select one or more Research Areas

Subject	Topic	Keyword
Economics	Economics (General)	
Medical and health interface	Mental Health	
Psychology	Gerontology [Primary]	
Sociology	Medical Sociology/Sociology of Health and Illness	
Tools, technologies and methods	Social Statistics, Computation & Methods	

#### Qualifier:

Qualifiers are terms that further describe the area of study and cover aspects such as approach and geographical focus. Please ensure you complete this section if relevant.

To add or remove Qualifiers use the links below.

Type	Name
Approach	Exploitation of existing datasets
Approach	International Comparative
Approach	Modelling
Approach	Qualitative
Approach	Quantitative
Approach	Technique/Method Development
Approach	Theory Development
Collaboration location region	South America
Collaboration location region	UK & Ireland
Collaboration location region	Western Europe
Geographic Area	Western Europe
Project Engagement by Sector	Academic Users
Project Engagement by Sector	General Public
Project Engagement by Sector	NHS Health Prof & Social Serv
Project Engagement by Sector	Third Sector
Public Engagement Audience	Retired people
Public Engagement Audience	Scientists/engineers/academia
Public Engagement Methodology	Attitude study
Public Engagement Methodology	Consultation
Public Engagement Methodology	Public dialogue discuss/debate
Public Engagement Methodology	Publication
Time Period	Contemporary

**Free-text Keywords:**

Free-text keywords may be used to describe the programme of study in more detail. To add a keyword, you first need to search existing Research Areas by entering the keyword in the Search box and selecting the Filter button.

If the keyword is adequately reflected by one of the terms displayed below, click in the corresponding checkbox then select Save. If no potential matches are displayed, or none of those displayed are suitable, select the Add New button followed by the Save button to add it as a descriptor.

To add or remove those previously added use the links below.




## **PRIDE - Pathways to impact**

The PRIDE study has emerged from key concerns from clinicians, academics, people with dementia, and carers about the social impact of diagnosis, the importance of lifestyle factors and the need for action to improve care. Dementia costs the nation over £17 billion a year through the provision of health and social care services and family carers also save the UK economy around £6 billion a year.

**Communication and engagement** - A website will be set up as a priority to make available resources from the programme as soon as possible and to provide a support network for interested services and organisations (eg [www.ucl.ac.uk/shield](http://www.ucl.ac.uk/shield)). A section for the general public, users and carers will be coproduced with older users. This website will be easy to navigate and have limited information on each page. The website will include a summary of the work and progress so far. Participants will be notified about the website and the option of being added to the mailing list to receive newsletter updates. These will be in a format for the public and will be overseen by our carer coapplicants Ula Htay and David Prothero and our PPI group. Press releases will be developed and circulated with our PPI group. Links with DENDRON and voluntary/carer organisations involved in the study will be used to publicise the results. Five regional UK workshops with health planners and policymakers will gather stakeholder views on dissemination and resources to support implementation in practice.

**Dissemination and application** - Each WP will generate several peer reviewed publications. Major papers (eg longitudinal and qualitative studies, trial, cost effectiveness) will target leading general or specialist journals. Researchers will submit abstracts for major conferences (eg Alzheimer's Disease International). Articles will be produced for professional journals (eg Journal of Dementia Care), and newsletters for lay readers including (eg Living with Dementia - Alzheimer's Society) and websites (eg Dementia UK). To aid implementation and in collaboration with PPI we will coproduce a Manual/DVD and training package (including slides/notes) on the social intervention for the stakeholders, carers and dementia advice workers (from the memory services). An adherence checklist and programme fidelity tool will be available via the PRIDE website. We will organise 2 national conferences to include all stakeholder groups including policymakers, practitioners, researchers, DENDRON, and service users, to present the results and receive feedback.

**Capability** - PRIDE builds on a significant programme of dementia research by the applicants and collaborators who are leaders in their field. They have NIHR/ESRC funding and have significant networks in dementia care, health economics, and the sociology, psychology and epidemiology of ageing. The Principal Investigator (PI) leads major research programmes in dementia care developing and evaluating psychosocial interventions and outcome measures and getting them into widespread practice. Cognitive Stimulation Therapy ([www.cstdementia.com](http://www.cstdementia.com)) has clear evidence of clinical and cost effectiveness, is translated into several languages and used in Europe, USA, Australia and Japan. CST is recommended by the UK NICE dementia guidance and Alzheimer's Disease International. The PI Chairs the UK Memory Services National Accreditation Programme (recently endorsed in the PM's Challenge), is Editor of the academic journal Aging & Mental Health and on the Board of Directors of the European Association of Geriatric Psychiatrists and the International Psychogeriatric Association, he also has close links with Alzheimer's Disease International. Manchester PSSRU is part of the NIHR School for Social Care Research, and has a team of 20 experienced researchers with support from NIHR, ESRC and the Department of Health for different studies.

INTERDEM is a European collaborative research network with a mission to: 1. To develop pan-European research on Early, Timely and Quality Psychosocial Interventions in Dementia; 2. To actively disseminate this and enhance practice, policy and the quality of life of people with dementia and their supporters, across Europe; 3. To place people with dementia and their supporters at the centre of European research and practice, by actively involving them in developing these activities. Each of the 20 INTERDEM countries has a named coordinator. EU funded projects include: EUROCODE - developing guidelines on psychosocial interventions in dementia; DIADEM – timely diagnosis and management of dementia; and AWARE - Awareness in early stage dementia: understanding, assessment and implications for early intervention. Since 1999 The INTERDEM collaboration has produced more than 25 peer-reviewed research papers. Many of the coapplicants have research links with other countries and/or are members of the INTERDEM Network.

This programme of work is closely aligned with INTERDEM (<http://www.interdem.org/>) both in terms of the collaborators and the aims of PRIDE and INTERDEM. The applicants Martin Orrell, Frans Verhey and Esme Moniz-Cook are on the INTERDEM Board. Myrra Vernooij-Dassen is Chair of the INTERDEM Board and also will Chair the PRIDE International Scientific Advisory Board which will meet annually and advise on the overall strategy of the PRIDE programme, management and research methods, and capacity development work. With INTERDEM we will: organise an international conference to promote excellence in social science research in dementia care inviting key policymakers from EU nations; and work to develop an academy to provide the organisational capacity to develop the next generation of researchers in dementia care. Conference workstreams will address (1) collaborative research using big longitudinal datasets from the UK, USA, Europe and beyond, (2) psychosocial interventions in early stage dementia. An INTERDEM consensus statement on best research practice in dementia care will be widely publicised.

INTERDEM Academy: We will collaborate with INTERDEM to develop an Academy to foster dementia research collaboration, knowledge exchange, capacity development, and provide a forum for talented researchers to fulfil their academic potential. This will provide the organisational capacity to develop the next generation of researchers in dementia care. It will include:

(1) Travel exchange fellowships for PhD students and post doc researchers allowing them to spend 3 months in another INTERDEM research centre. INTERDEM currently has an exchange programme for PhD students to pursue research in other INTERDEM centres. Students are encouraged to: contribute to ongoing research on psychosocial interventions; and attend relevant local University courses, seminars, and workshops. Researchers and students have been keen to do this but this has been difficult to implement since there is no budget allocated for his programme to cover basic requirements such as travel and relocation costs. PRIDE includes such a budget which will be a strong added incentive for students to participate in exchange.

(2) A biannual programme for students/researchers comprising:

a) seminars to discuss their work with peers and senior academics.

b) expert workshops & masterclasses to develop research ideas and expertise in the methodology of psychosocial research. INTERDEM organised such a workshop on methodology at the international conference of the International Psychogeriatric Association) in The Hague, Netherlands. This was overbooked, and judged to be a great success for all those attending.

(3) The INTERDEM Academy will organise annual international conferences to promote excellence in social science research in dementia care inviting key policymakers from EU nations.

**PRIDE - Case for support:** In the UK over 800,000 older people have dementia, which leads to social exclusion, loss of identity and loss of independence, due to both deterioration in cognition and activities of daily living, stigma and the reduced capacity for social participation. In this way dementia challenges society, and the individuals and their carers responding to it. Mild Cognitive Impairment (MCI) is not a reliable proxy for early dementia since many people who fit current definitions of MCI do not progress to dementia and many people with other cognitive deficits (who do not fit current MCI definitions) nevertheless go on to develop dementia (Palmer et al., 2008). Dementia has profound effects on family carers who through their actions save the UK government over £6 billion a year. In the UK the provision of health and social care services for people with dementia costs the nation over £17 billion a year. Despite the enormous costs to individuals and society, less than 10% of UK research funding is focused on health and social care research (JPND, 2012). However, most recent advances in biomedical dementia research have centred around the creation of new guidelines and the search for biomarkers rather than providing new treatments (Sperling & Johnson, 2012). The EU JPND research programme has highlighted the need for psychosocial interventions promoting social inclusion, dignity and the positive contributions to society that people with dementia can make (JPND, 2012). People with early stage dementia are generally satisfied with their lives and feel their quality of life is 'good' but often experience stigma which affects their lives (Katsuno 2005). They can feel hopeless and insecure, low self-esteem, low confidence about diagnosis (Martin et al., 2012). Due to the false assumption that there is little to offer people with dementia and the stereotype that they "forget the information given to them" (Mountain 2006) people with dementia are rarely encouraged to take an active role in managing their care. Key concerns of people with dementia (Craig and Mountain, 2012) include loss of power in the relationship with their family, need to maintain a role outside the family, and a lack of basic information about diagnosis, prognosis and care. Carers often misconstrue the values and preferences of people with dementia in relation to autonomy, control and safety, and consistently underestimate their decision making ability (Reamy et al., 2011). They may delay seeking help believing that by "doing nothing" they are protecting the self image of their relatives with early stage dementia (Gillies, 1995). People with cognitive impairment and dementia can experience 'excess disability' due to stigmatisation, loss of independence and a sense that relatives seek to take over their tasks and run their lives. Low expectations mean that staff and carers often don't encourage people with dementia to use their skills or learn new things, further contributing to decline. Hobbies and interests are often lost early in the disease process (Muo et al., 2005). The biopsychosocial model in dementia takes into account both positive and negative factors (Spector and Orrell, 2010) and provides a theoretical framework to demonstrate how excess disability can be reduced and sense of self and independence can be optimised. A recent systematic review indicated that provision of information/advice can improve quality of life in dementia (Corbett et al, 2011) with a mean effect size of 0.70. However there are concerns that delays in the assessment process are stressful, better information is needed, and information given without support can lead to fear and stigmatisation (Manthorpe et al 2013). This information needs to be delivered as an easy to implement, low cost intervention to improve support and care.

Dementia is a national priority and the All Party Parliamentary Group on Dementia (APPGD 2012) noted many people delay seeking help and highlighted the importance of better public awareness. However they also but stressed the need to know whether or not increased awareness of dementia may affect stigma and fear of the illness potentially deterring presentation to services. While many people with dementia remain undiagnosed, the UK government's commitment to early diagnosis in the National Dementia Strategy (NDS) and the Prime Minister's Challenge on Dementia means that memory services often see very many people with early stage dementia who are largely independent and able to participate in community activities. This emphasises the need to strengthen community

interventions including better information and support (APPGD 2012). Key objectives of the NDS include reducing social exclusion and discrimination, and improved early diagnosis, intervention and better access to information and advice (NDS, 2009).

Accumulated evidence from epidemiological research strongly supports a role for lifestyle risk factors in the development of dementia (Fratiglioni and Qiu, 2011). These include cognitive inactivity (relative risk 1.59) and physical inactivity (relative risk 1.82) (Yaffe and Barnes, 2011). Delaying the onset would significantly reduce the overall prevalence. and Yaffe and Barnes (2011) estimated that 25% reductions in cognitive inactivity/low education and in physical inactivity could prevent 2.2 million cases of Alzheimers disease worldwide. It is usually not possible to predict with any accuracy who will get dementia or how fast it will progress. Our initial analyses of the English Longitudinal Study of Ageing (ELSA) data suggests that use of email/internet reduces cognitive decline, and physical activity promotes recovery of living skills. Further large scale epidemiological database work is needed to understand the effects of changing lifestyles (increased computer use, exercise) on prevalence of dementia over the next 3 decades. Longitudinal studies suggest that computer use may improve cognition and reduce risks of dementia (Medeiros et al., 2012; vd Wardt, 2011; Almeida 2012). Cognitively stimulating leisure activities may also reduce risk, with the lowest risk observed for the most active (Verghese et al., 2003). However, results for brain training vary as although some studies suggest potential benefits (Ball et al, 2002; Willis et al, 2006), others have found that there is little gain beyond the specifically trained tasks (Owen et al., 2010) and take up is low. Exercise interventions can improve cognitive performance in older adults and may delay or prevent dementia (Stock et al., 2012) however results are inconsistent (Angevaren et al., 2008; Forbes et al., 2008), adherence to exercise regimes is low (Hogervorst, 2012), and psychological mechanisms may mediate the impact of exercise. There is growing interest in the potential for mental and physical exercise to maintain and improve cognitive function especially amongst patients attending memory clinics. Cognitive stimulation therapy improves cognition (Orrell 2012; Woods et al., 2012) and there have also been promising results for physical exercise (Hogervorst et al; 2012). Drug interventions and carer support are important but don't adequately address the NDS goal of living well with dementia, or reduce stigma, or improve self efficacy. This means there is a need to develop and evaluate a programme for people with dementia aimed at increasing self-efficacy, but which also works with the family carer (Craig and Mountain, 2012). Self-management interventions are a core part of current UK health policy and provision for chronic conditions to enhance quality of life (Department of health 2010a). They can be delivered and received in a variety of ways (individually and in a group) and may be computer assisted, mail-delivered, telephone and or face-to-face (Barlow et al., 2002). The aim is to live well with chronic illness, managing one's condition and its emotional impact, and maintain as active a life as possible (Barlow 2001). The limited research from self management programmes for people with dementia (Mather 2006, Clare et al., 2008, Barlow et al., 2002) suggests they may address the current "care gap" supporting people living with early stage dementia (National Audit Office, 2007). Lifestyle interventions need to consider options and preferences rather than using a one size fits all approach. People with dementia identified key topics and preferred a menu based approach offering choices, and tailored to individual needs and preferences (Craig and Mountain, 2012). Self-management approaches based on social cognitive theory (Bandura, 1997) can to help to understand the illness and build empowerment and coping strategies. This should enhance resilience, facilitate reciprocity, and maintain independence & sense of identity, activities, wellbeing, and relationships (Craig and Mountain, 2012). This study's strongly person-centred approach to maximise independence in all its critical aspects, reduce stigma and encourage positive approaches to mental/physical exercise, offers a potential solution to the impoverished post diagnostic experiences of some memory clinic attendees (Manthorpe et al 2013). This improves the

development and application of social science theory and evidence to address one of the most compelling concerns of the 21<sup>st</sup> century.

**How the proposal fits with the initiative:** it includes the 3 ESRC/NIHR themes:

(1) Prevention (WP1/2): The ELSA cohort will examine the role of social and lifestyle factors in cognitive decline and the relevance of changing lifestyle patterns in relation to dementia prevalence and the social and economic outcomes and include an international comparison with an ELSA replicant cohort in Brazil. We explore the changing social constructs of memory problems and dementia through the evidence of lived experience using follow up of the ELSA cohort, and a new longitudinal cohort of people with early stage dementia from memory services to assess social impact across time whilst developing appropriate outcome measures.

(2) Social interventions (WP2/3/4): Using the evidence from the first theme and a review of the literature we will develop and evaluate a social intervention promoting independence and quality of life firmly-focused on the experience of actively living with dementia.

(3) Delivery (WP4): The social intervention will be evaluated in a clinical trial set in memory services. This interdisciplinary and collaborative approach develops social scientific knowledge and theory to enhance and extend independence in dementia.

**Research questions:**

1) Which social and lifestyle factors are associated with improvement, maintenance or decline of cognition and activities of daily living; how do changing lifestyles impact on the future prevalence, responses to, and socioeconomic effects of dementia?

2) How do societal attitudes to ageing, cognitive decline, and dementia, influence willingness to seek help for memory problems; what are the social consequences of referral to memory services, the diagnosis of dementia, and the progression of dementia; and how do protective factors (eg self-efficacy) mitigate the social impact, and which social outcome measures are needed to assess these factors in people with dementia?

3) How can a participative research process, analysis of the ELSA cohort, and systematic review be used to develop a social intervention to help independence and quality of life; how best can the feasibility study assess rate of recruitment, practicality of outcomes, attrition, treatment effect, factors necessary for the successful intervention delivery, and ensure the method of implementation is based on best practice principles?

4) How far will a large multicentre randomised controlled trial show clinical and cost effectiveness of the social intervention compared to usual care for people with dementia, and what is needed to assure effective implementation?

**RESPONSE TO FEEDBACK FROM PANEL:** Introducer 1: We have looked at the option of a stepped approach but bearing in mind the variety of people's needs and preferences we believe a tailored approach based on self-management will be more appropriate.

Introducer 2: Attrition has been addressed in the Case for Support (WP1 paragraph 2)

Introducer 3: INVOLVE rates now specified in PPI costs, referencing has been clarified.

Introducer 4: The social intervention is a low cost self-management approach which aims for a moderate degree of benefit to a large number of people. It has been clarified that this is designed for new attenders at memory services with mild dementia who are likely to have only minor difficulties with cognition and daily living activities at the point of diagnosis (WP3 and WP4 paragraph 1).

PANEL: The criteria used to select interventions are described in WP3 (best evidence, consensus, PPI involvement, field testing). The social intervention is for newly diagnosed people with mild dementia and include a variety of options that can be tailored to meet individual need based on self-management. The likely benefits relative to the control group include improved independence in daily living and quality of life (WP4 outcome measures).

**Methods: WP1 Months 4-52: Longitudinal changes in lifestyle, cognition and ageing:**

The English Longitudinal Study of Ageing (ELSA) is well suited to the investigation of processes related to changes of cognition in older people. ELSA is a longitudinal panel study of a representative cohort of men and women living in England aged  $\geq 50$  years

(Steptoe et al., in press). The study began in 2002 with 11,391 members aged 50-100 years, and the sample is reassessed every two years. A range of cognitive processes including memory, executive function, numerical ability, and literacy have been assessed by face to face interview on each wave, with fluid intelligence added on wave 6 (2012/13). Additionally, ELSA includes extensive measures of demographics, socioeconomic circumstances, income and assets, consumption, expectations, physical and mental health, lifestyle, social and civic participation, well-being, and psychosocial factors, together with biomarkers and DNA. In the next two ELSA surveys (2014 and 2016) we will ask people about their expectations of ageing and independence including memory loss and dementia, the associated fear and stigma, and what would make it more or less likely for them to seek help if needed. ELSA was designed as a sister study to the Health and Retirement Study (HRS) in the USA, so as to allow direct comparison of harmonised measures (Banks et al., 2006). Data have been collected in the Study of Health Ageing and Retirement in Europe (SHARE) using the same methods, and in Brazil. ELSA is administered by a research group at UCL (PI. Andrew Steptoe) in collaboration with the Institute for Fiscal Studies, University of Manchester, and NatCen Social Research.

Because the same cognitive measures are used every two years in ELSA, it is possible to track changes over time as well as associations with other factors. The cognitive data have been studied in relation to well-being (Llewellyn et al., 2008), health behaviour (Llewellyn et al., 2009), savings and economic behaviour (Banks 2010), social isolation and loneliness (Shankar et al., in press) and mortality (Bostock et al., 2012) among other issues. Work has also been done on cross-national comparisons (Langa et al., 2009; Skirbekka et al., 2012). The advantage of a panel study of this type is that people are retained in the study even after they experience major health events such as dementia onset, or moving to a nursing home. A proxy interview system is in place to ensure that measures are obtained about people even when they are not capable themselves of completing the survey. This makes it possible both to investigate the role of socioeconomic circumstances and lifestyle as predictors of cognitive decline, and at the impact of cognitive impairment on future wealth, family connections, and social participation. As with all longitudinal studies, there is attrition over time. The proportion of individuals from Wave 1 who participated in wave 5 (2010/11) was 78% (Steptoe et al., in press). Attrition tends to be greater in less educated and wealthy individuals, and in those with chronic illnesses. The possible biases that attrition can introduce into studies of cognitive disorders have been investigated in detail, and they are substantially ameliorated by the use of proxies (Weir et al., 2011) if people are no longer able to give adequate responses. The analyses will be able to take account of any increase in attrition related to dementia. Death related attrition is unlikely to be significantly biased towards those with dementia since it is a protracted illness and the great majority of people with dementia will be over 75. In this age group death is far more likely to be due to other causes such as stroke, heart disease and cancer. The cognitive measures used in ELSA do not provide a direct index of mild cognitive impairment. However, parallel research with HRS has shown that the current cognitive tests predict dementia reasonably accurately (Crimmins et al., 2011), and additional cognitive measures are planned for the next wave of ELSA (2014/15) to provide more precise estimates of mild cognitive impairment. The analyses of ELSA that will be carried out in PRIDE, will include explorations of longitudinal changes in lifestyle in relation to cognition over 12-14 years. We will determine the relationship between change in financial status, social participation, and cognitive change. We will investigate the impact of cognitive change on family financial status and loss of productivity. We will also investigate whether uptake of individual lifestyle interventions may improve outcomes. The comparisons with other countries including Brazil, the USA and continental Europe will allow us to understand trajectories of cognitive change and decline in different cultural, social and policy environments, and in relation to lifestyle factors. Such work will allow us to distinguish processes that appear to be universal from

those that vary with the social and cultural context. We will use appropriate (depending on the type of outcome) regression models allowing for clustering. Results from these models will be presented as estimates of association with corresponding 95% confidence intervals.

We will use these data and analyses to develop an economic model looking at how lifestyle and social changes impact on the costs of dementia. The economic model will calculate the lifetime costs of dementia from NHS and personal social services and societal perspectives for a nationally representative cohort of people with dementia. It will have a Markov structure, with a range of dementia states that will depend on cognition, depression, agitation and function; these in turn will be linked to lifestyle and social changes. Each state will have attached to it a cost that will account for health and social care utilisation, medications, housing, welfare payments, impact on employment, and out of pocket costs borne by families and carers. We will model the transition between states over time based on the analyses of the ELSA data plus supplementary data from published literature and routine sources. We will estimate the lifetime costs of dementia for the cohort based on current lifestyles, social interactions and levels of cognition and then model the impact on total costs if these factors change. The model will be adapted and extended to model cost-effectiveness beyond the end of the follow-up period in the randomised controlled trial in WP4. We will determine the relationship between change in financial status, social participation, and cognitive change, and investigate impact of cognitive change on family financial status and loss of productivity. We will investigate whether uptake of individual lifestyle interventions may improve outcomes. We will adapt the economic model described above and repeat the analysis using Brazilian data.

**Florianopolis Sample:** The population of Florianopolis is around 400,000 with 96% living in the urban area of the city. Of these 46,000 (11.5%) are over 60. The Human Development Index (HDI) is a comparative measure of life expectancy, literacy, education, standards of living, and quality of life for countries worldwide. The municipal HDI was 0.875 in 2000 (high). The basic education for over 60s is low overall at 4.4 years for Santa Catarina state but compares to 4.1 years for Brazil overall. EpiFloripa Idoso is a cross-sectional household-based population study modelled on the ELSA cohort and collecting the same dataset. The first wave was conducted in 2009/2010 with 1656 individuals aged 60 years or older, living in Florianopolis, Southern Brazil. The response rate was 89.2%.

**WP2: Months 6-54: Social and personal constructs of dementia:**

Active and independent living with dementia and supporting people to do this, entails complex negotiation of and responsiveness to changing abilities to interact and articulate (MacQuarrie 2005). This appears to reflect ambivalence in both acknowledging memory problems and formal diagnoses while often also avoiding the prospect and actuality of managing them (Price, 2013). There are growing (re-)organisation pressures in health, social and voluntary sector services, and cultural and institutional changes in ideas about dementia. These are creating unique challenges and opportunities for generating innovative forms of action and understanding (Langdon et al, 2007) and collaborative means of coping (Hulko 2009). Interventions in dementia tend to be concerned with addressing biomedical factors and access to medical services. Encouraging independent living suggests the importance of attending to psychosocial and attitudinal factors, including the reasons which limit ability to address concerns for the future. Recent qualitative research suggests that diagnosis can be actively used by people with dementia to inform mutual orientation to memory problems in interactions, overcome stigma and as a resource to gain help and take action. Fewer observational studies of experiences of living and working with people with dementia have directly examined lives in community settings. To provide data relevant here, will require in-depth research to appreciate the stories and processes which contribute to the variety of such experiences over time. Existing work has generally been more likely to focus on carers and their perspectives, or includes people with a Mild Cognitive Impairment diagnosis rather than dementia only. There is no data yet available to systematically examine the direct experience of people

approaching and then living with dementia at a time when drugs to slow its progress are available. Studies have been typically small-scale, with samples of less than 100, often using convenience samples of clinic-based populations (eg Beard and Fox 2008) which are neither representative of a given population nor purposively designed for conceptual relevance. Ethnographic work, which has mostly examined care homes and other service settings, has helped confirm some elements of our method. The research proposed here would build on these studies, firstly by addressing direct experiences of living with dementia, secondly, amplifying this emphasis on the person with dementia by selectively including trained, supported peer researchers in interviewing and observation; and thirdly, by developing a broader based qualitative appreciation of the social and health context for these experiences. Our primary aim is to explore contemporary issues in actively living with dementia and to engage with their complexity by collecting and analysing a diverse prospective data across different groups of older people living without and with dementia at successive stages, together with carers and professionals helping support those in later stages of dementia. We will conduct a qualitative mixed methods study using texts, one-to-one interviews, and observation. This would be undertaken through a four -stage iterative approach using findings from each phase to inform further phases of data collection and interpretation. The aim is to deepen and sustain understandings from multiple perspectives. This in-depth approach has been widely used in healthcare settings for studies including the experience of living with dementia, inter-professional collaboration (Sinclair et al 2009) and in doctor-patient communication. The planned study will recruit one of the largest qualitative samples of people with dementia for in-depth systematic examination of their experiences.

i) Social and personal constructs of dementia (months 6-12): We will collect and analyse key documents social discourses of dementia with reference to independence and stigmatising and/or connecting processes drawing comparisons with other chronic progressive condition to investigate institutional norms and public discourses of care. We will draw comparisons with other chronic progressive conditions eg the 1980s AIDS crisis.

ii) We will develop a memory services cohort (months 12-36) of 600 people with recent onset dementia and their carers from 24 memory services across the UK to build a research register, track the social impact of dementia over 2 years, offer people an opportunity to be in the trial (or other research studies), develop new measures (e.g. self efficacy), and evaluate the psychometric properties of new and existing measures (e.g. CASP), and prospectively evaluate costs to the NHS, personal social services, patients and families of dementia. Service use data will use an adapted version of the CSRI.

iii) We will examine lived experiences of people with memory problems across the dementia trajectory from normal functioning to diagnosis to living with dementia (months 6-24). To do this we will conduct two in depth one-to-one open-ended semi-structured interviews at eighteen months intervals, and undertake indicative focused observations with (1) 20 people with and 20 people without subjective memory problems from the age group 70-79, (2) 20 people referred to memory services, 20 people after dementia diagnosis and 20 people with dementia 2 years after diagnosis, and their family carers. This will focus on perceived challenges in relation to their changing cognition and ways in which they have experienced this as impacting on their lives, including independence, social engagement and support. We will explore: efforts or intentions to change their lifestyle (health-related behaviours eg exercise); perceived barriers and facilitators to lifestyle change; and views about participating in research on this topic.

iv) We will systematically undertake indicative focused observations (months 18-30) of a range of everyday living situations with a purposively sampled, diverse sub-sample of 25 interviewees (five with and twenty without memory problems) on up to four occasions to collect field data in community and domestic settings. We will sample different times of the day and days of the week, observe different types of daily routine activity to include encounters and events involving healthcare staff, patients and families, We will include



short informal ethnographic interviews with individuals drawn from these groups. Findings from the first phase of semi-structured interviews will inform the development of an observation schedule to guide the collection of observation data. Focused observation visits by researchers, of 2-3 hours will be carried out over twelve months. Across the year, we expect to spend 1-2 days per week collecting field data, with an additional day spent in concurrent analysis. Observations will be recorded as detailed, written field notes. A primary goal will be to describe through thick description how everyday living is negotiated, articulated and accomplished in interactions observed by or discussed with the researchers. Qualitative data will be analysed using thematic and narrative analysis starting with independent textual coding by two researchers. Consensus about codes, categories and themes will be reached by discussion among researchers and participants. A key focus in analysis will be to explore both convergence and divergence in what policy documents and participants say about living with dementia and how this is articulated in examples of everyday living as we observe it.

### **WP3: Months 8-30: Development and piloting of the social intervention:**

We will systematically review the literature on psychological and social interventions in early stage dementia and use the best evidence, along with qualitative results from WP2, case vignette discussions, and a consensus process to coproduce with PPI representatives an optimised social intervention based on self-management principles (e.g. individual goal-setting, monitoring, action planning). The reviews will include the major scientific articles/reviews as well as key policy documents in the last 10 years. A recent systematic review (Barnes and Yaffe 2011) highlighted 7 key factors relating to dementia (diabetes, hypertension, depression) and lifestyle (obesity, smoking, cognitive activity, physical activity) which will be considered for inclusion in the social intervention in view of their wider impact in terms of: co morbidity (eg depression/diabetes); nutrition (eg obesity/diabetes); and frailty (physical exercise). As part of the review process we will identify behaviour change processes and seek to embed them within the intervention. The social intervention will be aimed at the very large number of people attending memory services with mild dementia (Clinical Dementia Rating 0.5-1.0) who are likely to have only minor difficulties with cognition and daily living activities at the point of diagnosis. This intervention will help people after diagnosis, since the consequences of receiving a diagnosis of dementia can be family distress and inactivity. The intervention will be manualised, based on a conceptual framework and mechanisms of action identified within the research programme. It will allow tailoring according to individual needs and circumstances and will be linked to an outcome-related set of activities. In Finland there is a proof of concept trial in progress investigating self-management for people with dementia. However this uses a group based approach and is not manualised (Laakkonen et al., 2012). The method for developing the social intervention will be based on the MRC Guidance for complex interventions and the principle of co-production and follow our own successful approaches e.g. developing cognitive stimulation therapy. The findings from WPs 2 and 3 will be discussed along with Version 1 of the manual in focus groups co-led by trained and supported PPI representatives comprising memory services staff (4 groups), carers (4 groups), people with dementia (4 groups), carers and people with dementia together (4 groups). The groups would look at feasibility, appropriateness, readability/design, and acceptability. The feedback from the discussions would be used to produce Version 2 which would then be validated/revised through a consensus conference including all stakeholders to produce Version 3. Version 3 will be field tested with 20 dyads of people with dementia and their carers to get qualitative feedback on implementation, ease of use, feasibility and overall design. This information will be used in conjunction with a final email stakeholder consultation and modified Delphi process to make any final amendments and produce Version 4. Martin et al., (2012) identified 5 key domains for self management in dementia (relationship with family; maintaining active lifestyle; psychological wellbeing; techniques to cope with memory changes; information on

dementia) and highlighted the need for further research. In developing the programme we will draw on the work of Mountain (a coapplicant) and Craig (2012) who identified and validated key themes for a dementia self management programme. The social intervention content would include information concerning best practice lifestyle advice, physical and cognitive activity, maintenance of wellbeing and independence. As the goals related to the intervention would be individually tailored (but based on the manual) we would expect to optimise benefit for each person. The intervention will acknowledge the personal strengths and concerns of people with dementia and their families when receiving a diagnosis of dementia. It will provide advice on the maintenance of pleasure and relationships, as well as information that addresses the fears identified. Understanding the nature of stigma experienced will help in the shaping of positive attitudes and lifestyle following a dementia diagnosis. Changing behaviour is not easy, but is more effective if interventions are based on theory and evidence-based principles of behaviour change (Abraham and Michie 2008, Albarracin et al., 2005; Noar et al., 2005). The social intervention manual will be organised around individual goal-setting, monitoring, and action planning and is likely to include:

1. educational information about dementia
2. lifestyle advice including:
  - a. health/wellbeing (diabetes, hypertension, depression, obesity, smoking)
  - b. maintaining/promoting cognitive activities/exercise (using a range of activities following the approach of cognitive stimulation therapy)
  - c. maintaining/promoting physical activities/exercise (using a range of physical exercise of varying intensity and frequency eg walking/resistance/aerobic)
3. self-management techniques based on social cognitive theory (Bandura, 1997) to promote self-efficacy, engagement with peer support and social participation, and help increase independence and quality of life.
4. cognitive approaches with carers to help them adapt and improve their mood.

Each participant and carer will have 3 sessions with a dementia advice worker. The 1<sup>st</sup> will develop a tailored formulation, action plan, and a structured diary. This will be reviewed/improved at the 2<sup>nd</sup> session one month later. The formulation and action plan will be refined in the light of the experience of efforts to implement the initial action plan. This will be reviewed at the 3<sup>rd</sup> and final session and a maintenance plan will be developed to encourage long-term change. Participants will also have access to a phone helpline, phone text, web-based support, peer support, plus an optional 3 month review. Dementia advice workers will receive a 2 day workshop-based training which will include carers and people with dementia from our PPI team to impart self-management principles as well as specific intervention techniques. The final stage of WP3 will include pilot/feasibility testing Version 4 with 40 participant pairs in five memory services. This will indicate recruitment rates, withdrawal rate, missing data, fidelity of intervention delivery, adverse events, and will generate strategies to optimise recruitment, indicate the number of services needed to recruit on schedule, and review outcome measures prior to the full study (eg time for completion, feasibility, applicability). Research assistants will collect the outcome measures at baseline, and 6 weeks. We will record other activities to enable a description of treatment as usual. To investigate the intervention process we will ask carers and people with dementia to complete checklists assessing fidelity based on the active components of the social intervention. We will also develop fidelity checklists for completion by the dementia advice workers. Qualitative semi-structured interviews on the experience of taking part in the interventions will be conducted with 10 carers, 10 people with dementia and 10 dementia advice workers. Those people involved in the intervention will complete surveys to provide feedback on their impressions of the intervention and its benefits and challenges. This will help ensure that it is acceptable, user friendly and responsive to the range of abilities, needs and risks encountered.

**WP4: Months 30-52: Multi-centre, pragmatic, single blind randomised controlled trial (RCT) of the social intervention.**

Population: Eligibility criteria will include people with mild dementia (CDR 0.5-1; DSM-IV criteria), living in community settings, who have a family carer, willing and able to participate in the study, attending as new appointments at local memory services. To maximise generalisability we will recruit from a range of services across the UK. The Memory Services National Accreditation Programme (MSNAP) is chaired by the Martin Orrell and includes 55 services across the UK (41 accredited and 14 others). Memory services will be stratified by whether they have accreditation. New standards introduced in response to the PM's challenge on dementia require services to provide opportunities for research and keep a list of attendees who are interested. The close involvement with MSNAP gives us excellent access to the services which are geared up for research to ensure that we will achieve the required number of sites. Our recent survey of almost 600 attenders found that the quality of information provided was poor (Hodges et al., 2013). Recruitment (months 30 to 40) will take place over 10 months (2 to 3 dyads per service per month) allowing for all data for the primary end point to be collected by month 46. Wide experience from our other recent multicentre trials (eg HTA funded individual CST for dementia - currently recruiting 30+ dyads per month from only 8 sites) has demonstrated that this recruitment rate should be readily achievable.

**Intervention:** Participants will be randomised into: (a) treatment as usual, (b) social intervention. The baseline, 26 week (primary end point) and 52 week assessments will collect data on costs, adverse incidents, and outcomes. This is long enough to assess the extended effects of the social intervention and allow for some measurable deterioration in dementia. The study outcome measures data at all the time points will be collected by research assistants who will be blind to group allocation. We will also conduct an estimation of the integrity of blinding.

**Control:** The services and interventions available to people with dementia and family carers randomised to receive TAU will naturally vary between and within centres and may change over time, and will also be available to those in the social intervention group.

**Primary outcome:** *Bristol Activities of Daily Living Scale (BADLS)* (Bucks et al., 1996) as the functional domain of independence, measured at 26 weeks. BADLS is a carer rated instrument with good reliability and validity consisting of 20 basic and instrumental daily-living abilities such as; dressing, bathing, food preparation and use of the telephone. BADLS shows sensitivity to change over time (Byrne et al., 2000) and correlates strongly with cognitive decline, and with change in response to anticholinesterase medication (Courtney et al., 2004). It assesses level of independence through activities of daily living.

**Secondary outcomes:** (*BADLS at 52 weeks*).

**Client Service Receipt Inventory** (Beecham et al., 1992): The CSRI will be adapted for the study. It provides data from which to estimate the costs of dementia care, unpaid carer inputs and wider carer impacts and is needed for all the cost analyses. This accurately records use of drugs and services and any changes that occur. We will ask carers and people with dementia from both groups to complete weekly checklists of the range and frequency of their other activities.

**ADAS-Cog** (Rosen et al., 1984): Brief, widely used test of cognitive function, with good reliability and validity which measures the severity of the most important cognitive symptoms of dementia. This is needed to assess cognitive functioning over time.

**DEMQOL** (Smith et al., 2005): Measures five domains of quality of life and has good reliability and validity. Recent research has derived preference weights to derive utilities from DEMQOL values for calculation of quality adjusted life years (QALYs) for economic evaluations and we will use these measures in our analysis.

**CASP 19** (Hyde 2003): This is a 19 item needs satisfaction measure of quality of life in old age with 4 key domains: control, autonomy, pleasure, and self-realization.

**Timed up and go test:** (Podsiadlo 1991): A reliable and valid test for quantifying functional mobility, useful in following clinical change over time. The person is observed and timed

while he rises from an arm chair, walks 3 meters, turns, walks back, and sits down again. The test is quick, requires no special equipment or training, and is easily conducted.

*Number of social contacts and social activities per week:* Included as a measure of social functioning which may improve following the intervention.

*Carer Outcomes: Quality of life:* The EQ-5D (EuroQoL Group, 1990) provides a descriptive profile and single index value for health status which can evaluate quality of life of carers and derive utilities for calculation of QALYs (Charlesworth et al., 2005).

*Mental Health:* GHQ-28 (Goldberg and Hillier, 1979) widely used in carer research and covers anxiety, depression, insomnia, social dysfunction and somatic symptoms.

*Fidelity checklist:* A checklist will be developed for carers and people with dementia to self-rate fidelity to the social intervention using Michie's 12 domains in relation to identifying and understanding behaviour change and implementation.

*Qualitative study:* This will run alongside the RCT to investigate the experienced impact of the intervention. An 18 month longitudinal interview and focused-observational study, with a purposive sample of 20 participants and their carers in both the intervention and control arms (total 40 dyads). The methods of sampling and collecting data draw on the principles described in WP2 to provide data on ways in which the intervention and treatment as usual are being contextualised in everyday life experiences and practices. The sample, recruited early in WP4, will enable comparison of experiences in the the two arms over time.

*Clinical Trials Unit:* Registration of patients and randomisation to treatment arm by blinded intervention code will be via a web based service managed by PRIMENT. Randomisation will be stratified by centre. People with dementia and their family carers who satisfy the entry criteria including informed consent/assent will be eligible. Essential baseline information will be recorded at registration and checked for eligibility. To assess generalisability a log will be maintained of people who satisfy the entry criteria for the trial but are not randomised; this will consist of basic demographic and clinical details as well as the reasons for not consenting to randomisation.

*Analyses:* Descriptive analyses using means (with SD), medians (with IQ ranges), counts and proportions will be used as appropriate, to summarise the baseline characteristics of the participants. A linear regression model allowing for clustering and adjusting for baseline BADLS and the stratification factor will be used to compare the 26 week BADLS between the social intervention and control groups. If assumptions of normality are not satisfied, a suitable transformation will be used. Appropriate regression models allowing for clustering will be used to analyse the secondary outcomes. We will also conduct a secondary analysis to examine the effect of intervention over time on BADLS at 26 and 52 weeks using a regression model that allows for clustering within memory services, repeated measures and adjusting for time and baseline values. Results from all secondary analyses will be treated as exploratory and presented as estimates with 95% confidence intervals. Bias due to missing data will be investigated and if required a sensitivity analysis (taking account of the clustered nature of the data) will be carried out to assess the impact of missing data. Analyses will be based on intention to treat. A more detailed analysis plan will be prepared nearer the analysis stage.

*Sample size:* The mean BADLS score in people with mild dementia is 8.7 with a SD of 8.4 (Bucks, Haworth 2002). A difference of 0.3 SD due to intervention (about 2.5 points for BADLS) is considered to be clinically important. Based on a two sample t-test for the primary analysis, a total of 350 participants is needed to detect an effect size of 0.3 SMD using a 5% significance level and 80% power (Stata version 12). Since this is a cluster randomised trial we have inflated the sample size to 520 using an average cluster size of 17 (based on the number of participants available per cluster after allowing for 15% attrition) and ICC of 0.015 and 15% attrition (both estimated based on the HTA REMCARE dementia trial). A minimum of 26 clusters is thus required.

*Economic Analysis:* Costs for the primary analysis will be conducted from the NHS and social care services perspective based on the within-trial period, with a secondary analysis

from a societal perspective that will include impact on carers and costs to other government departments. Resource use for the social intervention will include the cost of the intervention including the cost of implementation and any training costs. For both groups costs will include health and social care resource use and medication, and for the societal analysis housing, welfare payments, employment impact where appropriate and the cost to society and the carer of carer time for unpaid carers. We will calculate the incremental cost per QALY gained of the social intervention compared to usual care. Resource use data will be collected using a modified version of the client service receipt inventory (CSRI) for dementia and will be costed using nationally published unit costs. Outcomes will include the trial primary outcome (BADLS) and QALYs. QALYs will be calculated using data from the trial on survival and health-related quality of life. The latter will be measured using DEMQOL and DEMQOL-Proxy. We will base the QALY calculations on the DEMQOL-U and DEMQOL-Proxy-U measures, which have been constructed for use in economic evaluations, allowing QALYs to be measured for people with dementia (Rowen et al., 2011). The analysis from the societal perspective will also include an analysis of the impact of the intervention on QALYs for family and carers, measured using the EQ-5D ([www.euroqol.org](http://www.euroqol.org)). We will calculate the incremental cost per change in BADLS of the social intervention compared to usual care. A budget impact analysis will examine what the total NHS costs would be if the intervention was implemented nationally. The primary analysis will be for the duration of the trial (52 weeks) but we will develop a decision analytical model, incorporating information from ELSA, to extrapolate costs and outcomes beyond the end of the trial, taking a lifetime time horizon. Confidence intervals and the probability that the intervention is cost-effective for a range values of willingness to pay for a QALY gained for the primary analysis will be constructed using non-parametric bootstrapping with replacement. Full deterministic and probabilistic sensitivity analyses will be conducted for the decision analytical model.

*Florianopolis Sample:* The social intervention will be translated, adapted and piloted in Brazil to ascertain the feasibility and appropriateness of implementing it in a different country. The Florianopolis memory service is based at South of Santa Catarina University (UNISUL). The memory service has a central location with good access and there is free public transport for the over 60s. It is integrated with the community services including family practice, geriatrics, neurology, psychiatry, psychology, and physiotherapy. The service has two nurses, neuropsychologists, and 8 medical students. Investigations eg blood tests and brain scans are provided by SUS (Brazilian Health System) resources.

**WP5: Months 0-60: Career development and capacity building:**

This will support the pathway to senior academic posts in ageing and dementia care research from research assistant/PhD student level, through to postdoc and senior postdoc levels. It is anticipated by the end of PRIDE several of the researchers in the programme will be in an ideal position to be promoted to Lecturer or Senior Lecturer posts to join the formal academic career ladder. Career development opportunities include 3 ESRC funded PhD studentships plus 3 matched UCL funded PhD studentships in key areas. Moreover, 2 highly talented postdocs have already been identified as being appropriate for key posts within PRIDE. Dr Vasiliki Orgeta has a psychology of ageing background and runs a large HTA funded trial developing and evaluating individual cognitive stimulation therapy (CST) would be appropriate for promotion to the programme manager post. Dr Elisa Aguirre has a background in clinical and health psychology and gerontology, developed and coordinated the maintenance CST trial, and would be suitable for the postdoc in psychology. UCL is also providing 2 new fellowships and a senior academic post in gerontology to develop research capacity. For the all researchers associated with the programme we will develop an interdisciplinary mentor system with a continuing professional development programme. This will include opportunities to (1) assume roles in work packages, (2) develop/lead public engagement projects (3) organise

seminars for peers/practitioners, (4) presentations at conferences, (5) write both academic papers and materials for the public. This work package will also provide an international platform for European researchers to develop the necessary research skills, abilities and expertise. The INTERDEM Academy will have an international impact improving dementia care by fostering research collaboration, improving knowledge exchange and developing junior researchers. INTERDEM is the world's largest international network for dementia care research and provides the ideal infrastructure for this goal. Besides the development of pan-European research on early, timely and quality psychosocial interventions in dementia, INTERDEM's mission statement is to actively disseminate this and enhance practice, policy and the quality of life of people with dementia and their supporters, across Europe, which nicely fits in the aim of this proposal. We will build on the successful cohort of researchers coming through major grant programmes led by the applicants from the UK and the wider INTERDEM community. The INTERDEM Academy will include: (1) Travel exchange fellowships for PhD students and post doc researchers allowing them to spend 3 months in another INTERDEM research centre. (2) A biannual programme for students/researchers comprising: a) seminars to discuss their work with peers and senior academics. b) expert workshops & master classes to develop research ideas and expertise in the methodology of psychosocial research. (3) The INTERDEM Academy will organise annual international conferences to promote excellence in social science research in dementia care inviting key EU policymakers.

**Institutional support:** This is a joint application from the UCL Faculty of Brain Sciences (FBrS) and Faculty of Population Health Sciences (FPHS) and aligns with our Faculty strategies with regard to this important disease. Dementia constitutes a significant individual, family and societal burden, and thus has both clinical and public health dimensions that require urgent multidisciplinary attention. To this end the Faculty Deans propose to support the application, if successful, with further investments, both internally and with other funders and collaborators, to include: a senior academic clinical gerontology post; two Fellowships; three PhD studentships. There are other means by which the Faculties will support the work and ensure its success. In FPHS, the development of two new Institutes, of Clinical Trials & Methodology and of Health Informatics, will both offer substantive methodological expertise to PRIDE, and in FBrS, senior appointments in neurodegeneration and neuroprotection in the recently awarded £20M Leonard Wolfson Experimental Neurology Centre (LWENC) will provide complementary support for this programme of research.

#### **Datasets review - included in web form**

**Approach to engagement of research users** - We have a proactive, comprehensive and flexible approach to engaging all the potential research users (see pathways to impact). We will follow good practice established in the SHIELD and other research programmes to consistently improve the involvement of carers and people with dementia in the development, governance and dissemination of research eg by identifying priorities for research by talking to users and carers. We work closely with the DENDRON PPI group, and in partnership with Age Concern and Uniting Carers (from the charity Dementia UK).

**Patient and public involvement:** We follow good practice from our other research involving carers and people with dementia in the design, delivery, governance and dissemination of research. Developing this proposal we consulted 18 people with dementia, 14 carers, and 7 care staff, from 2 care homes, 2 community centres, plus the DENDRON PPI group. DENDRON PPI gave 'very strong' support for this study due to the emphasis on involving patients and carers productively throughout. People highlighted the taboo of dementia, the gradual loss of identity, and the need to maintain autonomy. The qualitative components in WP2 and WP4 will include trained, supported peer researchers who are themselves with dementia which will further enhance the focus on and validation of the experience on people with dementia. This will reflect the research team's extensive experience of collaborative and participative research.

**PRIDE - Justification of resources:** The costings reflect the significant volume of work and expertise required in this 5 year research programme. 1.1.14 to 31.12.18

**Directly incurred: Staff Costs**

*Programme manager:* This senior post to needed to set up and manage the programme, and supervise the research assistants and psychology post doc. Involved in analysis of results and write up.

*Programme Administrator:* This senior admin post to support the coordination of the programme which will include secretarial support for the programme manager, photocopying, meeting organisation, liaison between researchers and centres, and support for the international centres.

*Postdoctoral researcher psychology:* This post is needed for the development of memory services cohort and support for RAs, systematic literature review, the development and piloting of the social intervention, and implementation of the social intervention in the RCT.

*Postdoctoral researcher sociology:* This post is required for the collection of the qualitative data and the support and supervision of PPI researchers and RAs also involved in data collection. This post will also lead on analysis and write up of qualitative material.

*Research Assistants (RA):* The research assistants will be needed for recruitment and data collection in both the qualitative and quantitative studies. This will include involvement in the development and testing of the social intervention. The RAs will be involved in several workpackages each of which involve recruitment and assessments of participants: WP2ii Recruitment of the memory services cohort (600); WP2iii (100 x 2 qualitative interviews); WP2iv (25 x 4 qualitative interviews); WP3 (assist with 16 focus groups; field testing of social intervention with 20 dyads; piloting of intervention with 40 dyads and assisting with 40 qualitative interviews). For WP4 (RCT) based on our previous experience in the REMCARE study for recruitment we would expect to need to screen around 3 patient/carer dyads for each one recruited. Assuming we can recruit one third (200) of the memory services cohort this mean we would need to screen 320x3 dyads (960) in order to recruit the 520 for the RCT. Each of the 520 pairs would require 3 assessments (baseline/6/12 months) making 1560 in all. Assuming the RAs are involved with half the qualitative assessments this means participant contacts for 2520+96+750 = 3366 screening/assessments in total plus travel time. Time is also needed to set up the project in each area, attend meetings/conferences/training, annual leave, and to input and check data. This means 3 RAs are needed for 3 years each.

*PRIMENT Trials Unit:* This is a complex project which requires excellent trial management, and PRIMENT is a well established Clinical Trials Unit with a growing reputation. An experienced Senior Trial Coordinator will oversee the management of the trial, and will supervise the trial manager The Trial Manager responsibilities will include the day to day coordination of the trial across the 26 centres, recruitment, data collection, and the trial completion and write up. This level of responsibility requires certain expertise and experience and this post has therefore been costed at Grade 7. The research assistant will support the trial manager and provide assistance with audits and quality assurance processes. The trial secretary provides administrative support including preparation of data packs, photocopying, meeting organisation, and liaison between researchers and centres.

*Statistician:* This postdoc includes two main aspects: trial statistician responsible for overseeing the randomisation procedures, the set up and management of the database data analysis, and preparing reports for the DMEC supervised by RO; and complex analysis of the ELSA datasets supervised by RO and ASt. This will also involve liaison with AX/EO about analysis of the Florianopolis sample.

*Health Economist:* The complexity of the cost data and ELSA data and the need for appropriate analyses necessitates the involvement of a postdoc health economist supervised by Prof Morris.

**£48000 - Directly incurred:**

**Travel and subsistence: £48000**

Travel for assessments: Travel expenses are required for 3572 assessments/contacts costed at £8 per visit by car/public transport: £28576

Other travel expenses: travel between sites, travel to meetings: £11830

National/international conferences (Alzheimer Europe, Alzheimers Disease International, International Psychogeriatric Association): travel, subsistence: £7594

**Directly incurred: other costs:**

**£31500 Consumables:** photocopying questionnaires and outcome measures, laser toner cartridges, stationery and postage for questionnaires, NVIVO software for qualitative analysis.

**£12000 Equipment:** computers 7 x £640 = £4480, laser printer £470 x 2. Mobile phones needed to be able to contact researchers and for personal safety £940 x 7 staff = £6580.

**£10000 IT support and website development:** to promote PRIDE programme and act as resource for staff (web based protocols, standard operating procedures etc).

**£1500 Recruitment and advertising costs** for staff directly employed on the project

**£8000 Costs of meetings** (eg PSC/DMEC) £1600 x 5 years: room hire, travel & subsistence.

**£39300 Costs of database setup and randomisation**

**£24000, Staff training:** including courses in methodology/research governance/GCP.

**£16000 Production of manuals/DVDs:** costs of dissemination, conference fees (see above)

**Costs of carer coapplicant and user/carer involvement: £55000**

Costs of peer researchers: 8 researchers x20 hours x £20 per hour (INVOLVE rates) = £3200, PPI time: training dementia advisors 40 hours x £20 = £1600

PPI coapplicant time (2 carers - David Prothero and Ula Htay): 50 hours/year x 5 years x £20 x 2 = £10000

PPI coapplicant expenses/travel/telephone costs/consumables = £2000

Conference fees, travel and subsistence for carers and people with dementia to attend & present at conferences/events: £3000

DEMENTIA UK: Funding (£4500x 5 years) to support Uniting Carers (a dementia carers organisation part of Dementia UK) for carer/person with dementia involvement/support in studies: £22250

AGE CONCERN: Funding to support Andrew Haines time (£2000) and support for training dementia advisors: staff costs, room hire, subsistence £10950.

**Directly allocated: see staff roles**

**Exceptions:** 3 FT PhD Studentships based in UCL Doctoral Training Centre (Economics & econometrics, Psychology/Sociology, Health Psychology) (6-54) including fees, stipend allowable expenses.

**International costs:**

(1) £139000 - OVERSEAS - Costs for Brazil: PI time Xavier £26708 and & D'Orsi' £29040, research assistant time for epidemiology study & social intervention feasibility trial & adaptation of materials for Brazil £64526, other expenses and overheads £18726.

(2) £113000 - OVERSEAS: INTERDEM Academy: researcher travelling fellowships 8 x £3500; admin support & Prof Verhey's time £55000; workshops/masterclasses, travel, room hire, conference organisation £6000 x 5 years = £30000.

**Indirect and Estates: see main form**

**NHS costs: see attached**



## MARTIN ORRELL

Professor Martin Orrell

Professor of Ageing and Mental Health, Unit of Mental Health Sciences, University College London.

### Education/ Qualifications

2007 Fellow of the British Association of Medical Managers (BAMM) 2001

Fellow of the Royal College of Psychiatrists (FRCPsych)

1994 Doctor of Philosophy (PhD, Institute of Psychiatry, University of London) 1988

Member of the Royal College of Psychiatrists (MRCPsych)

1982 Bachelor of Medicine, Bachelor of Surgery (BM, BS, Nottingham University) 1980

Bachelor of Medical Sciences (BMedSci, Hons, Nottingham University)

### Professional history

2004- Professor of Ageing and Mental Health, Department of Mental Health Sciences, University College London.

2000- Honorary Consultant Old Age Psychiatrist, North East London Foundation Trust

2001- Associate Medical Director/Director for Research and Development, North East London Foundation Trust

2003-2009 Clinical Director/Associate Medical Director, Mental Health Services for Older People, North East London Foundation Trust

1991-2004 Senior Lecturer/Reader in Psychiatry of Ageing, University College London

### Selected relevant publications

Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, Orrell M (2003) An RCT investigating the effectiveness of an evidence-based cognitive stimulation therapy programme for people with dementia. *Brit J Psychiat* 183, 248-254.

Knapp M, Thorgrimsen L, Patel A, Spector A, Hallam, A, Woods B, Orrell M (2006) Cognitive Stimulation Therapy for dementia: is it cost effective? *Brit J Psychiat* 188, 574-580.

Orrell M, Hancock G, Hoe J, Woods B, Livingston G, Challis D (2007) An RCT to meet the needs of people with dementia living in residential care. *Int J Geriatr Psychiat*, 11, 1127-34.

Moniz-Cook E, Orrell M et al for the INTERDEM group (2008) A European Consensus on outcome measures for psychosocial interventions in dementia care. *Aging Ment Health*. 12, 14-29.

Miranda-Castillo C, Galboda K, Oomman S, Olojugba C, Woods B, Orrell M (2010) The unmet needs, social networks and quality of life of people with dementia living at home. *Health Qual Life Outcomes*  
<http://www.hqlo.com/content/8/1/132>.

### Relevant current and recent research grants

2006-2011 NIHR/HTA - Trials grant: £2,194,000 - HTA-SADD study of antidepressants for depression in dementia – a definitive multicentre pragmatic randomised controlled trial of clinical and cost effectiveness (PI: S BANERJEE, G Livingston, M Orrell and others)

2007-2012 NIHR - Programme Grant: £1,981,952 - Support at Home - Interventions to Enhance Life in Dementia (SHIELD) (PI: M ORRELL, B Woods, I Russell, D Challis, E Moniz-Cook, M Knapp, G Charlesworth, J Wilson)

2007-2012 NIHR - Programme Grant £1,999,514 - DEMCARE Management of challenging behaviour in dementia at home and in care homes. (PI: E MONIZ-COOK, A Mason, C Mozley, B Woods, I Russell, R Jones, I Markova, P Camp ion, A Hilton, G Stokes, I James, M Downs, M Orrell)

2007-20 11 NIHR/HTA - Trials Grant: £1,237,018 - REMCARE - Reminiscence groups for people with dementia and their family caregivers: pragmatic 8-centre trial of joint reminiscence and maintenance v usual treatment. PI: B WOODS, M Orrell, I Russell, E Moniz-Cook, E Bruce, RT Edwards, J Keady).

2009-2010 Medical Research Council: £50,000 - Challenges and healthy ageing: the role of resilience across the life course (ResNet) (\*G WINDLE B Woods, V Burholt, Gopal Netuveli, Cherie McCracken, Richard Mitchell, Kate Bennett, A Sacker, M Orrell, D Naylor)

2009-2014 NIHR - Programme Grant: £1,998,346 - An Optimized Person Centred Intervention to Improve Mental Health and Reduce Antipsychotics amongst People with Dementia in Care Homes. (PI: C BALLARD, J Fossey, M Orrell, J Murray, R Howard, M Knapp, E Moniz -Cook , B Woods, I Russell, S Day, D Aarsland, B Woodward-Carlton, E McLaughlin E).

2010-2014 NIHR/HTA - Trials Grant: £1,273,286 - Individual Cognitive Stimulation Therapy for dementia (iCST Trial). (PI: M ORRELL, B Woods, I Russell, E Moniz-Cook, M Knapp, A Spector, A Burns).

2010-2013 NIHR Research for Patient Benefit (RfPB) Programme £237,210 - "I can't forget to worry": A pilot randomised controlled trial of CBT for anxiety in people with dementia. (PI: A SPECTOR, M Orrell, G Charlesworth, A Qazi, J Hoe, S Saffer, M King)

2012-2016 NIHR - Programme Grant £1,999,845 - Valuing Active Life In Dementia (VALID) (PI: ORRELL M, Mountain G, Russell IT, Sackley C, Challis D, Moniz-Cook E, Vernooij -Dassen M, King M, Hill J, Brouder J, Morris S, Poland F, Omar R, Michie S, Wenborn J, Rooks S)

### **Research outputs, innovation and development that have improved NHS service provision**

Involved in 6 Cochrane reviews on the effectiveness of different treatments for dementia. With Bob Woods developed and evaluated CST a useful and cost effective therapy for dementia with a similar effect size to drug treatments. CST is recommended in NICE dementia guidelines, widely used and published as a manual in the USA and UK. [www.cstdementia.com](http://www.cstdementia.com).

Led the development of the Camberwell Assessment of Need for the Elderly (CANE) an effective, valid, and reliable assessment of needs, widely used in the UK and Europe to map needs/evaluate services. A book including a manual was published in 2004. [www.ucl.ac.uk/cane](http://www.ucl.ac.uk/cane).

### Education/ Qualifications

1999- 2001	BSc in Health Psychology	Deusto University, Spain
2001- 2003	MPhil in Health Psychology	Deusto University, Spain
2008	MSc Gerontology	Vrijeke University, Netherlands
2008-20 12	PhD (submitted)	University College London

### Professional history

2008-To date	Research Assistant SHIELD programme	University College London and NELFT
2005-2008	Outreach and development worker	Alzheimer's Society

### Publications

- Woods B, Aguirre E, Spector A, Orrell M. (2012) Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews* ; Issue 2. Art. No.: CD005562. DOI:10.1002/14651858.CD005562.pub2.
- Aguirre E., Woods B., Spector A., Orrell M. (2012) Cognitive stimulation for dementia: A review of the evidence of effectiveness from Randomised controlled trials. *Aging Research Reviews*, 10.1016/j.arr.2012.07.001.
- Spector A, Aguirre E, Orrell M. (2010) Translating Research Into Practice: A Pilot Study Examining the Use of Cognitive Stimulation Therapy (CST) after a one-day training course. *Non-pharmacological Therapies in Dementia Journal*; 1 (1) 61-70.
- Aguirre E., Spector A., Hoe J., Streater A., Russell IT., Woods RT., Orrell M. (2011) Development of an evidence- based extended programme of maintenance cognitive stimulation therapy (CST) for people with dementia. *Non-pharmacological Therapies in Dementia Journal*, 1 (3) 198- 215.
- Aguirre, E., Spector, A., Streater, A., Burnell, K., Orrell, M. (2011) Service users' involvement in the development of a maintenance Cognitive Stimulation Therapy (CST) programme: A comparison of the views of people with dementia, staff and family carers. *Dementia*, 10 (4) 459–473.
- Aguirre, E., Spector, A., Hoe, J., Russell, TI., Knapp, M., Woods, TR., Orrell M. (2010) Maintenance Cognitive Stimulation Therapy (CST) for dementia: A single-blind, multi-centre, randomized controlled trial of Maintenance CST vs. CST for dementia. *Trials*, 11:46.
- Aguirre E., Hoare Z., Streater A., Spector A., Woods B., Hoe J., Orrell M. (2012) Cognitive Stimulation Therapy (CST) for people with dementia- who benefits most?. *International Journal of Geriatric Psychiatry*, 10.1 002/gps.3 823.
- Aguirre E., Spector A., Hoare Z., Streater A., Woods B., Streater A., Donovan H., Hoe J., Russell I., Orrell M. Maintenance Cognitive Stimulation Therapy (CST) for dementia: A single -blind, multi-centre, randomized controlled trial of Maintenance CST vs. CST for dementia. *BMJ*, submitted
- Aguirre E., Spector A., Streater A., Hoe J., Woods B. and Orrell M (2011). Making a Difference 2: Volume Two: An Evidence-based Group Programme to offer Maintenance Cognitive Stimulation Therapy (CST) to people with dementia Hawker Publications: UK.
- Streater A., Spector A., Aguirre E., Hoe J., Hoare Z., Woods R., Russell I., Orrell M.(2012) Maintenance Cognitive Stimulation Therapy (CST) in practice: study protocol for a randomized controlled trial. *Trials*, 13:9

Professor David Challis,  
 Professor of Community Care Research and Director PSSRU, School of Community Based Medicine, University of Manchester

### Education/ Qualifications

B.A. (Social Science) Class 2, Division 1; (Honours). University of York. Certificate in Education, University of Birmingham.  
 Certificate in Psychiatric Social Work (C.Q.S.W.), University of Manchester.  
 M.Sc. University of Manchester  
 Ph.D. University of Kent

### Professional history

1996– present: Professor of Community Care Research and Director PSSRU, School of Community Based Medicine, University of Manchester..  
 1994– 1996: Professor of Social Work and Community Care, PSSRU, University of Kent.  
 1989 – 1994: Reader in Social Work and Social Care, PSSRU, University of Kent  
 1986 – 1989: Assistant Director and Senior Research Fellow, PSSRU, University of Kent.  
 1976 – 1986: Research Fellow, PSSRU University of Kent.  
 1971 – 1976: Psychiatric Social Worker in Lancashire and Salford

### Selected publications

- Challis D, Clarkson P, Williamson J, Hughes J, Venables D, Burns A, Weinberg A. (2004) The value of specialist clinical assessment of older people prior to entry to care homes, *Age and Ageing*, 33, 25-34.
- Abendstern, M., Reilly, S., Hughes, J., Venables, D. and Challis, D. (2006) Levels of integration and specialisation within professional community teams for people with dementia. *International Journal of Geriatric Psychiatry*, 21, 77-85.
- Venables, D., Reilly, S., Challis, D., Hughes, J. and Abendstern, M. (2006) Standards of care in home care services: A comparison of generic and specialist services for older people with dementia. *Aging and Mental Health*, 10, 2, 187- 194.
- Reilly, S., Venables, D., Hughes, J., Challis, D. and Abendstern, M. (2006) Standards of care in day hospitals and day centres: a comparison of services for older people with dementia. *International Journal of Geriatric Psychiatry*, 21, 460-468.
- Worden, A., Challis, D. and Pedersen, I. (2006) The Assessment of Older People's Needs in Care Homes. *Aging and Mental Health*, 10, 5, 549-557
- Sutcliffe, C., Burns, A., Challis, D., Mozley, C.G., Cordingley, L., Bagley, H. and Huxley, P. (2007) Depressed Mood, Cognitive Impairment and Survival in Older People admitted to Care Homes in England, *American Journal of Geriatric Psychiatry*, 15, 708-715.
- Tucker, S., Hughes, J., Burns, A. and Challis, D. (2008) The balance of care: Reconfiguring services for older people with mental health problems. *Aging and Mental Health*, 12,81-91.
- Hughes, J., Bagley, H., Reilly, S., Burns, A., Challis, D. (2008) Care Staff working with people with dementia: Training, knowledge and confidence, *Dementia*, 7, 227-23 8
- Reilly, S., Abell, J., Brand, C., Hughes, J., Berzins, K. and Challis, D. (2011). Case management for people with long term conditions: impact upon emergency admissions and associated length of stay. *Primary Health Care Research and Development*, 12, 223-236
- Clarkson, P., Challis, D., Davies, S., Donnelly, M., Beech, R., Hirano, T. (2010). Comparing how to compare: an evaluation of alternative performance measurement systems in the field of social care. *Evaluation*, 16, 59-79.
- Manthorpe, J., Stevens, M., Rapaport, J., Jacobs, S., Challis, D., Wilberforce, M., Netten, A., Knapp, M. & Glendinning, C. (2010). Gearing Up for Personalisation: Training Activities Commissioned in the English Pilot Individual Budgets Sites 2006-2008. *Social Work Education*, 29(3), 319-331.
- Abendstern, M., Hughes, J., Clarkson, P., Sutcliffe, C. Wilson, K. and Challis.D. (2010). 'We need to talk': communication between primary care trusts and other health and social care agencies following the introduction of the Single Assessment Process for older people in England. *Primary Health Care Research and Development*, 11, 61-71.
- Clarkson, P., Hughes, J., Challis, D., Linda Thorley and Carole Kilshaw. (2010). Targeting, Care Management and Preventative Services for Older People: The Cost-Effectiveness of a Pilot Self-Assessment Approach in

One Local Authority. *British Journal of Social Work*, 40, 2255-2273

- Reilly, S., Hughes, J. and Challis, D (2010). Case management for long-term conditions: implementation and processes. *Ageing and Society*, 30, 125-155.
- Abendstern, M., Hughes, J., Clarkson, P., Sutcliffe, C. and Challis D. (2011). The pursuit of integration in the assessment of older people with health and social care needs. *British Journal of Social Work*, 41(3), 467.
- Stevens, M., Glendinning, C., Jacobs, S., Moran, N., Challis, D., Manthorpe, J., Fernandez, J.L., Jones, K., Knapp, M., Netten, A. and Wilberforce, M. (2011). Assessing the Role of Increasing Choice in English Social Care Services. *Journal of Social Policy*, 40, 257-274
- Tucker, S., Brand, C., O'Shea, S. Abendstern, M., Clarkson, P., Hughes, J. Wenborn, J. and Challis, D. (2011). An evaluation of the use of self-assessment for the provision of community equipment and adaptations in English Local Authorities. *British Journal of Occupational Therapy*, 74(3), 119-128.
- Wilberforce, M., Harrington, V., Brand, C., Tucker, S., Abendstern, M. and Challis, D. (2011). Towards integrated community mental health teams for older people in England: progress and new insights. *International Journal of Geriatric Psychiatry*, 26(3), 221.
- Abendstern, M., Harrington V., Brand C., Tucker S., Wilberforce M. and Challis, D. (2012). Variations in structures, processes and outcomes of community mental health teams for older people: A systematic review of the literature. *Aging & Mental Health*,
- Chengqiu Xie, Jane Hughes, Caroline Sutcliffe, Helen Chester & David Challis. (2012). Promoting Personalization in Social Care Services for Older People. *Journal of Gerontological Social Work*, 55, 2 18-232
- Clarkson, P. Abendstern, M. Sutcliffe, C. Hughes, J. Challis, D. (2012). Identification and recognition of depression in community care assessments: impact of a national policy in England. *International Psychogeriatrics*, 24(2), 261-269.

## Grants

- PSSRU at Manchester (core grant) Dept of Health (DH) £1.3 million 2006-2011 (PI)
- A systematic Assessment of The Single Assessment Process DH £335,000 2003-2007 (PI)
- National Evaluation of Individual Budgets Pilot Study DH £749,000 2006-2008 (Co -PI)
- The use of local metrics: performance measurement in social care for older people. ESRC £276,000 2006-2009 (PI)
- Shifting between hospitals and the community: Policy implications for care, clients and providers Canadian Institute for Health Research \$2,900,000 2006-2011 (Co-I)
- Enhancing the efficiency and Effectiveness of assessment in Social Care of Older People DH £266,000 2006-2008 (PI)
- National Trends and Local Delivery in Old age Mental Health Services, NIHR PGfAR £1.3 million 2007-2012 (PI)
- Health Care Support for Older People in Care Homes, BUPA £99,100, 2010-2012 (Co-I)
- National Evaluation of the Common Assessment Framework for Adults, DH, £1,453,290, 2010-2012 (Co-PI)
- Recognition of and Consultation for memory problems among South Asian Elders, NIHR RfPB, £202,661, 2011-2013 (PI)
- Resource allocation at the micro level in adult social care: determinants, methods and Guidance, NIHR SSCR, £528,000, 2011 -2014 (PI)
- RightTimePlaceCare: Improving health services for European citizens with dementia, EU, £240,344, 2010-2013 (Co -I)
- Senior Investigator Award, NIHR, £60,000, 2009 -2013
- Valuing Active Life In Dementia, NIHR PGfAR, £1,999,845 (Co-I)

## GEORGINA MARY CHARLESWORTH

Dr Charlesworth Georgina  
Research Department of Clinical, Educational and Health Psychology, 1-19 Torrington Place, London

### Education/ Qualification

- 2009 PhD An evaluation of two psychological interventions for family carers of people with dementia. University of London
- 1997 Post Qualification Diploma in Cognitive Therapy. Clinical Distinction. Department of Continuing Education, University of Oxford.
- 1995 Doctorate in Clinical Psychology ClinPsyD  
School of Health Policy & Practice, University of East Anglia, Norwich.
- 1993 MPhil Psychopathology  
Pembroke College, University of Cambridge
- 1991 BA(Hons) Psychology (Natural Sciences Tripos) Class 2i.  
Converted to MA (Cantab) March 1995. Pembroke College, University of Cambridge

### Professional history (post-qualification)

- 2001 to date Lecturer , University College London & Honorary Consultant Clinical Psychologist, North East London (NHS) Foundation Trust 1998 –
- 2001 Alzheimer's Society Research Fellow (1.0wte)  
School of Health Policy and Practice, University of East Anglia. 1997 –
- 1998 Lecturer in Clinical Psychology (0.6wte)  
Doctoral Programme in Clinical Psychology, University of East Anglia Concurrently, Clinical Psychologist (0.4wte) North East Essex Mental Health (NHS) Trust
- 1995 - 1997 Clinical Psychologist (1.0wte)  
Elderly Division, North East Essex Mental Health (NHS) Trust

### Selected Publications

- Charlesworth, G. (2008) Living with Dementia. In Murna Downs et al (eds) *Excellence in Dementia Care: Principles and Practices*. pp.285-300 Maidenhead: Open University Press, McGraw-Hill Education, 285-300.
- Charlesworth, G. Higgs, F., Poland, F. (2008). *Complementarity of welfare provision in the 'mixed economy' of care for carers of people with dementia: a longitudinal study: Full Research Report*. ESRC End of Award Report, RES-000-22-2020. Swindon: ESRC
- Charlesworth, G., Shepstone, L., Wilson, E., Reynolds, S., Mugford, M., Price, D., Harvey, I & Poland, F. (2008) Befriending carers of people with dementia: a randomised controlled trial. *British Medical Journal*, 336; 1295-1297
- Charlesworth, G., Shepstone, L., Wilson, E., Thalanany, M. Mugford, M., & Poland, F. (2008) Does befriending by trained lay workers improve psychological well-being and quality of life for carers of people with dementia, and at what cost? A randomised controlled trial. *Health Technology Assessment*, 12, 4. <http://www.hta.ac.uk/1233>
- Charlesworth, G, Tzimoula, X, & Newman, S (2007) Carers Assessment of Difficulties Index (CADI): psychometric properties for use with carers of people with dementia. *Aging and Mental Health*, 11(2), 218-225.
- Charlesworth, G., Tzimoula X., Higgs P. and Poland F (2007). Social Networks, Befriending and support for family carers of people with dementia. *Quality in Ageing-Policy, Practice and Research*, 8(2), 37-44.

- Wilson, E., Thalanany, M., Shepstone, L., Charlesworth G, Poland F, Harvey I, Price D, Reynolds S, Mugford, M (2009) Befriending Carers of People with dementia a cost utility analysis. *International Journal of Geriatric Psychiatry*, 24, 6 10-623.
- Charlesworth, G., Burnell, K., Beecham, J., Hoare, Z., Hoe, J., Wenborn, J. Knapp, M., Russell, I., Woods B., Orrell, M. (2011) Peer support for family carers of people with dementia, alone or in combination with group reminiscence in a factorial design: study protocol for a randomised controlled trial, *Trials*, 12:205 <http://www.trialsjournal.com/content/12/1/205> ('highly accessed')
- Gallagher-Thompson, D., Tzuang, Y.M, Au, A. Brodaty, H., Charlesworth, G., Gupta, R, Lee, S.E, Losada, A & Shyu, Y-I (2012) International Perspectives on Nonpharmacological Best Practices for Dementia Family Caregivers: A Review. *Clinical Gerontologist* ,35(4), 3 16-355

### **Current academic supervision at UCL**

2 x PhD (Secondary Supervisor); 1 x Clinical Psychology Doctorate (Primary Supervisor)

### **Grants (80K plus)**

Lead Applicant/Chief Investigator for:

- |   |          |
|---|----------|
| 2007- 2008 ESRC Small Grant (RES-000-22-2020)   | £80,896  |
| Complementarity of welfare provision in the 'mixed economy' of care for carers of people with dementia: a longitudinal study (MECADA). Co-applicants Paul Higgs (UCL), Fiona Poland (UEA)   |          |
| 2002 –2006 NHS R&D Health Technology Assessment (HTA)   | £642,903 |
| Co-applicants: S Reynolds, I Harvey, D Price, F Poland, L Shepstone, M Mugford (UEA) 'Befriending and Costs of Caring' (BECCA) project. Cost –effectiveness RCT of befriending for carers of people with dementia (ISRCTN08 130075) |          |
| Plus Department of Health ad-hoc funding  | £104,305 |
| 1998 –2001 Alzheimer's Society Research Fellowship  | £122,465 |
| RCT of cognitive therapy vs support as usual for depressed carers of people with dementia (ISRCTN84429490)  |          |

**Co-applicant** for:

- |   |            |
|---|------------|
| 2010-12 NIHR Research for Patient Benefit (PB-PG-0609-18230).   | £237, 210  |
| "I can't forget to worry": A pilot randomised controlled trial of CBT for anxiety in people with dementia. Lead Applicant: Aimee Spector                            |            |
| 2007 – 2012 NIHR Programme Grant for Applied Research   | £2million  |
| Support at Home – Interventions to Enhance Life with Dementia (SHIELD) Lead applicant: Prof Martin Orrell, UCL  |            |
| 2006- 2010 NHS R&D Health Technology Assessment (HTA)   | £1,563,608 |
| Study of antidepressants for depression in dementia - a definitive multicentre pragmatic randomised controlled trial of clinical and cost effectiveness (HTA-SADD). |            |
| Lead Applicant: Prof Sube Banerjee, IOP.  |            |

Dr Eleonora d'Orsi.

Lecturer in Epidemiology Department of Public Health, Federal University of Santa Catarina, Brazil

**Education/ Qualifications**

1989	BDS	Medicine	University of Rio de Janeiro, Brazil
1992	Specialist Certificate	Public Health	Escola Nacional de Saçede Pœblica, Brazil
1996	MSc	Epidemiology/Public Health	Escola Nacional de Saçede Pœblica, Brazil
2003	PhD	Epidemiology/Public Health	Escola Nacional de Saçede Pœblica, FIOCRUZ, Brazil
2009	Post-Doctoral	Epidemiology/Public Health	Universidade Federal de São Paulo, Brazil
2012	Post-Doctoral	Epidemiology/Public Health	University College London, UK

**Professional history**

January 2000- December 2005	Lecturer in Epidemiology, University of South of Santa Catarina, Brazil
August 2011- July 2012	Academic visitor, Department of Epidemiology and Public Health, University College London, London, UK
January 2006 to present	Lecturer in Epidemiology Department of Public Health, Federal University of Santa Catarina, Brazil

**Selected publications 2012 and in press**

1. Corseuil, M. W., Schneider, I. J. C., Corseuil, H., Benedetti, T., D'orsi, E. Physical activity and environment perception among older adults: a population study in Florianópolis, Brazil. *Revista de Saçede Pœblica* , v.3, p.1 - 15, 2012.
2. Watanabe T, Knobel R, Suchard G, Franco MJ, D 8217 Orsi E, Consonni EB, Consonni M. Medical students' personal choice for mode of delivery in Santa Catarina, Brazil: a cross-sectional, quantitative study. *BMC Med Educ.* 2012 Jul 20;12(1):57.
3. Leal, M. C., Silva, A. A. M., Dias, M. A. B., Gama, S. G. N., Rattner, D., Moreira, M. E., Theme Filha, M. M., Domingues, R. M. S. M., Pereira, A. P. E., Torres, J. A., Bittencourt, S. D. A., D'orsi, E., Cunha, A. L., Leite, A. J. M., Cavalcante, R. S., Lansky, S., Diniz, C. S. G., Szwarcwald, C. L. Birth in Brazil: national survey into labour and birth. *Reproductive Health.*, v.9, p.1 - 18, 2012.
4. Benedetti, T., D'orsi, E., Schwingel, A., Chodzko -Zajko, W. "Convivência" groups: building active and healthy communities of older adults in Brazil. *Journal of Aging Research.* , v.20 12, p.612918 - ,2012.
5. Medeiros, F L, Xavier, A J, Schneider, I J C, Ramos, L R, Sigulem, D, d'Orsi, E. Digital inclusion and functional capacity of older adults living in Florianópolis, Santa Catarina, Brazil (EpiFloripa 2009-2010). *Revista Brasileira de Epidemiologia (Impresso).* , v.15, p.106 - 122, 2012.
6. Aziz, Marina Meneses, Calvo, Maria Cristina Marino, d'Orsi, Eleonora Medicines prescribed to the elderly in a city in southern Brazil and the Municipal Medicines List. *Cadernos de Saçede Pœblica (ENSP. Impresso).* , v.28, p.52 - 64, 2012.
7. Weber Corseuil, Maru', Hallal, Pedro Curi, Xavier Corseuil, Hertton, Jayce Ceola Schneider, Ione, d& Safety from Crime and Physical Activity among Older Adults: A Population-Based Study in Brazil. *Journal of Environmental and Public Health.* , v.20 12, p.1 - 7, 2012.
8. Finucane, Mariel M, Stevens, Gretchen A, Cowan, Melanie J, Danaei, Goodarz, Lin, John K,



- Paciorek, Christopher J, Singh, Gitanjali M, Gutierrez, Hialy R, Lu, Yuan, Bahalim, Adil N, D'Orsi, E. National, regional, and global trends in body -mass index since 1980: systematic analysis of health examination surveys and epidemiological studies with 960 country-years and 9.1 million participants. *Lancet (British edition)*. , v.377, p.557 - 567, 2011.
9. Corseuil, M. W., Schneider, I. J., Silva, D. A. S., Costa, F. F., Silva, K. S., Borges, L. J., D'Orsi, E. Perception of environmental obstacles to commuting physical activity in Brazilian elderly. *Preventive Medicine (1972)*. , v.53, p.289 -292, 2011.
  10. Rizzatti, K., Schneider, I. J. C., D'orsi, E. Epidemiologic profile of sun exposure in Florianópolis citizens. *Epidemiologia e Serviços de Saõde*. , v.20, p.459 -469, 2011.
  11. Aziz, M. M., Calvo, M. C. M., Schneider, I. J. C., Xavier, A. J., D `Orsi, E. Prevalence and factors associated with access to medication among the elderly in a city in southern Brazil: a population-based study. *Cadernos de Saõde Põblica (ENSP. Impresso)*. , v.27, p.1939- 1950, 2011.
  12. d `Orsi, E, Xavier, A J, Ramos, L R. Work, social support and leisure protect the elderly from functional loss: EPIDOSO Study. *Revista de Saõde Põblica (USP. Impresso)*. , v.45, p.685 - 692, 2011.
  13. Pinheiro, C E A, Peres, M A, d«Orsi, E . Increased Survival among lower birthweight children in Southern Brazil. *Revista de Saõde Põblica (USP. Impresso)*. , p.9 - 0, 2010.
  14. Xavier, A. J., D'orsi, E., Sigulem, D, Ramos, L R. Time orientation and executive functions in the prediction of mortality in the elderly: Epidoso study. *Revista de Saõde Põblica (USP. Impresso)*. , v.44, p.148 - 158, 2010 .
  15. Sakae, T M, Freitas, P F, D'orsi, E. Factors associated with cesarean section rates in a university hospital. *Revista de Saõde Põblica (USP. Impresso)*. , v.43, p.472 - 480, 2009.
  16. Gama, A S, Giffin, K M, Angulo-Tuesta, A, Barbosa, G P, D'orsi, E, Women's representations and experiences with vaginal and cesarean delivery in public and private maternity hospitals. *Cadernos de Saõde Põblica (ENSP. Impresso)*. , v.25, p.2480 - 2488, 2009.
  17. Schneider, I J C, D'orsi, E. Five-year survival and prognostic factors in women with breast cancer in Santa Catarina State, Brazil. *Cadernos de Saõde Põblica (ENSP. Impresso)*. , v.25, p.1285 - 1296, 2009.
  18. Schneider, I. J. C., Ribeiro, C, Breda, D., Skalinski, L. M., D'orsi, E. Epidemiological profile of the clientele in HIV Testing and Counseling Centers in Santa Catarina State, Brazil, 2005. *Cadernos de Saõde Põblica (ENSP. Impresso)*. , v.24, p.1675 - 1688, 2008.
  19. Xavier, A. J., Reis, S. S., Paulo, E. M., D'orsi, E. Time of adhesion to the Family Health Strategy protects elderly against cardiovascular and cerebrovascular accidents in Florianópolis, 2003 to 2007. *Ciõncia e Saõde Coletiva (Impresso)*. , v.13, p.1127 - 1132, 2008.

### **Selected current grants**

Issue Date: 0 1/08/2008

Grant Number: 569834/2008 2

Period: 01/08/2008-3 1/07/2011 (3 years)

Conselho Nacional de Desenvolvimento Cient'fico e Tecnolõgico, CNPq, Brazil

Title: Health Conditions of older adults living in Florianópolis, Santa Catarina, Brazil, population based survey.

Major goal: To estimate prevalence and factors associated with health and social conditions of older adults

Amount: £20,000.00 (financial support), £12,480.00 (MSc and undergraduate scholarships)

## ANDREW HAINES

Mr Andrew Haines

Chief executive of Age Concern Havering

Successful chief executive for 21 years in a highly regulated and competitive environment for three similar but contrasting organisations. Proficient internal and external communicator, advocate and representative. Extensive knowledge of governance and organisational culture. National leadership experience including representing sector with government to ministerial level. Former and maintainer of key relationships with stakeholders, commissioners, allied and regulatory agencies; individual and corporate supporters. Demonstrable record for the innovatory creation of sustainable services that serve people well and reliably from a healthy corporate base.

### Education/ Qualifications

Education/teaching – Certificate of Education – Liverpool University

Social care & special education – Bachelor of Philosophy – Newcastle University

Psychology of Education – Master of Arts – Institute of Education - London

Management - Civil Service Top Management Programme

Currently in the final year of a taught MA in Society & Ageing in the Department of Gerontology at Kings College London

### Professional history

Chief Executive of Age Concern Havering

On entering post in January 2011, I facilitated the evaluation which saw the trustees that March decide not to join the new national brand of Age UK, but to build upon a 60 year history of service to older people by remaining a fully independent stand alone local charity. An organisational review has resulted in a new senior management team and revised infrastructure systems to better support services. New staff & volunteer development programmes are already enhancing the reliability of services and their further qualitative improvement. A new strategic plan sets out how ACH might confirm its contribution within new commissioning and delivery arrangements whilst broadening its range of services to older people and particularly those in most acute need.

Chief Executive (Interim) - Shaftesbury Young People

I accepted a one year appointment to provide leadership at a time of genuine organisational crisis. The situation was stabilised and the underlying problems addressed. A review of future options indicated a merger, although I tried hard to create a ‘meld’ of three organisations. In the event both proved unachievable within

the necessary timescale and an alternative model was produced for a sustainable stand-alone future.

Achieving the conditions for this model to be implemented took a further year. Along the way all governance, operational and corporate systems were reviewed then confirmed or amended. Central overheads were reduced proportionately. £ 1m+ budget deficits projected in both years were avoided by producing a £1 50k surplus in 8/9 and a deficit of only £1 00k for 9/10. Turnover reduced, but new business was won with the potential for more. A permanent chief executive was recruited and the organisation has a secure two year window in which to re-grow or re-position; probably in a variety of partnership arrangements, the seeds of which are sown.

Chief Executive – The Together Trust (formerly BGWS)

On my appointment in 1990, BGWS, founded in 1870, was in serious decline as a service providing children’s charity. It had six social care and education services which were underused and unrated. In 1989/90 income was £1 .2m, the deficit £300k and liquid reserves almost spent. When I stood down as CEO in December 2007 the Together Trust had a national reputation for innovation and sustained quality; it provided over 40 social care and special education services; worked with over 30 local authorities; employed 850 staff; served around 1,500 children and an increasing number of adults each year, who all had very special needs. In 2006/7 the Trust’s income was £23m (surplus £1 .5m). In the year to March

2008 the turnover was £24m and a similar surplus achieved. It continues to be one of the largest service at Together Trust, providing children's organisations in the UK and a top 200 charity.

## **Achievements**

Created then melded 40+ semi autonomous and differently regulated/funded services (SME 's) into a cohesive corporate entity

Constantly improved performance despite frequent modernising change to legislation, commissioning bodies, quality standards, funding mechanisms and best practice expectations.

Ensured a regional charity 200 miles from London achieved genuine national moment in its contribution to legislation, policy and best practice.

Regularly outperformed fellow voluntary, public and private competitors.

Fostered environments where gifted and dedicated professionals could do their best work and staff generally cited training and development opportunities as major positives of their employment.

Produced a year-end surplus in sixteen out of seventeen years, whilst seldom having more than 6/8 weeks cash at bank and never using an overdraft.

Compiled a property portfolio which substantially enlarged the asset base and future security of the charity  
Conceived, planned, commissioned and delivered a new administrative/ conference centre under budget which now also enjoys a national reputation .

Made the organisation a responsible and rewarding partner of choice .

Developed, changed and developed again several high performing senior management teams (learning all the while!).

Took on the challenge of re-branding with a mix of internal and external resources and made it work successfully.

At Shaftesbury Young People

Ensured the continuance of some valued services for young people in need and a 165 year legacy of service  
Found a way forward for the organisation when all the conventional indicators were negative

Proved my knowledge, skills and experience were transferable and effective in a contrasting environment.

## **Other positions**

Trustee of Caritas Social Care Network (national): ex-trustee of Addiction and Dependency Services

(regional): Start-up board of a not-for-profit organisation seeking to help small/medium sized charities benefit from an extended relationship with successful entrepreneurs.

Paul Fredrick Higgs

Professor of Sociology of Aging, Department of Mental Health Sciences, University College London, London, W1W 7EY

### **Education/ Qualification**

1988 PhD Social Policy and Administration, Kent University 1982

BSc Sociology 2:1 Polytechnic of North London

### **Professional history (post-qualification)**

2001 to date **Lecturer**, University College London & Honorary Consultant Clinical 2004- 2008

Reader in Medical Sociology Centre for Behavioural and Social Sciences in Medicine, UCL

1999-2004 Senior Lecturer in Medical Sociology Department of Psychiatry, UCL 1994-1999

Lecturer in Medical Sociology Department of Psychiatry, UCL

1990-1994 Eleanor Peel Lecturer in Social Gerontology St George's Hospital Medical School, University of London

1988-1990 Research Fellow, St George's Hospital Medical School, University of London

### **Selected Publications**

1. Price D., Bisdee D., Daly T., Livsey L. & Higgs P. Financial planning for social care in later life: the 'shadow' of fourth age dependency *Ageing and Society* (in press)
2. Williams S., Higgs P. and Katz S. (2012) Neuroculture, active ageing and the 'older brain': problems, promises and prospects *Sociology of Health and Illness* 34: 64-78
3. Stevenson, F., Higgs, P. (2011) 'Ageing well': competing discourses and tensions in the management of knee pain *Health Sociology Review* 20(4):369-377
4. Moffatt S., Higgs P., Rummery K. and Jones I. (2012) Choice, consumerism and devolution: growing old in the welfare state(s) of Scotland, Wales, and England. *Ageing and Society* 32(5):725-46
5. Gilleard C, and Higgs P. (2011) Frailty, disability and old age: A re-appraisal *Health: 15* (5): 475-490
6. Daneski K; Higgs P and Morgan M (2011) How far can Foucault take us? An analysis of the changing discourses and limitations of the medical treatment of apoplexy and stroke *Health: 15* (4) : 369-84
7. Scherger S., Nazroo J. and Higgs P. (2011) Leisure activities and retirement: do structures of inequality change during old age? *Ageing and Society* 31: (1) 146-72
8. Gilleard C. and Higgs P. (2011) Aging, abjection and embodiment in the Fourth Age *Journal of Aging Studies* 25 (2) 135-42
9. Higgs P. and Gilleard C. (2010) Generational conflict, consumption and the ageing welfare state in the UK *Ageing and Society* 30 (8):1439-1451
10. Jones I.R. and Higgs P. (2010) The natural, the normal and the normative: Contested terrains in ageing and old age *Social Science and Medicine* 71 : (8) 15 13-19
11. Gilleard C, and Higgs P. (2010) Theorizing the fourth age: Aging without agency *Aging and Mental Health* 14:121-28
12. Daneski K., Higgs P. and Morgan M. (2010) From gluttony to obesity: moral discourses on apoplexy and stroke, *Sociology of Health and Illness* 32: 730-44
13. Jones I.R, Leontowitsch M, Higgs P. (2010) The experience of retirement in second modernity: generational habitus among retired senior managers *Sociology* 44:103-20

14. Higgs P, Leontowitsch M., Stevenson F and Jones I.R. (2009) 'Not just old and sick': the will to health in later life *Ageing and Society* 29:687-707
15. Higgs P, Hyde M, Gilleard C, Victor C, Wiggins R and Jones IR. (2009) From Passive to Active Consumers? Later life consumption in the UK from 1968-2005. *Sociological Review* 57: 102-24
16. Gilleard C., and Higgs P. (2009) The power of silver: ageing and identity politics *Journal of Aging and Social Policy* 21: 277- 95
17. Higgs P and Jones I. R (2009) *Medical Sociology and Old Age: Towards a sociology of health in later life* Routledge, London
18. Jones I. Hyde M, Victor C, Wiggins D, Gilleard C and Higgs P. (2008) *Ageing in a consumer society: from passive to active consumption in Britain* Policy Press, Bristol
19. Gilleard C. and Higgs P. (2008) Internet use and the digital divide in the English Longitudinal Study of Ageing *European Journal of Ageing* 5: 233-39
20. Gilleard C, Hyde M and Higgs P. (2007) Age, length of residence, neighbourhood status and the experience of 'community' amongst the over fifties in England. *Research on Ageing* 29(6), 590-605
21. Moffat S and Higgs P. (2007) Charity or entitlement? Generational habitus and the welfare state among older people in North East England. *Social Policy and Administration* 41(5): 449-64
22. Gilleard C, Hyde M and Higgs P. (2007) Communication and community in the third age: the impact of internet and cell phone use on the attachment to place in later life in England. *Journals of Gerontology B Social Sciences* 62 (4): S276-S283
23. Higgs P & Gilleard C (2006) Departing the margins: social class and later life in a second modernity *Journal of Sociology* 42: 2 19-41
24. Gilleard C and Higgs P (2005) *Contexts of Ageing: Class, Cohort and Community* Polity Press, Cambridge
25. Gilleard C, Higgs P, Hyde M, Wiggins D, Blane D. (2005) Class, Cohort and Consumption: the UK experience of the Third Age *Journals of Gerontology: Social Sciences* 60B: S305 -10
26. Higgs P, Hyde M, Wiggins, R and Blane D. (2003) Researching Quality of Life in Early Old Age: The Importance of the Sociological Dimension *Social Policy and Administration* 37: 239-52
27. Higgs P, Mein G, Ferrie J, Hyde M, Nazroo J. (2003) Pathways to Early Retirement: Agency and Structure in the British Civil Service. *Ageing and Society* 23:761-78

### Grants

ESRC 2012-13 £168 500 Adult Survivors of Childhood Liver Transplant; Personal Narratives of an Emerging "New" Ageing Population (Co-investigator) (RES/J002445/1) ESRC Research Seminars Competition 2009-2011 'New Ageing Populations' £15,000 (Co- applicant) (RES-45 1-26-0655)

ESRC, 2007-2008, £100,000 'Complementarity of welfare provision in the 'mixed economy' of care for carers of people with dementia: a longitudinal study'. (Co-investigator) (RES-000- 22-2020)

ESRC, 2005-2007, £126,000 'From passive to active consumers: Ageing and consumption in Britain 1963 -1998'. (Principal Investigator) (RES-154-25-0007)

NIH (USA), 2000-2005, \$5,067,750 'English Longitudinal Study of Ageing'. (Named Collaborator)

NIH (USA), 1999-2004, \$1,763,140 'Health: Socio-economic Status and Pathways. \$1,763,140 (Named Collaborator)

ESRC, 1999-2001, £84,000 'Influences on Quality of Life in Early Old Age' (Grantholder)

Professor Eef Hogervorst

Professor of Biological Psychology, School of Sport, Exercise and Health, Loughborough

### Education/ Qualifications

1993-1998 PhD in Age-related Cognitive Decline, Department of Neuropsychology & Psychiatry, Maastricht

1987-1993 BA/MSc in Mental Health Sciences, Department of Experimental Psychopathology, University of Limb

### Professional history

2005-present **Professor of Biological Psychology**, School of Sport, Exercise and Health, Loughborough University

2011-present **Visiting Professor** Respati University Yogyakarta Indonesia

2009-present **Adjunct Professor**, University of Indonesia, Jakarta, Indonesia

2004-2010 **Visiting Senior Research Fellow**, Department of Public Health & Prim Care University of Cambridge

2004-2005 **Senior Research Associate**, Department of Psychiatry, University of Cambridge

1999-2005 **Research Scientist**, 'Oxford Project To Investigate Memory and Ageing', University of Oxford.

2005 Ad hoc **lecturer** PG Summer School Medical Epidemiology, University of Heidelberg

2004/2006 Ad hoc **lecturer** PG Summer School Nutritional Medicine, University of Surrey

2003-2006 **Research Associate Professor**, Department of Geriatrics, UAMS, Little Rock USA.

1999-2004 **Lecturer**, MSc Cognitive Neuroscience Oxford Brookes University, Oxford.

2001 **Statistical consultant** 'Cognitive Drug Research, Reading, U.K.

1998– 1999 **Post-Doc** Blaschko Fellow 'Hormones & AD' University of Oxford

1997 – 1998 **Post-Doc** 'Age, Hormones and Behaviour' Maastricht University

1992 – 1999 **Lecturer** and tutor for Health Sciences & Biological Psychology at Maastricht University (50%)

1993-1997 **Research assistant**, (AIO employment) Maastricht University (50%)

1991-1993 **Research assistant**, (CBT therapist intern and psychometrist) Ambulant mental health care (RIAGG)

1989 **Research Assistant** Institute for Drugs, Safety, & Behaviour (I.G.V.G.) in Maastricht

1987 Home Care for the elderly, Amsterdam

### Selected publications

Leishaar, K, H-ABC including Hogervorst, E. (2012) The relationship of vitamin B12 and sensory and motor peripheral nerve function in older adults JAGS (in press)

Hogervorst, E., Rahardjo, T., Jolles, J., Brayne, C., Henderson, V.W. (in press). Gender differences in verbal memory with age: effects of systematic differences in education and health. *Aging Health* (invited paper)

Clifford, A., Bandelow, S., Hogervorst, E. & Rahardjo, T.B. (2012). A Cross-sectional Study of Physical Activity and Health- Related Quality of Life in an Elderly Indonesian Cohort. *BJOT*

Stock, J., Clifford, A., Hogervorst, E. (2012) Exercise interventions to improve cognitive performance in older adults – Potential psychological mediators to explain variation in findings. *European Neurological Review*, 7(2): 107-12

Hogervorst E, Clifford A, Stock J, Xin X, Bandelow S (2012) Exercise to Prevent Cognitive Decline and Alzheimer's disease: For Whom, When, What, and How Much? *J Alzheimers Dis Parkinsonism* (invited paper)

Arifin, E., Braun, K., Hogervorst, E. (2012). Three pillars of active ageing in Indonesia. *Asian Population Studies*, 8(2):48 -56. Vd Wardt, V., Bandelow, S., Hogervorst, E. (2012) ICT use, mood and cognition in elderly. *Gerotechnol*, 10(4), 1-21

Thornton V, Warden D, Talbot C, S S Mastana, Bandelow S, Hogervorst E. (2011) Modification of estrogen's association with Alzheimer's disease risk by genetic polymorphisms. *Brain Res. Mar*

16;1379:213-23.

Clifford, AH, Bandelow, S., Hogervorst, E. (2011) Preventing cognitive decline in the elderly through physical activity in midlife Alzheimer's & Dementia: The Journal of the Alzheimer's Association Vol. 7, Issue 4, S95 S96

Vd Wardt, V, Bandelow, S., Hogervorst, E. (2011) Cognitive abilities, well-being and Internet search performance in older people. Alzheimer's & Dementia: The Journal of the Alzheimer's Association Vol. 7, Issue 4, Page S502

Hogervorst, E. Mursjid, F., Priandini, D., Setyawan, H., Ismail, R.I., Bandelow, S., Rahardjo, TB. (2011) Borobudur revisited. Invited paper Brain Research, epub Oct 28 2010, Mar 16;1379:206-12. (IF 2.46)

Kirby, L., Bandelow, S, Hogervorst, E. (2010) Visual impairment in Alzheimer's disease. JAD Jan;21(1): 15-34.

Hogervorst, E., Matthews, F.M., Brayne, C. (2010). Are optimal levels of testosterone associated with better cognitive function in healthy elderly women and men? Biochim Biophys Acta. 2010 Oct; 1800(10): 1145-52. Epub 2010 Jan 7. (IF 2.713) Helen T Butler,

Donald R Warden, Eva Hogervorst, Jiannis Ragoussis, A David Smith, Donald J Lehmann(2009) Association of the aromatase gene with AD in women Neurosci Lett14;468(3): 202-6 (IF 2.2)

Hogervorst, E., Yaffe, K., Richards, M., Huppert, F.A. (2009) Hormone replacement therapy to maintain cognitive function in women with dementia-update. Cochrane-Database-Syst-Rev.(2): CD003799. 100

Clifford, A.H., Yesufu, A., Edwards, L., Bandelow, S., Hogervorst, E. (2009) Maintaining cognitive health in elderly women.

Women's Health (special October issue, invited review) Future Medicine Aging Health, Vol. 5, No. 5, Pages 655-670

Kalaria, RN. et al (including Hogervorst E. for the World Federation of Neurology Dementia Research Group) Alzheimer's disease and vascular dementia in developing countries: prevalence, management, and risk factors. Lancet Neurology 2008

Hogervorst, E., Huppert, F, Matthews, F, Brayne, C (2008). Thyroid function and cognitive decline in the MRC Cognitive Function & Ageing Study. Psychoneuroendocrinology Aug;33(7):1013 -22.

## Grants

Agency ART	Period: 01/09/2011-31/08/2012
Dementia screening in Indonesia (PI)	
Institute: Collaborative Research and Development Healthcare Bioscience iNet East Midlands	Period 01/09/2010-01/09/2011
Eye scanning to diagnose dementia (Co-PI)	
Institute Universitas Indonesia	Period 01/09/2010- 01/06/2011
Tofu and tempeh can affect cognitive decline in female OVX rats (Co-PI)	
Institute Universitas Indonesia.	Period 01/09/2010- 01/08/2011
Description and monitoring of Depok as an Age friendly city (Co-PI)	
Institute: Graduate School of Health Loughborough University	Period: 01/09/ 2010 -01/09/2013
LU Development PhD studentship (PI)	
Agency New Dynamics of Ageing (RES-353-25-0008)	Period: 01/10/2008-31/12/2011
Sustaining IT use by older people to promote autonomy and independence (£1,392,052) PI	
L.Damodaran WP2 PI EH Psychological performance in the elderly and ICT use)	
Agency: Gatergrade Sport Science Institute	Period: 01/08/2008-1/9/2009
Changes in brain volume with exercise/heat induced hypohydration in men (Co-PI)	
Agency YSTF	Period 01/04/2007-1/11/2008
Classification systems for athletes with learning dsability (Co-PI)	
Agency Nestec	Period 0 1/9/2006-1/04/2007
Caffeine, cognition and sports performance (PI)	
Agency ART	Period:10/3/2006-10/3/2007
Relationship of salivary phytoestrogens to age-related cognitive decline possible dementia in Indonesia (PI)	

## ULA HLA HTAY

Mr U Hla Htay

A full time carer for my wife with dementia for 15 years with rolling program of caring at home and at a respite care centre. Experienced Social Care, Dementia Care (at home and at respite care) Service User on behalf of my wife.

### Education/ Qualifications

- 1961 BSc, Rangoon University
- 1966 Shipping Diploma, Chamber of Shipping and City of London Polytechnic
- 1985 Member of Chartered Institute of Shipbrokers' Association, London
- 1991 Associate member of Chartered Institute of Arbitrators, London
- 2011 MSc Mental Health Sciences, UCL, London

### Professional history

- 1996-2011 A full time carer after stood down as a practising Maritime Arbitrator
- 1996-1976 In shipping industry at various ship owners', dry cargo and LPG & NPG shipbrokers' offices in London: managing and operating liner services, handling owners' & charterers' accounts, disputes resolution.
- 1976-1977 With colleagues formed a Thai national shipping line in Bangkok and ran liner services in Far East.
- 1964-1976 A Deputy European Representative, Burma Five Star Line - Antwerp and London offices.
- 1961-1964 European Line Manager, Burma Five Star Line, Rangoon.

### Selected publications and relevant experience

Co-author Cochrane Review *Non-pharmaceutical interventions for wandering of cognitively impaired people in institutional setting* at the Cochrane Dementia & Cognitive Improvement Group, Cochrane Library Issue 4, 2009.

U Hla Htay (2009). *We learn to enter her world*, In Lucy Whitman (Ed.). *Telling Tales of Dementia*. Jessica Kingsley

Developed mental health clinical trials pilot website (commissioned by NIMHE) with TwoCan Associates, further developed at the TriMe Project ([www.trime.org](http://www.trime.org)).

A Dementia Carer Supporter at INVOLVE and participated in their and NIHR PPI activities and in compilation of *Public Information Pack* (PIP).

A Steering Group member at UK Clinical Research Network (UKCRN) with INVOLVE in developing People in Research project. ([www.peopleinresearch.org](http://www.peopleinresearch.org))

Expert Panel member at National Cancer Research Network (NCRN) and Emergency Care Research Institute (ECRI) in developing *Clinical Trials Explained*, 2005 NCRN/BMJ unpublished.

Health Promoting Behaviour and Coping in family carer of people with dementia, 2011. An MSc thesis at the Ageing Mental Health Sciences, University College London.

### PPI activities

Research Network Volunteer, formerly Quality Research in Dementia (QRD) Consumer Network, Alzheimer's Society, UK: prioritising, selecting, monitoring research grants on cause, cure, care and prevention of dementia and disseminating the research results & findings, since 1998.

A consumer reviewer of protocols and reviews and co-author at the Cochrane Collaboration Review Groups and a member of Cochrane Consumer Network (CCNet) email discussion list. A Consumer



member of the Cochrane Dementia and Cognitive Improvement Group. A CCNet Representative at the International Association of Patients' Organizations (IAPO- a global patients' associations).

A Public Panel member at the Medical Research Council and Human Genetic Commission. A Consumer Forum member and Deputy Chair at the Royal College of Psychiatrists.

A PPI Forum member at the London DeNDRoN Coordinating Centre.

A member of College Experts, HTA Clinical Evaluation and Trials Programme, Southampton University.

A Family Dementia Carer/Service User Forum and External Reference Group member at the Mental Health Foundation.

A Carer Advisory Member at the Standing Commission on Carers.

Give regular talks at the dementia training courses run by Dementia UK and Mental Health Nurse dementia course at the KCL run by Admiral Nurse.

Facilitate workshops at the INVOLVE Conferences, UK Dementia Congresses and at the Alzheimer's Society AGMs.

### **Current involvement in research activities**

At University College London, a Data Monitoring Committee member at START (STrategies for RelaTives) study; co-applicant of Music Therapy for people with dementia Study and co-applicant of THIN ( The Health Improvement Network) study; a Carer Panel Member at the SHIELD (Maintenance of CST) study. Consultant at the iCST (Individual Cognitive Stimulation Therapy programme funded by NIHR. A participant at the Assisted Dying and Euthanasia of people with dementia and dementia carer Study.

Advisory Committee Member at the Trading Times web site- for employment of dementia carers (Dementia UK).

At King's College London, an Advisory Committee Member at the Social Care Practices with Care Groups. On going Research Network Volunteering work at the Alzheimer's Society, UK on various research.

## RACHAEL HUNTER

Rachael Hunter provides advice and support on the health economics component of clinical trials for a number of departments in UCL, for the Primary Care & Mental Health Clinical Trials Unit (<http://www.ucl.ac.uk/priment/>) and the UCL London Research Design Service ([www.rdslondon.co.uk](http://www.rdslondon.co.uk)). She has also provided advice to the Department of Health and NHS London on the cost effectiveness of government policies.

Previously she has worked for the NHS on improving and monitoring the quality of mental health services and as a Programme Manager for the Public Health And Substance Misuse team in Offender Health, Department of Health. She was a member of the project team for Lord Kamlesh Patel's Prison Drug Treatment Strategy Review Group, providing advice on health economics and coordinated a research project to examine service user views on prison drug treatment.

### Education/ Qualifications

Nov-2003	BPsych (Hon)	Sydney University, Australia
Oct-2005	PG Dip Health Services Management	University Technology Sydney,
Dec-2010	MSc Economic Evaluation in Health Care	Australia City University, UK
Mar 2011	Advanced modelling methods for health economic evaluation	York University
May-2008	Analytical Models for Decision Making	London School of Hygiene and Tropical Medicine
Jul-2007	Certificate in Prince II	
Apr 2005	Analysing and Interpreting Financial Data	Institute of Public Administration Australia

### Professional history

Aug-2010	Current	Senior Research Associate (Health Economics)	UCL
Dec-2009	Jul-2010	Performance Manager	South London and Maudsley Mental Health Trust
May-2006	Dec-2009	Programme Manager, Public Health and Substance Misuse Team, Offender Health	Department of Health
Feb-2004	Oct-2005	Graduate Health Management Trainee	Sydney South West Area Health Service

### Publications

Maynard A., Street A. and Hunter R. (2011) Using 'payment by results' to fund the treatment of dependent drug users – proceed with care. *Addiction*, 106 (10); pp. 1725-1729

Morris S., Hunter R., Vallejo-Torres L., Kinge J., Kendall. (2011) Cost-effectiveness of Physiological Science Service Accreditation (PSSA): Final Report; in press.

Patel, K., Bashford, J., Hasan, S. and Hunter, R. (2009) Reducing Drug Related Crime and Rehabilitating Offenders. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/DH\\_119851](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/DH_119851)

## **Grants held**

Dec 2011- Nov 2016: Co-applicant. NSPCC Grant for the Evaluation of “Minding The Baby” Programme. £349,414 (5 years)

Jan 2012 - Dec 2018: Co-applicant. NIHR HTA Grant for Health-Related Quality of Life in two treatment pathways for open angle glaucoma and ocular hypertension: a randomised controlled trial of initial selective laser trabeculoplasty versus conventional medical therapy. £1,809,209 (6 years)

## ANDRE JUNQUEIRA XAVIER

Dr Andre Junqueira Xavier  
Lecturer, University of South of Santa Catarina, Brazil

### Education/ Qualifications

1989	Medicine	Universidade do Rio de Janeiro, Brazil
1994	Geriatrics	Pontifícia Universidade Católica do Rio Grande do Sul, Brazil
2001	Geriatrics and Gerontology	Escola Nacional de Sãede Pœblica, Brazil
2002	Geriatrics	Brazilian Medical Association
2003	Informatics	Universidade Federal de Santa Catarina, Brazil
2007	Informatics in Health	Universidade Federal de São Paulo, Brazil
2012	Epidemiology/Public Health	University College London, UK

### Professional history

January 2003 to present Lecturer, University of South of Santa Catarina, Brazil

January 2009- January 2011 President of the Brazilian Society of Geriatrics and Gerontology – Santa Catarina Branch, Brazil Board of the Brazilian Society of Geriatrics and Gerontology

August 2011- July 2012 Academic visitor, Department of Epidemiology and Public Health, University college London, London, UK

### Selected relevant publications

- Medeiros, F L, Xavier, A J, Schneider, I J C, Ramos, L R, Sigulem, D, d'Orsi, E. Digital inclusion and functional capacity of older adults living in Florianópolis, Santa Catarina, Brazil (EpiFloripa 2009- 2010). *Revista Brasileira de Epidemiologia (Impresso)*. , v.15, p.106 - 122, 2012.
- Danaei, Goodarzi ; Finucane, Mariel M ; Lin, John K ; Singh, Gitanjali M ; Paciorek, Christopher J; Cowan, Melanie J ; Farzadfar, Farshad ; Stevens, Gretchen A ; Lim, Stephen S ; Riley, Leanne M ; XAVIER, A. J. . National, regional, and global trends in systolic blood pressure since 1980: systematic analysis of health examination surveys and epidemiological studies with 786 country-years and 5 4 million participants. *Lancet (British edition)*, v. 377, p. 568 -577, 2011
- Aziz, M. M., Calvo, M. C. M., Schneider, I. J. C., Xavier, A. J., D `Orsi, E. Prevalence and factors associated with access to medication among the elderly in a city in southern Brazil: a population-based study. *Cadernos de Sãede Pœblica (ENSP. Impresso)*. , v.27, p.1939 - 1950, 2011.
- d `Orsi, E, Xavier, A J, Ramos, L R. Work, social support and leisure protect the elderly from functional loss: EPIDOSO Study. *Revista de Sãede Pœblica (USP. Impresso)*. , v.45, p.685 -692, 2011.
- Xavier, André J. ; Eleonora d'Orsi ; Ramos, Luiz R. ; Sigulem, Daniel ; dos Santos, Josenei B. ; Quialheiro, Anna ; Olivieri, Giovana ; Pedroso, Lenemar N. ; Berger, Ranier ; Baldin, Monique ; XAVIER, A. J. . Cognitive stimulation and rehabilitation mediated by computers and internet: A controlled study. In: ICAD 2010, 2010, Honolulu. ICAD 2010, 2010
- Xavier, A. J., D'orsi, E., Sigulem, D, Ramos, L R. Time orientation and executive functions in the prediction of mortality in the elderly: Epidoso study. *Revista de Sãede Pœblica (USP. Impresso)*. , v.44, p.148 - 158, 2010.
- André Junqueira Xavier, ; Luiz Roberto Ramos, ; d& ; Josenei Braga Dos Santos, ; Daniel Sigulem,. Factors related to learning time of digital instruments by elder people with cognitive impairments. In: International Conference on Alzheimer's Disease, 2009, Viena. *Alzheimer's & Dementia*, 2009. v. 5. p. 276-277.
- Xavier, André Junqueira ; d& ; Ramos, Luiz Roberto ; Faé, Andressa ; Marques, Fœlvia ; Sigulem, Daniel; Screening cognitive impairments based on elders' performance in learning digital instruments. In: ICAD 2009, 2009, Wien. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association Supplement*, 2009.

v. 6. p. 163.

d'Orsi Eleonora ; Xavier, André Junqueira; Sigulem, Daniel ; Ramos, Luiz Roberto ; XAVIER, A. J.. A new Functional Cognitive Index and its evaluation as a predictive factor of survival in elders. In: ICAD 2009, 2009, Wien. Alzheimer & Dementia the Journal of The Alzheimer's Association Supplement, 2009. v. 5. p. 393.

d'Orsi Eleonora; Xavier, André Junqueira; Sigulem, Daniel ; Ramos, Luiz Roberto ; XAVIER, A. J.. A new Functional Cognitive Index and its evaluation as a predictive factor of survival in elders. In: ICAD 2009, 2009, Wien. Alzheimer & Dementia the Journal of The Alzheimer's Association Supplement, 2009. v. 5. p. 393.

d'Orsi Eleonora; André Junqueira Xavier, ; Daniel Sigulem, ; Emil Kupek, ; Luiz Roberto Ramos, ; XAVIER, A. J. . Temporal orientation is the best discriminative item of the Folstein's Mini Mental Status Examination. In: ICAD 2009, 2009, Wien. The Alzheimer's Association., 2009. v. 5. p. 275.

Xavier, A. J., Reis, S. S., Paulo, E. M., D'orsi, E. Time of adhesion to the Family Health Strategy protects elderly against cardiovascular and cerebrovascular accidents in Florianópolis, 2003 to 2007. *Ciência e Saúde Coletiva (Impresso)*. , v.13, p.1127 - 1132, 2008.

Ramos, L.R. . Computation and networking - Compunetics : Promoting digital inclusion of elderly, cognitively impaired, and Alzheimer's patients. *Gerontechnology (Valkenswaard. Gedrukt)*, v. 3, p. 123-125, 2005.

Xavier AJ; Sales M ; Ramos L ; Ançõ M; Sigulem D . Cognition, interaction and ageing: an Internet workshops exploratory study. *Studies in Health Technology and Informatics*, v. 103, p. 289-295, 2004.

#### Grants

Issue Date: 01/12/2010

Grant Number: 563449/2010-1

Period: One year

Conselho Nacional de Desenvolvimento Científico e Tecnológico, CNPq, Brazil.

Title: Oficina da Lembrança: Inclusão Digital, estimulação e reabilitação cognitiva para Idosos.

(Remembrance workshop: digital literacy, stimulation and rehabilitation for Elder people.

Major goal: To provide digital literacy, cognitive stimulation and rehabilitation to two hundred elder people with memory complaints.

Amount: £ 20.000

Professor Susan Michie

Professor of Health Psychology, Department of Clinical, Educational and Health Psychology, University College London.

### Education/ Qualifications

1976	B.A. in Experimental Psychology	Oxford University
1978	M.Phil in Clinical Psychology	London University
1982	D.Phil in Developmental Psychology	Oxford University
1978	Chartered Clinical Psychologist	British Psychological Society
1993	Chartered Health Psychologist	British Psychological Society
2001	Fellow of the British Psychological Society	British Psychological Society
2007	Fellow of the European Health Psychology Society	European Health Psychology Society
2010	Fellow of the Academy of Social Sciences	Academy of Social Sciences

### Professional history

1989-2002	Senior Research Fellow in Clinical Health Psychology	Royal Free & UC Medical School
1993-2002	Deputy Director, Psychology & Genetics Research Group	King's College London
1993-2001	Research Fellow/ Senior Research Fellow	King's College London
2001-2002	Reader in Health Psychology	King's College London
2002-	Co-Director, Centre for Outcomes Research &	University College London
2002-2006	Reader in Clinical Health Psychology	University College London
2005-	Chair in Health Psychology, Department of Psychology	University College London
2006-2009	Senior Scientist, MRC Health Services Research (p/t secondment)	University of Bristol

### Selected publications 2012 and in press

1. Michie S, West R, Spring B. (In press). Moving from theory to practice and back in social and health psychology. *Health Psychology*.
2. Michie S, West R. (In press). Behaviour change theory and evidence: a presentation to government. *Health Psychology Review*.
3. Michie S, Free C, West R. (In press). Characterising the 'Txt2Stop' smoking cessation text messaging intervention in terms of behaviour change techniques. *Journal of Smoking Cessation*.
4. Stone S, Fuller C, Michie S, McAteer J, Charlett A. (In press). What is the optimal period for measuring hand-hygiene compliance: are longer periods better than 20 minutes? *Infection Control and Hospital Epidemiology*.
5. Fuller C, Michie S, Savage J et al.. (In press). The Feedback Intervention Trial (FIT) – improving hand- hygiene compliance in UK healthcare workers: a stepped wedge cluster randomized controlled trial. *PLoS ONE*.
6. Miners A, Harris J, Felix L, Murray E, Michie S, Edwards P. (In press). An economic evaluation of adaptive e-learning devices to promote weight loss via dietary change for people with obesity. *BMC Health Services Research*.
7. Michie S, Brown J, Geraghty A, Miller S, Yardley L, Gardner B, Shahab L, McEwen A, Stapleton J, West R. (2012). Development of StopAdvisor, a theory-based interactive, internet-based smoking cessation intervention. *Translational Behavioral Medicine*. doi: 10.1007/s1 3142-012-0135-6.
8. Lorencatto F, West R & Michie S (in press). Specifying evidence-based behaviour change techniques to aid smoking cessation in pregnancy. *Nicotine and Tobacco Research*.
9. Gardner B, Cane J, Rumsey N, Michie S. (2012). Behaviour change among overweight and socially disadvantaged adults: a longitudinal study of the NHS Health Trainer Service. *Psychology & Health* . 27, 1178-1193
10. Michie S, Whittington C, Hamoudi Z, Zarnani F, Tober G, West R. (2012). Identification of behaviour change techniques to reduce excessive alcohol consumption. *Addiction*, 107, 1431 -1440.
11. Teasdale E, Yardley L, Schlotz W, Michie S. (2012). The importance of coping appraisal in behavioural responses to pandemic flu. *British Journal of Health Psychology*, 17, 44-59. Doi: 10.1111 /j .2044- 8287.201 1.02017.x

12. French SD, Green SE, O'Connor DA, MacKenzie JE, Francis JJ, Michie S, et al (2012). Developing theory-informed behaviour change interventions to implement evidence into practice: a systematic approach using the Theoretical Domains Framework. *Implementation Science*, 7.
13. Cane J, O'Connor D, Michie S. (2012). Validation of the Theoretical Domains Framework for use in behaviour change and implementation research. *Implementation Science*, 7, 37. Doi: 10.1186/1748-5908-7-37.
14. Morrison LG, Yardley L, Powell J, Michie S. (2012). What design features are used in effective eHealth interventions? A review using techniques from critical interpretative synthesis. *Telemedicine and e-Health*, 18, 137-144.
15. French DP, Stevenson A, Michie S. (2012). An intervention to increase walking requires both motivational and volitional components: a replication and extension. *Psychology, Health and Medicine*, 17, 127-135. Michie S, Johnston M. (2012). Theories and techniques of behaviour change: developing a cumulative science of behaviour change. *Health Psychology Review*, 6, 1-6. Doi: 10.1080/17437199.2012.654964.

### **Selected current grants**

2012-2017 Orrell M, Mountain G, Russell IT, Sackley C, Challis D, Moniz -Cook E, Vernooij-Dassen M, King M, Hill J, Brouder J, Morris S, Poland F, Omar R, Michie S, Wenborn J, Rooks S. Valuing active life in dementia (VALID). NIHR Programme, £1,999,845. (RP -PG-0610 -10108).

2012-2017 Johnson A, Hayward H, King M, Michie S, Raine R. NIHR School for Public Health Research (UCL). NIHR, £2,150,000.

2012-2013 Rubin GJ, Amlot R, Fear N, Michie S, Potts H. Evaluating and improving communication with the public during a pandemic, using rapid turn-around telephone surveys. NIHR NETSCC project grant [with six month extension pre-approved for the next flu pandemic], £168,671. 10/45/21).

2011-2016 Osborn D, Antoniou A, Walters K, Nazareth I, Johnston C, Michie S, et al. Prediction and management of cardiovascular risk for people with severe mental illnesses. A research programme and trial in primary care. (PRIMROSE) NIHR Programme, £2,029,234. (RP -PG-0609 -10 156).

2011-2016 Murray E, Paul K, Barnard M, Michie S et al. Development, evaluation and implementation of a computer -based self -management programme for people with type 2 diabetes. NIHR Programme, £1,992,472.

2012-2017 West R, Michie S, McNeill A, Aveyard P. Smoking cessation: population and clinical approaches. Cancer Research UK. £1,655,000.

2011-2014 Yardley L, Mascolo C, Michie S, Musolesi M, Rentfrow PJ, de Roure, D, Smith P, Weal M. UB have: ubiquitous and social computing for positive behaviour change, EPSRC, £1,463,061.

2011-2014 Pilling S, Michie S, Roth A and Fonagy P. Continued funding of the Psychological Processes and Clinical Effectiveness Programme Grant. British Psychological Society. £1,537,746

2010-2013 Michie S, Johnston M, Abraham C, Francis J, Hardeman W and Eccles M. Methods for strengthening evaluation and implementation: specifying components of behaviour change interventions. Medical Research Council . £509,200.

2009-20 12 Michie S, West R (joint PIs), Yardley L, McEwen A, Stapleton J, Wills G. The development and evaluation of an internet-based smoking cessation intervention (ISCI) Medical Research Council, £494,876

2009-20 12 Michie S, West R, McEwen A. (joint PIs) NHS Centre for Smoking Cessation and Training. Department of Health, £2,967,354.

2009-2012 Gilbody, S., Lester, H., Michie, S. et al. Smoking cessation for people with severe mental illness: a pilot study and definitive randomized evaluation of a bespoke service. NIHR Health Technology Appraisal Programme , £711, 409.

2008-2011 Yardley, L., De Roure, D., Michie, S. & Wills, G. Development and evaluation of a Behavioural Intervention Grid (BI -Grid). Economic and Social Research Council, £669,515. (RES-149-25-1069)

2007-2012 Michie, S. and Cameron, R. Changing behaviour: towards best practice in the development of complex interventions. Medical Research Council, £203,000

**Education/ Qualifications**

1977	BSc Hons III Psychology	University of Leeds
1983	Diploma in Clinical Psychology	British Psychological Society
2001	Ph.D. Psychology	University of Wales, Bangor
1988	A.F.B.Ps.S	British Psychological Society
1989	C.Psychol	British Psychological Society

**Professional history**

1977-1980	Probationer Clinical Psychologist, South Glamorgan Area Health Authority
1981-1983	Clinical Psychologist Brothers of Charity Services; Cork; Ireland
1983-1985	Senior Clinical Psychologist Leeds (East) Health Authority
1985-1987	Senior Clinical Psychologist ,Wakefield Health Authority
1983-1988	Lecturer ( Hon) - Clinical Psychology, Department of Psychiatry, University of Leeds
1987-1997	Lecturer (Hon) - Clinical Psychology, University of Hull; Consultant Clinical Psychologist/ Old Age Clinical Psychology -Head
1997 -2004	Senior Clinical Lecturer (Hon) –University of Hull (0.5) Consultant Clinical Psychologist /Old Age Clinical Psychology –Head (0.5)
2004 -2006	Professor ( Hon) – Clinical Psychology 0.5 University of Hull (March 2004 – September 2006) Consultant Clinical Psychologist /Old Age Clinical Psychology –Head (0.5)
2006 -	Professor (Hon) – Institute of Rehabilitation University of Hull 0.5 October 2006 ( re-organisation to Faculty of Health and Social Care in August 2012) Consultant Clinical Psychologist / Lead Old Age Clinical Psychology (0.5) NHS Centre for Dementia Research and Practice [CoDRaP] from 2012

**Current appointments**

1999	Founder Member ( 1999) and Chair (2006), now Co-chair of INTERDEM (an eighteen country Pan European research network in early and timely Interventions Dementia <a href="http://www.interdem.org/">www.interdem.org/</a> )
2001	Humber NHS Foundation Trust Lead - Older People R&D
2006	Member of DeNDRoN (Dementias and Neurodegenerative Disease Research Network ) - Primary Care Clinical Studies Workgroup funded by the Dept of Health as part of the UK Clinical Research Network (UKCRN)
2009	Alzheimers Society Research Advisory Committee -member <a href="http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1139">http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1139</a>
2009	International Journal Editorial Board – <i>Ageing and Mental Health</i> <a href="http://www.tandf.co.uk/journals/journal.asp?issn=1360-7863&amp;linktype=145">http://www.tandf.co.uk/journals/journal.asp?issn=1360-7863&amp;linktype=145</a>
2012	NIHR Programme Grant for Applied Research - college of experts

**Selected relevant publications**

- 1)Vernooij-Dassen, M Moniz-Cook, E. et al for the INTERDEM group (2005) Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma *I JGP* 20, 377-386
- 2) Moniz-Cook E & Vernooij Dassen M (Eds) 2006 Psychosocial interventions in Primary Care : Special Issue *Dementia: The International Journal of Social Research and Practice* 5, 3
- 3)Moniz-Cook et al (2006) Facing the future: a qualitative study of older people referred to a memory clinic prior to assessment and diagnosis. *Dementia: The International Journal of Social Care* 5, 3, 375 -395



- 4) Mountain GA & Moniz-Cook ED (2007) Rehabilitation for People with Dementia: Development of an evidence-based framework. In P Dorenlot (Ed) *Non Pharmacological Interventions in Dementia: Benefits, Potentials, Perspectives*, Paris : *Les Cahiers de la Fondation Médéric Alzheimer*, 3, 57-66
- 5) Moniz-Cook ED (2008) Assessment and Psychosocial Intervention for older people with suspected dementia: a Memory Clinic perspective In Laidlaw & Knight *Handbook of Emotional Disorders in Late Life: Assessment and Treatment* OUP
- 6) Jolley D and Moniz-Cook E. (2009) Memory clinics in context. *Indian Journal of Psychiatry*, 51:S70-6.
- 7) Jolley D and Moniz-Cook E (2009) Memory clinics are all about stigma, not screening *BMJ*, 338: b860
- 8) Moniz-Cook E & Manthorpe J (2009) Personalising Psychosocial Interventions to Individual Needs and Context In Moniz-Cook & Manthorpe Eds (2008) *Early Psychosocial Interventions in Dementia: Evidence-based Practice* J Kingsley
- 9) Moniz-Cook, E, Gibson, G, Harrison J, & Wilkinson H (2009) Timely Psychosocial Interventions in a Memory Clinic In Moniz-Cook & Manthorpe Eds (2008) *Early Psychosocial Interventions in Dementia* J Kingsley
- 10) Moniz-Cook E (2010) Early Psychosocial Interventions in Dementia: Translating Evidence into practice *Healthcare Counselling Psychotherapy* 10 2-3
- 11) Wolverson (Radbourne) E, Clarke C & Moniz-Cook E (2010) Remaining Hopeful in Early Stage dementia: A qualitative study *AMH* 14 (4) 450 – 460
- 12) Moniz-Cook et al & the Interdem network (2011) Psychosocial Interventions in dementia care research: The INTERDEM manifesto *AMH* 15, 3, 283-29
- 13) Moniz Cook ED, et al (2012) Functional analysis-based interventions for challenging behaviour in dementia (2012). In *Cochrane Database* 2012, Issue 2.
- 14) Corbett A Stevens A Aarsland D Day S Moniz-Cook E et al (2012) [Systematic review of services providing information and/or advice to people with dementia and/or their caregivers](#) *IJGP* 27 628-636
- 15) Vasse E, Moniz-Cook E, et al (2012) The development of quality indicators to improve psychosocial care in dementia. *Int Psychoger* 24 921-30

#### **Relevant current and recent research grants**

- 1) with Woods et al (2007 -2011) *REMCARE* Reminiscence groups for people with dementia and their family caregivers: pragmatic 8-centre trial of joint reminiscence and maintenance v usual treatment HTA Trials Grant £1,536,395 to University of Bangor <http://www.hta.ac.uk/1655>
- 2) Moniz-Cook E, Mason A Woods B, Mozley C, Russell I, Campion P Hilton A Edwards R Markova I, Downs M Stokes G James I & Orrell M (2007 -2012) *Challenge Demcare* Challenging Behaviour in Dementia at home and in Care Homes NIHR Programme Grant £ 1,933, 925 over 5 years (to Humber NHS FT)
- 3) with Orrell, et al (2007-2012) *SHIELD* Support at Home - Interventions to Enhance Life in Dementia £1,979,387 NIHR Programme Grant (to NEL FT)
- 4) Moniz-Cook E (2009 -2010) *Enhancing post-diagnostic recovery in older people with dementia and their families at a Memory Clinic*. Enhancing the Healing Environment Programme: The King's Fund in partnership with the Department of Health (to Humber NHS FT) £ 40,000 plus over £70,000 matched
- 5) with Ballard et al (2010 -2015) *WHELD* An Optimized Person Centred Intervention to Improve Mental Health and Reduce Antipsychotics in Care Homes NIHR Programme Grant £1,998,346 (to Oxford and Buckinghamshire NHS FT)
- 6) with Orrell et al (2010-2013) *iCST Trial* Individual Cognitive Stimulation Therapy for dementia HTA Trial Grant £1,131,252 (to UCL)
- 7) with Orrell et al (2012 – 2016) *VALID – Valuing Active Life in Dementia* NIHR Programme Grant over 5 years £1,994,446 (to NELFT)
- 8) with Gridley et al (2012 -2015) Improving care for people with dementia: development and initial feasibility study for evaluation of Life Story Work in dementia care. £430,648 NIHR Health Services Research programme (to University of York). **To be announced**

Professor Stephen Morris

Professor of Health Economics, UCL; Head of Health Economics Group, UCL

### Education/ Qualifications

May 2002. Ph.D. in Economics, City University.

July 1994. M.Sc. Health Economics (Merit), University of York (recipient of Magellan Prize for Health Economics).

July 1993. B.A. Joint Honours Economics and Philosophy (2i), University of Nottingham.

### Professional history

March 2009-present. Professor of Health Economics. UCL Research Department of Epidemiology and Public Health. University College London

July 2006-March 2009. Reader. Health Economics Research Group. Brunel University

September 2002-June 2006. Senior Lecturer in Health Economics. Imperial College Business School. Imperial College London.

September 1994-August 2002. Lecturer in Health Economics. Department of Economics. City University

### Selected relevant publications in 2012 (53 prior)

1. Rice T., Morris S., Tortella B., Wheeler A., Christensen M. Deviations from evidence based clinical management guidelines increase mortality in critically injured trauma patients. *Critical Care Medicine* 2012; 40: 778-86. (See also the related editorial in the same issue of the Journal: Napolitano L. Guideline compliance in trauma: Evidence-based protocols to improve trauma outcomes? *Critical Care Medicine* 2012; 40: 990-2.)
2. Chambers J., Morris S., Neumann P., Buxton M. Factors predicting medicare national coverage: an empirical analysis. *Medical Care* 2012; 50: 249-56.
3. Chitty L., Hill M., White H., Wright D., Morris S. Noninvasive prenatal testing for aneuploidy—ready for prime time? *American Journal of Obstetrics and Gynaecology* 2012; 206: 269-75.
4. Vallejo-Torres L., Morris S. Income-related inequity in health care utilisation among individuals with cardiovascular disease in England – accounting for vertical inequity. *Health Economics* (forthcoming).
5. Burns F., Edwards S., Woods J., Haidari G., Calderon Y., Leider J., Morris S., Tobin R., Cartledge J., Brown M. Acceptability and feasibility of universal offer of rapid point of care testing for HIV in an acute admissions unit: results of the RAPID project. *PLoS ONE* (forthcoming).
6. Navani N., Lawrence D., Kolvekar S., Hayward M., McAsey D., Kocjan G., Falzon M., Capitanio A., Shaw P., Morris S., Omar R., Janes S. EBUS-TBNA prevents mediastino copies in the diagnosis of isolated mediastinal lymphadenopathy: a prospective trial. *American Journal of Respiratory and Critical Care Medicine* (forthcoming).
7. Sive J., Ardesna K., Cheesman S., LeGrange F., Morris S., Nicholas C., Peggs K., Statham P., Goldstone A. Hotel-based ambulatory care for complex cancer patients: A review of the University College London Hospital experience. *Leukemia and Lymphoma* (forthcoming).
8. Hill M., Fisher J., Chitty L., Morris S. Women and health professional preferences for prenatal tests for Down syndrome: a discrete choice experiment to contrast non-invasive prenatal diagnosis with current invasive tests. *Genetics in Medicine* (forthcoming).
9. Morris S., Baio G., Kendall E., von Wagner C., Wardle J., Atkin W., Halloran S., Handedley G., Logan R., Obichere A., Rainbow S., Smith S., Snowball J., Raine R. Socioeconomic variation in uptake of colonoscopy following a positive Faecal Occult Blood test result: a retrospective analysis of the NHS Bowel Cancer Screening Programme. *British Journal of Cancer* (forthcoming).

### **Relevant current and recent research grants**

2010-2015. NIHR Programme Grants for Applied Research. Reliable Accurate Prenatal non -Invasive Diagnosis (RAPID): an integrated project to refine and implement safer antenatal testing. PI: L.Chitty. Morris is a Co -app. £1,991,445.

2011. NHS London. Evaluation of the London Stroke Service. PI: Morris. £90,000.

2011-2016. NIHR Programme Grants for Applied Research. Reducing socioeconomic inequalities in uptake of bowel cancer screening. PI: R. Raine. Morris is a Co-app. £1,999,000.

2011-2014. NIHR Cochrane Collaboration Programme Grant. Systematic reviews and cost-effectiveness analyses of surgical interventions for liver, pancreas and gallbladder disease. PI: B. Davidson. Morris is a Co- app. £299,000.

2012-2017. NIHR HTA Programme. Preoperative intravenous iron to PREVENT blood Transfusion in major surgery (PREVENTT). PI: T. Richards . Morris is a Co-app. £3,408,860.

2012-2017. NIHR PGfAR. Do Specialist Cancer Services for Teenagers and Young Adults (TYA) Add Value? PI: J. Whelan. Morris is a Co-app (Oncology, UCL). £1,999,957.

2012-2017. NIHR PGfAR. Valuing Active Life In Dementia (VALID). PI: M. Orrell (Mental Health Sciences, UCL). Morris is a Co-app. £1,994,446.

2012-2016. NIHR HTA. Comprehensive staging of newly diagnosed lung and colorectal cancer: Prospective multicentre comparison of whole body Magnetic Resonance Imaging with standard diagnostic imaging pathways. PI: S. Taylor (Medical Imaging, UCL). Morris is a Co-app ( £1,434,883)

### **Membership of committees**

2007-2009. Member, HTA Clinical Trials Board.

2008-present. Member, Public Health Interventions Advisory Committee, NICE.

2008-present. Member, NIHR Programme Grants for Applied Research expert sub-panel.

2009-present. Member, NIHR HTA Commissioning Board.

2011-present. Member, NIHR Public Health Research Programme Research Funding Board.

### **Other professional activities**

2011-present. Joint National Organiser of the Health Economists' Study Group (HESG)

2000-present. List owner of the Health Economists' Study Group (HESG) JISCmail electronic mailbase.

Professor Gail A Mountain  
Professor of Health Services Research, University of Sheffield

### Education/ Qualifications

1999: Doctor of Philosophy, the University of Leeds. 1990: Master of Philosophy, the University of Leeds. 1976: Diploma of the College of Occupational Therapists, Derby School of Occupational Therapy

### Professional history

June 2009 onwards: Chair in Health Services Research (Assisted Living Research) School of Health and Related Research, University of Sheffield.

February 2008 - May 2009: Senior Academic and Co-director Lab4living, Sheffield Hallam University  
November 2001 – January 2008: Head of Research and then Director of the Centre for Health and Social Care Research, Sheffield Hallam University

February 1998– September 2001: Research and Development Officer, College of Occupational Therapists,  
November 1994 - January 1998: Research Fellow, Collaborative Research Centre for Priority and Community Services Research, Nuffield Institute for Health, University of Leeds

October 1991-August 1994: Area Occupational Therapy Manager (Specialisms), Leeds Community and Mental Health Services NHS Trust

September 1990, September 1991: Research Fellow, Social Policy Research Unit, University of York

March 1987-September 1990: Research Assistant, Department of Psychiatry, University of Leeds.

August 1976 - December 1987: Various occupational therapy management and practitioner posts in West Yorkshire

### Selected publications

Mountain G & Craig CL (2012) What should be in a self management programme for people with early stage dementia? *Aging and Mental Health* 16(5): 576-583.

Mountain GA, Craig CL (2011) The lived experience of redesigning lifestyle post-retirement in the UK. *Occupational Therapy International* 18(1 ):48-58

Parker J, Mountain GA & Hammerton J (2011) A review of the evidence underpinning the use of visual and auditory feedback for computer technology in post-stroke upper-limb rehabilitation. *Disability and Rehabilitation: Assistive Technology*. 6(6):465-472

Rosser BA, McCullagh P, Davies R, Mountain GA, McCracken L & Eccleston C (2011) Technology-Mediated Therapy for Chronic Pain Management: The Challenges of Adapting Behavior Change Interventions for Delivery with Pervasive Communication Technology. *Journal of Telemedicine and e Health*, 17(3):211-216 Apr 2011

Burns WP, Davies RJ, Nugent CD, McCullagh PJ, Zheng H, Black ND, Mountain GA (2010) A Personalised Self-Management system for Chronic Heart Failure. *Computers in Cardiology* 37:1075-1078 2010

Moniz-Cook E, Vernooij-Dassen M, Woods R, Verhey F, Chattat R, De Vught M, Mountain G, Lavalley S, Dros R & Orrell M (2008) A European Consensus on outcome measures for psychosocial measures for psychosocial intervention research in dementia care. *Aging and Mental Health*, 12:1, 14-29

Mountain G, Mozley C, Craig C & Ball L (2008) Occupational therapy led health promotion for older people: feasibility of the Lifestyle Matters programme. *British Journal of Occupational Therapy*, 71(10), 406-413

Mountain GA & Moniz -Cook ED (2007) Rehabilitation for People with Dementia: Further Development of an evidence based framework. *Les Cahiers de la Fondation Médéric Alzheimer*, 3, 5--66.

Mountain G (2008) Assessment. In *Excellence in Dementia Care* Eds. Down M and Bower B  
Milton Keynes: OU Press.

Craig C & Mountain G (2007) *Lifestyle Matters: maintaining the health and wellbeing of older people*.  
Speechmark publishers: Bicester.

Mountain G (2006) Self management and Dementia: an exploration of concepts and evidence  
*Dementia: The International Journal of Social Research and Practice* 5(3), 429 – 447.

### **Selected current grants (last five years)**

2011: VALID: valuing active life in dementia. National Institute for Health Research; £2,300,000 (Co-I)

2011: Lifestyle Matters: Randomised controlled trial. MRC Lifelong Health and Wellbeing:  
£1,131,276.80 (PI)

2011: Putting Life in Years (PLINY): Randomised controlled trial of telephone befriending for older  
people. NIHR Public Health Board: £799K (PI)

2011: The Script project; (supervised care and rehabilitation involving personal telerobotics). EU STREP:  
3,311,998 euro (Co-I)

2010: Overcoming barriers to mainstreaming Assisted Living Technologies (ALTs). ESRC and TSB ALIP  
programme: £1,800,000 (Co-I)

2010: Richard project (regional ICT based clusters for healthcare applications and R&D integration.  
EU FP7: 2,749,999.68 euro (named collaborator)

2008: K-T Equal: Bringing ageing and disability research into practice. EPSRC: 1,833,000 (PI)

2008: Working with people with PD to establish their current coping mechanisms in order to identify  
appropriate self management skills. Parkinson's Society: £9,100 (Co-I and supervisor)

2008: Living Rooms. British Council: Connect Initiative £33,000 (Co-I)

2008: South Yorkshire Collaboration for Leadership in Applied Health Research and Care; Technologies for  
management of long term conditions – fitness for purpose, evidence and potential for the future. NIHR:  
£1,900,000 (Co-theme lead with Professor Mark Hawley)

### **Funding for studentships**

2011: ESRC Mental Health and Ageing Research: White Rose Initiative (MARWIN)

2011: Lead for PIPIN (Promoting independence through personalised interactive technologies) PhD student  
network University of Sheffield Digital World cross cutting initiative.

Dr Rumana Z Omar

Reader in Medical Statistics at the Department of Statistical Science, UCL and head of the Biostatistics Group within the UCLH/UCL/Royal Free Research Support Centre.

### Education/ Qualifications

PhD in Medical Statistics

University of Reading 1991

### Professional history

Oct 2007	Present	Reader Dept. of Statistical Science, Head of Biostatistics Group, UCLH/UCL/Royal Free Research Support Centre & Senior Statistician, PRIMENT CTU	University College London
2000	2007	Senior Lecturer, Department of Statistical Science, and Head of Biostatistics Group, UCLH/UCL Biomedical Research Unit	University College London
1996	2000	Lecturer, Dept. of Medical Statistics & Evaluation	Imperial College
1994	1996	Lecturer, Dept. of Epidemiology & Medical Statistics	Barts. & Royal London Hospital School of Medicine & Dentistry, QMW
1991	1994	Research fellow, Dept. of Epidemiology and Population Sciences	London School of Hygiene and Tropical Medicine

### Selected publications

1. Ambler G, Seaman S and Omar RZ (2012). An evaluation of penalised survival methods for developing prognostic models with rare events. *Statistics in Medicine*, Statist. 311150–1161.
2. Killaspy H, Marston, L, Omar RZ, King M. Service quality and clinical outcome: an example from mental health rehabilitation services in England. *British Journal of Psychiatry* (in press).
3. Navani N, Lawrence DR, Kolvekar S, Hayward M, McAsey D, Kocjan G, Falzon M, Capitanio A, Shaw P, Morris S, Omar RZ, Janes SM.(2012) Endobronchial Ultrasound-guided Transbronchial Needle Aspiration Prevents Mediastinoscopies in the Diagnosis of Isolated Mediastinal Lymphadenopathy: A Prospective Trial. *Am J Respir Crit Care Med*. 186(3):255-260.
4. Beeken JR, Croker H, Morris S, Leurent B, Omar R , Nazareth I, Wardle J (2012). Study protocol for the 10 Top Tips (1 OTT) Trial: Randomised controlled trial of habit-based advice for weight control in general practice. *BMC Public Health*, 12:667. DOI: 10.1186/1471-2458-12-667
5. Burt J, Plant H, Omar R, Raine R. (2010) Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients. *Palliative Medicine* 24(6):64 1-50
6. Thayyil,S., Chandrasekharan,M., Bainbridge,A., Omar R., Murad,S *et al* (2009). Quantitative magnetic resonance biomarkers for prediction of long term outcome following neonatal encephalopathy: a meta-analysis. *Pediatrics* Vol. 125, 382-395.
7. Omar RZ, O' Sullivan, Peterson I, Islam A and Majeed A (2008). A model based on age, gender and mortality explains variation in UK general practice. *BMJ*;337:a238.
8. Rahman A, Reed E, Underwood M, Shipley ME and Omar RZ (2008). Factors affecting self-efficacy and pain intensity in patients with chronic musculoskeletal pain seen in a specialist rheumatology pain clinic. *Rheumatology*, doi:10.1093.
9. Edwards S and Omar RZ (2008). Ethics Review of Research: in Pursuit of Proportionality *JMed Ethics* 34:568-5 72.
10. Omar RZ, Barber J Ambler G *Designing Health Studies (2007): Basic Science Techniques in Clinical Practice*, edited by Shergill I S, Ayra M and Patel H. Springer Verlag. 2007.
11. Barber J Ambler G Omar RZ *Analysing Health Studies (2007): Basic Science Techniques in Clinical Practice* edited by Shergill I S, Ayra M and Patel H. Springer Verlag.

12. Ambler G, Omar RZ and Royston P (2007). A comparison of imputation techniques for handling missing predictor values in a risk model with a binary outcome. *Statistical Methods in Medical Research*, 16: 277 -298
13. Ambler,G., Omar, RZ., et al (2006). A generic, simple risk stratification model for heart valve surgery. *Circulation* 112, 224-231.
14. Peregrine, E., O'Brien, P, Omar, R., Jauniaux, E. (2006). Clinical and ultrasound parameters to predict the risk of cesarean delivery after induction of labor. *Obstetrics and Gynecology* 107(2), 227-233.
15. Turner R. M., Omar RZ, Thompson S.G. (2006). Modelling Multivariate Outcomes in Hierarchical Data, with Application to Cluster Randomised Trials. *Biometrical Journal* 48(3), 333-345.
16. Turner, R. M. Omar RZ., Thompson S. G. (2006). Constructing intervals for the intraclass correlation coefficient using Bayesian modelling, and application in cluster randomized trials. *Statistics in Medicine* 25(9), 1443-56.
17. Turner R. M., Omar, RZ. Thompson S.G. (2006) . Modelling Multivariate Outcomes in Hierarchical Data, with Application to Cluster Randomised Trials. *Biometrical Journal* 48(3), 333-345.

### Selected current grants

1. 2012. An investigation into the use of shrinkage methods to alleviate over-fitting of prognostic models for independent and clustered data with few events. MRC/NIHR Methodology £300,445. (PI)
2. 2012: Bayesian Modelling of Disease Progression in Juvenile Dermatomyositis. NIHR Research Methods Opportunity funding: ( £30,000). (NIHR investigator)
3. 2011/2016 Prediction and management of cardiovascular risk for people with severe mental illnesses. A research programme and trial in primary care (PRIMROSE). NIHR Programme Grants for Applied Research: £2,029,234.
4. 2011 CIRCLE Randomised controlled trial of the effectiveness and cost-effectiveness of a psychological intervention incorporating adjunctive contingency management for reduction of cannabis use in first episode psychosis. HTA Clinical Trials call; £2,042,835.
5. 2012/2015 The Marie Curie Dementia Research Programme: developing an intervention to improve end of life care in advanced dementia. £1,048,508.
6. 2011/2014 Shape Up-LD Piloting a manualised weight management programme for overweight and obese persons with mild-moderate learning disabilities £237,220.
7. 2012/2017 Valuing active life in dementia (VALID). NIHR Programme Grant. £1,935,262.
8. 2011: The effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia, NIHR HTA, £162,428
9. 2011: A Randomised Placebo Controlled Trial of Trimetazidine Therapy in Hypertrophic Cardiomyopathy, (NIHR UCLH/UCL Biomedical Research Centre £138,983).
10. 2009: NIHR Research Methods Opportunity funding: ( £30,000) (NIHR investigator and co-PI)
11. 2009. Validating risk factors for developmental dysplasia of the hip, (£1 56,275) Arthritis Research Campaign.
12. 2001-2005: Department of Health: Using Risk Adjustment Models to explain variation in Primary Care outcomes ( £1 57,000). (Primary supervisor of DH Fellowship)
13. 200 1-2003: Garfield Weston Trust: Risk model for short term mortality following cardiac surgery. (£102,000) PI
14. 2000: Garfield Weston Trust: *Guidelines for formulation and validation of risk models* , (£45,000). PI

Dr Fiona Poland

Senior Lecturer in Health and Society, School of Allied Health Professions, Director Enterprise & Engagement, School of Allied Health Professions, University of E Anglia

### Education/ Qualifications

1978 BA Econ (Hons) Social Anthropology, University of Manchester  
 1983 MA Econ, Applied Social Research, University of Manchester  
 1992 PhD, University of Manchester  
 2001 PG Cert in Teaching in Higher Education, University of Wales, Bangor

### Professional history

1998 - present Senior Lecturer in Health and Society, School of Allied Health Professions, Director Enterprise & Engagement, School of Allied Health Professions, University of E Anglia  
 1992 - 1998 Lecturer in Sociology, Acting Coordinator Research Division, School of Nursing & Midwifery Studies, University of Wales, Bangor  
 1992 Topic facilitator with Nurse Tutor Sociology Teams, University of Wales, Bangor.  
 1991 - 1992 Development Officer, Research Exchange, University of Manchester  
 1990 - 1991 Census Officer, 1991 Census, OPCS  
 1988 - 1992 Freelance Consultancies in social research and evaluation (as below)  
 1986 - 1988 Research Associate, ethnographer and time budget diary progress chaser, ESRC Social Change and Economic Life Initiative, Rochdale Team, Manchester University  
 1980 - 1986 Freelance consultancies in social research, evaluation, training , research training with independent agencies and Higher Education research projects in health and social care  
 1985 - 1986 Development Officer, Research Exchange, Manchester  
 1978 - 1985 Research Assistant (Inner City) Manchester Social Services Department

### Selected publications

- \* Nacul L, Lacerda, E, Campion P; Pheby D, Drachler, M, Leite, J, Poland F; Howe A, Fayyaz, S, Molokhia, M (2011) The functional status and well being of people with myalgic encephalomyelitis/chronic fatigue syndrome and their carers. *BMC Public Health*, 11:402
- \*Horton S, Poland; Kale; Drachler, M, Leite, J, McArthur M, Campion P; Pheby D; Nacul L (2010) Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) in adults: perspectives from professional practice, *BMC Family Practice*.
- \*Murdoch J, Poland F, Salter C. (2010) Using a Data-Sharing Focus Group for Triangulation with Face-to-Face Interviews to Contextualize the Production of Talk about Prophylactic Asthma Medicine-Taking, *Qualitative Health Research* 20 (5).
- \*Drachler, M, Leite, J, Hooper, L, Hong, CS, Pheby, D, Nacul, L, Lacerda, E, Campion, P, Killett, A, McArthur M and Poland, F (2010) The self-expressed needs of people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A systematic review. *BMC Public Health*, 9: 458  
<http://www.biomedcentral.com/1471-2458/9/458>
- \*Wilson, E C F, Thalanany, M, Shepstone, L, Charlesworth, G, Poland, F, Harvey, I, Price, D, Reynolds, S and Mugford, M (2008) Befriending carers of people with dementia: a cost utility analysis, *Int Jnl of Geriatric Psychiatry* 2008; 23: 1–12.
- \*Scarpello, T, Poland, F, Lambert, N and Wakeman, T (2009). A Qualitative Study of Food-Related Experiences of Rural Village Shop Customers. *Jnl Hum Nutr & Dietetics*. 22 (2), 108-15.
- \*Charlesworth, G M, Shepstone, L, Wilson, E, Reynolds, S, Mugford, M, Price, D, Harvey, I, Poland, F (2008) Befriending carers of people with dementia: a randomised controlled trial. *BMJ* (2008 ) 336:1295-97.
- \*Higgs P, Tzimoula X, Poland F & Charlesworth G.(2007) To those who have, more is given'; Network type & service use of carers of people with dementia in England. *Gerontol*, 47 Sp Iss1:623
- \*Charlesworth , G M, Tzimoula, X.M. Higgs, P and Poland, F (2007) Social networks, befriending and support for family carers of people with dementia, *Quality in Ageing*, 8 (2): 37-44.
- \* Lambert, R A, Harvey, I and Poland, F (2006) A pragmatic, unblinded RCT comparing an occupational



therapy-led lifestyle approach and routine GP care for panic disorder treatment in primary care. *Jnl of Affective Disorders*, 99, ( 1- 3): 63-71.

\* Stewart S, Harvey I, Poland F, Lloyd-Smith W, Mugford. M, Flood C (2005) Are occupational therapists more effective than social workers when assessing the frail elderly? Results of CAMELOT, a randomised controlled trial. *Age & Ageing*, 34 (1): 41-6.

### Relevant projects and activities

2012-16 NHS NIHR Applied Research Programme. Valuing Active Life in Dementia. Orrell (PI), Mountain, Russell, Sackley, Challis, Moniz-Cook, Vernooij-Dassen, King, Hill, Brouder, Morris, Rumana, Michie, Wenborn, Poland. £1,993, 842.

2011-2013 NIHR Health Services Research/INVOLVE Programme. Wilson (PI), Goodman, Kendall, Cowe, Munday, Howe, **Poland**, Peckham, Staniszewska. Public involvement in research: a realist evaluation of approaches, processes and outcomes £306,372

2011-12 NIHR Policy Prog PANICOA Research Prog, Killett (CI), Gray, **Poland**, Hyde (UEA team with 3 other university teams), Contexts and pre-disposing factors leading to positive and negative care experiences in elder care homes (CHOICE). £ 551,408

2011 Suffolk Joint Agency Prostitution Strategy Group. Poland (PI) Killett, Boswell, Fordham, Jarrett. An evaluation of the implementation of a multi-agency prostitution strategy in Suffolk (EVISSA2), £39,428

2010 NHS Norfolk & Waveney Mental Health NHS Foundation Trust, Fox M (PI), **Poland**, Fox C. Scoping study for a research programme for the Clinical Academy in Dementia Care, Norfolk, £30,000

2010-12 Arthritis Research UK, **Poland** (PI), Pfeil, MacGregor, Armon, Qualitative study of Experiences of Multidisciplinary treatment of Benign joint hypermobility syndrome In Childhood (EMBIC). £33,085

2009-11 NIHR Policy Prog PANICOA Research Prog, Killett ((PI), Gray, **Poland**, Hyde, Organisational dynamics of respect and dignity in elder care in care homes (RESPECT). £391,978. Ref. 0250054 (PR-AN-0608-10022)

2009-10 NHS NIHR Research for Patient Benefit Prog. Sargen (PI), Spalding, McCulloch, **Poland**, Vicary, Improving Preoperative Education for Colorectal Surgery Patients., £205,442

2009-12 Stroke Association. Cross, J (PI), Pomeroy, McGlasha, **Poland**, Watson, O'Driscoll, Clark and Barton, Functional strength training to improve walking and upper limb function in people at least 1 year post-stroke (qualitative sub-study lead). A phase II trial, £280,000.

Boston Borough Council, **Poland (PI)**, Fordham, Lambert N, Hooper, Lambert R. Scoping Study For A Healthy Café For Boston. UEA Consulting Ltd. Norwich, £45,000

2008-13 Named collaborator, PPI lead and Norfolk Site PI on £2M National Institute for Health Applied Research Programme, SHIELD Support at Home - Interventions to Enhance Life in Dementia (multi-disciplinary team led by Martin Orrell, UCL and NE London Foundation Trust) £1981952.

2007-8 Ipswich Joint Agency Streets Strategy Group. **Poland (PI)**, Killett, Boswell. An evaluation of the implementation of a multi-agency strategy to reduce street prostitution in Ipswich (EVISSA) £39,700.

2007 Arthritis Research Council. Watts (Principal Grantholder), Scott, Poland, Spalding. A mixed methods study of vasculitis patient information and education £40,000.

2006-7 Economic and Social Research Council (ESRC). Charlesworth (**PI**), Higgs, **Poland**. Complementarity of welfare provision in the 'mixed economy' of care for carers of people with dementia: a longitudinal secondary analysis of BECCA data £79, 421.

2007 Economic and Social Research Council (ESRC). Hooper (**PI**), Poland, Skidmore. Changes Around Food Experience. A qualitative interview study of the impact of reduced contact with food on social engagement and wellbeing of older women)(CAFf) £77,700.

2006-10 Big Lottery Fund. Drachler (Joint PI), Campbell, Howe, Nacul, **Poland (Joint PI)**. Establishing a Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME) Observatory for socially-inclusive epidemiological and social research. £503,000.

2001-6 DH HTA Programme Charlesworth (PI), Harvey, Mugford, **Poland**, Price, Reynolds, RCT to evaluate whether befriending by trained lay workers improve psychological well-being and quality of life for carers of people with dementia and at what cost (BECCA) £573,500

## DAVID PROTHERO

I cared for my late wife for ten years through the early and intermediate stages of Alzheimer's until her sad sudden death at age 65 from an unrelated cancer four years ago. Together we had cared for her father who had Parkinson's and a related Lewy bodies dementia. He died ten years ago at age 87. During those twenty years I developed a close personal understanding of the dementia condition and a growing and still continuing interest in the disease and its practical management.

My own natural interests are music (I have played the violin since age 8) and buildings. I studied the latter for a career and after graduating with an honours degree in Civil Engineering from Leeds University joined a large UK based international construction company as an engineer both on site and also in the design office involved with large heavy engineering infrastructure projects. First as an indentured trainee and subsequently as senior engineer and then a project site manager. I became an associate Member of the Institution of Civil Engineers where I retain affiliate membership. During this time I also studied with Urwick Orr and Partners, a large London based management consultants and became interested in the new thinking on project programme analysis, monitoring and management.

Progressively my construction interest moved towards buildings – which require greater involvement with people and their needs. I became one of the first members of staff in the newly formed building division of the company and worked initially as a site based project manager on many schemes including, schools, hospitals, housing, retail buildings, offices etc. and latterly as contracts manager on several concurrent projects. I extended my studies accordingly and took the professional exams to gain membership of the Chartered Institute of Building.

The onset of a cancer in my mid forties gave me a sudden insight into serious and uncertain illness, the impact of its diagnosis, major surgery, and slow recovery process. Also a realisation of the full potential and real impact of this on my own life and that of my wife and children and others close around me.

Although initially uncertain, my health progressively recovered and I returned to work but in a different office based role. This coincided with the introduction of the personal computer into the workplace at the end of the 1980's. The machines allowed the programme management techniques, which I had become aware of as a young engineer, now to be put into practice. I successfully set up and developed a new modern project planning department. The nature of my work now widened greatly, extending from client concept, through all major project stages to eventual building completion and occupation by users. I therefore further extended my own knowledge accordingly with a Masters degree, with distinction, in Economics and Construction Management including my thesis which explored existing (strangely patchy) use of diagrams in the control and management of construction projects (which are otherwise essentially drawing based).

Inevitably my work day skills began to inform my approach and developing thoughts about the planning, monitoring and management of dementia – eventually focusing on the maintenance of quality of life for both myself and my wife, and with this an increasingly positive approach to the condition. At the time these ideas ran somewhat contrary to much general legacy thinking on dementia around us. However we did achieve, and indeed enjoyably exceeded, our aim, and I have since given several illustrated lectures on this journey and its thinking and our methods at local NHS staff training days, Kent dementia groups, and Admiral Nurse / Dementia UK dementia days for nursing students at both Greenwich University and Christ Church University Canterbury.

During the last four years I have been appointed to the committee of the NHS Medway Older Peoples' Strategic Change programme with particular interest in dementia matters and planning, and spoken at training days associated with that. I have been a member of the steering committee of the national pilot dementia advisors' trial in Medway, current chairman of the Friends of the Horticultural Project, which is an intervention initiative for people within the earlier stages of dementia, and a continuing member of the Kent DemSIG (Dementia Spirituality Special interest Group) which raises awareness of the spiritual needs of people with dementia and their carers.

Throughout my life I have continued to play music, always with other people, in various chamber music and band groups and in orchestras; in concert, for functions and especially for straight enjoyment. All this keeps me very aware of the value of emotional involvement and activity such as this, towards maintaining quality of life. Additionally I learnt the importance and enjoyment of working socially with others and the skills that this requires. I am currently chairman of the large local symphony orchestra and its seasons of major concerts.

Interest, life experiences, work skills, personal activities, educational background and involvement with charities, including Dementia UK's Uniting Carers with Dementia, have all increasingly drawn me towards the new research work into the better management of the dementia condition for both principal carer and the person with dementia. For the last four years I have served on the Programme Steering Committee, the Data Monitoring and Ethics sub committee and act as Independent Advisor for the UCL SHIELD (Support at Home: Interventions to Support Life in Dementia) research project and I am currently on the Programme Management group of the VALID (Valuing Active Life in Dementia) five year UCL research project which started this year.

I meet regularly now with a long standing friend who is recently diagnosed with young onset dementia, and I am thus able to continue exploring and experiencing the rewards of maintaining and extending the quality of another's life with dementia. We play music, go out drawing, and enjoy time together. The rewards are mutual and significant.

*DP (30Aug2012)*

Dr Greta Rait

Clinical Senior Lecturer, Research Department of Primary Care and Population Health (PCPH), UCL

### Education/ Qualifications

1986-1991 MB ChB: University of Manchester

1995 MRCP : Royal College of General Practitioners

2001 MD: University of Manchester

2002 MSc Epidemiology: London School of Hygiene and Tropical Medicine

### Professional history

Clinical Senior Lecturer, MRC General Practice Research Framework, London (2003- 2012)

Salaried General Practitioner, Clerkenwell Medical Practice, London (2001- to date)

Honorary Senior Academic GP, NHS Islington, (Oct 2005- to date)

MRC Training Fellow (Health Services Research), PCPH, UCL, (2000-2003)

Lecturer in Primary Care, PCPH, UCL (Jan 1998-Aug 2000)

### Selected relevant publications

1. Rait G, Burns A & Chew C. Age, ethnicity & mental illness: a triple whammy. *British Medical Journal*. 1996; 313: 1347-1348.
2. Rait G & Burns A. Appreciating background and culture. The South Asian elderly & mental health. *International Journal of Geriatric Psychiatry*. 1997; 12: 973-977.
3. Rait G, Morley M, Lambat I & Burns A. Modification of brief cognitive assessments for use with elderly people from the South Asian sub-continent. *Aging & Mental Health* 1997; 1:356 -63.
4. Rait G & Burns A. Screening for depression & cognitive impairment in older people from ethnic minority backgrounds. *Age & Ageing*. 1998; 27: 271-275.
5. Rait G, Burns A, Baldwin R, Morley M, Chew-Graham C, St Leger S & Abas M. Screening for Depression African-Caribbeans Elders. *Family Practice* 1999; 16: 591-595.
6. Rait G. Counting heads may mask cultural & social factors. *British Medical Journal* 1999; 318: 306.
7. Rait G, Burns A, Baldwin R, Chew-Graham C, Morley M & St Leger S. Validating Screening Instruments for Cognitive Impairment In Older South Asians In the United Kingdom. *International Journal of Geriatric Psychiatry* 2000; 15: 54-62.
8. Rait G, Morley M, Burns A, Baldwin R, Chew-Graham C & St Leger S. Screening for dementia in older African-Caribbeans. *Psychological Medicine* 2000; 30: 957-963.
9. Walters K, Iliffe S & Rait G. The diagnosis & management of dementia in primary care: an agenda for education & training. *Dementia Reviews* 2000; 3: 1-4.
10. Iliffe S, Walters K & Rait G. Shortcomings in the diagnosis & management of dementia in primary care: towards an educational strategy. *Ageing & Mental Health* 2000; 4: 286-291.
11. Iliffe S, Wilcock J, Austin T, Walters K, Rait G et al. Dementia diagnosis & management in primary care: approaches to learning. *Dementia* 2002; 1: 11-23.
12. Rait G, Fletcher, A, Smeeth, L, Brayne C, Stirling S et al. Prevalence of cognitive impairment: Results from the MRC trial of assessment and management of older people in the community. *Age and Ageing* 2005; 34: 242-248.
13. Buszewicz M, Rait G, Griffin M, Patel A, Nazareth I et al An RCT of an Arthritis Self Management Programme in Primary Care. *British Medical Journal* 2006; 333: 879-80.
14. S Iliffe, L Robinson, C Brayne, C Goodman, G Rait, J Manthorpe, P Ashley for the DENDRON Primary Care Clinical Studies Group. Primary care & dementia: 1 Diagnosis, screening and disclosure. *International Journal of Geriatric Psychiatry* 2009; 24:895-901
15. Patel A, Buszewicz M, Beecham J, Griffin M, Rait G, Nazareth I, Atkinson A, Barlow J, Haines A. Economic evaluation of arthritis self management in primary care. *BMJ* 2009;339:b3532, doi: 10.1136/bmj.b3532

16. L Robinson, S Iliffe, C Brayne, C Goodman, G Rait, J Manthorpe, P Ashley for the DENDRON Primary Care Clinical Studies Group Primary care and dementia: 2. long-term care at home: psychosocial interventions, information provision, carer support and case management. *International Journal of Geriatric Psychiatry* 2009. DOI: 10.1002/gps.2405
17. G Rait, K Walters, M Griffin, M Buszewicz, I Petersen, I Nazareth Recent trends in the incidence of recorded depression and depressive symptoms in primary care. *British J of Psychiatry* 2009; 195: 520-524. doi: 10.1192/bjp.bp.108.058636
18. Lancaster G, Campbell MJ, Eldridge S, Farrin A, Marchant M, Muller S, Perera R, Peters TJ, Prevost AT, Rait G. Trials in primary care: statistical issues in the design, conduct and evaluation of complex interventions. *Stat Methods Med Res.* 2010; 19:349 -77.
19. G Rait, K Walters, C Bottomley, I Petersen, S Iliffe, I Nazareth. Survival of People with a Clinical Diagnosis of Dementia in Primary Care. *BMJ* 341:doi:10.1136/bmj.c3584
20. G Livingston, G Leavey, M Manela, D Livingston, G Rait, E Sampson, S Bavishi, K Shahriyarmolki C Cooper. Making decisions for people with dementia who lack capacity: A qualitative study of family carers in the UK: *BMJ* 341 :doi:10.1136/bmj.c4184
21. S Iliffe, L Curry, K Kharicha, G Rait, J Wilcock, D Lowery, A Tapuria, D Kalra, C Ritchie. Developing a Dementia Research Registry: a descriptive case study from North Thames DeNDRoN and the EVIDEM programme. *BMC Medical Research Methodology* 2011, 11:9
22. L J. Horsfall, G Rait, K Walters, D M. Swallow, S P. Pereira, I Nazareth, I Petersen. Serum bilirubin and risk of respiratory disease and death. *JAMA* 2011;305: 691-697

### Relevant projects and activities

Livingstone G, Rosser M, Leavey G, Rait G, Nurock S, Cooper C, Sampson E. CHOICE study –Choice Optimisation for Carers. BUPA (2008-2010): (£150,000). Co-applicant

Iliffe S, Murdoch C, Warner J, Goodman C, Manthorpe J, Wilcock J, Drennan V, Rait G EVIDEM: Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life. National Institute for Health Research: Programme Grant for Applied Research (RP-PG-0606-1005), October 2007-September 2012 (£1,724,583). Co-applicant.

Rait G, Nazareth I, Darbyshire J, Meredith S, Tierney J, Harding S. Recruitment to, and reduction of attrition from, RCTs. MRC Population Health Services Research Network (PHSRN30). 2008-11. (£158,822). Chief Investigator

J Cassell, G Rait, C Estcourt, H Smith, P White, J Richens, A Copas, C Llewellyn, M Macintosh. The relative clinical and cost-effectiveness of three contrasting approaches to partner notification for curable sexually transmitted infections (STIs): a cluster randomised trial in primary care. HTA (07/43/01) 2009-2012 (£1,224,556). Co-applicant

Bunn F, Goodman C, Garlick R, Robinson L, Rait G, Brayne C, Iliffe S. An exploration of patient experiences around diagnosis and treatment of dementia: implications for service development. Research for Patient Benefit (PB-PG-0808-16124). 2010-2012: (£134,392). Co-applicant.

Brayne C, Katona C, Fox C, Rait G, Denning T. A systematic review of screening for dementia in the older population. The BUPA Foundation Grant (Oct 2010- Oct 2011): £131,623. Co-applicant.

Walters K, Rait G, Iliffe S, Petersen I, Nazareth I. Predictors of Dementia in Primary Care: A cohort study using The Health Improvement Network (THIN) database. National School for Primary Care Research (1\_79) 2012-2013. (£96,837). Co-applicant

Bunn F, Goodman C, Rait G, Brayne C, Robinson L. Comorbidity and dementia: improving healthcare for people with dementia (CoDem). NIHR Health Services and Delivery Research Programme (11/1017/07). Oct 2012-Sept 2014. (£371,250). Co-applicant

Dr Aimee Spector

Senior Lecturer in Clinical Psychology, University College London

**Education/ Qualifications**

2001 – 2004	University College London	DClinPsy (Doctorate in Clinical Psychology)
1998 - 2001	University College London	PhD (The development and evaluation of an evidence-based psychological therapy programme for dementia)
1993 - 1996	University of Manchester	B.Sc (Hons) Psychology (Class 2 (i))

**Professional history**

Sept2006 - present	Senior Lecturer in Clinical Psychology, University College London	Key research interest: dementia. Coordinator of Old Age teaching module. Supervising doctoral theses, marking reports and exams, tutoring students.
June 2005 – Aug 2007	Clinical Psychologist within Mental Health for Older People Services (South Bedfordshire NHS)	Assessment, feedback and treatment within a multi-disciplinary Memory Clinic, individual and group therapy, clinical supervision of Trainee Psychologists, staff training, establishment of new Cognitive Stimulation Therapy service.

**Selected relevant publications**

Goyder J, Orrell M, Wenborn J & Spector A (2012). Staff training using STAR: A pilot study in UK care homes. *International Psychogeriatrics*, 4: 1-10.

Spector A and Orrell M (2010). Using a Biopsychosocial model of dementia as a tool to guide clinical practice. *International Psychogeriatrics*, 22 (6): 957-965.

Spector A, Orrell M & Woods B (2010). Cognitive Stimulation Therapy (CST): effects on different areas of cognitive function for people with dementia. *International Journal of Geriatric Psychiatry*, 25 (12): 1253-1258.

Knapp M, Thorgrimsen L, Patel A, Spector A, Hallam, A, Woods B, Orrell M (2006) Cognitive Stimulation Therapy for dementia: is it cost effective? *British Journal of Psychiatry*, 188: 574-580.

Spector A and Orrell M. (2005) Quality of life in dementia: a comparison of the perceptions of people with dementia and care staff in residential homes. *ADAD*, 20 (3): 160-165.

Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, Orrell M (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *British Journal of Psychiatry*, 183, 248-254.

### **Relevant current and recent research grants**

1999-2001 :NHS Executive London Region, Responsive Funding. "A randomised controlled trial of psychological therapies in dementia". (M Orrell, \*A Spector et al). £85,000

2010 – 2015: Health Technology Assessment (HTA). "A randomised controlled trial on Individualised CST". (M Orrell, \*A Spector et al). £1,131,952

2010 – 2013: National Institute for Health Research (NIHR), RfPB programme. "A pilot randomised controlled trial of CBT for anxiety in people with dementia." (\*A Spector et al) £237,210

### **Selected Invited Conference presentations**

Alzheimer's Disease International (ADI), London 2012, British Association of Behavioural and Cognitive Psychotherapies (BABCP), Guildford 2011 and Exeter 2009; Non-Pharmacological Therapies in Dementia: International Congress, Madrid, 2009.

### **Examples of other activities and responsibilities**

Run 'CST for dementia training' in the UK and developed / oversee CST website ([www.cstdementia.com](http://www.cstdementia.com))

Associate Editor for 'Ageing and Mental Health', on editorial board for 'Non-Pharmacological Therapies for Dementia'. Member of 'Interdem'(international network of professionals in dementia research).

Professor Andrew P A Steptoe

Professor of Psychology, Department of Epidemiology and Public Health, University College London

### Education/ Qualifications

Cambridge University	BA 1971, MA 1976	Natural Sciences Tripos, 1 <sup>st</sup> class
Oxford University	DPhil 1976	Psychology
London University	DSc 1995	Psychology

### Professional history

1977 - 1987 Lecturer to Senior Lecturer in Psychology, St George's Hospital Medical School

1987 - 1988 Reader in Psychology, St George's Hospital Medical School, University of London.

1988 –2000 Professor of Psychology and Chair of the Department of Psychology, St. George's Hospital Medical School, University of London.

### Awards and other Honours

1988	Fellow	British Psychological Society
1990	Fellow	Society of Behavioral Medicine (USA)
2001	Academician	Academy of Social Sciences
2003	Fellow	Academia Europaea
2008	Fellow	Academy of Medical Sciences
2011	Fellow	American Psychological Society

### Selected relevant publications from 2012

Bostock S, Steptoe A. (2012). Association between low functional health literacy and mortality in older adults: longitudinal cohort study. *Br Med J*, 344, e 1602.

Brydon L, Lin J, Butcher L, Hamer M, Erusalimsky JD, Blackburn EH, Steptoe A. (2012). Hostility and cellular aging in men from the Whitehall II cohort. *Biol Psychiatry*, 71, 767-773.

Demakakos P, Marmot M, Steptoe A. (2012). Socioeconomic position and incidence of type 2 diabetes in middle-aged and older men and women. *The English Longitudinal Study of Ageing. Euro J Epidemiol*, 27, 367-378.

Evans RE, Beeken RJ, Steptoe A, Wardle J. (2012). Cancer information and anxiety: applying the extended parallel process model. *J Health Psychol*, 17, 579-589.

Hamer M, Steptoe A. (2012). Cortisol responses to mental stress and incident hypertension in healthy men and women. *J Clin Endocrin Metab*, 97, E29-E34.

Hamer M, Endrighi R, Venuraju SM, Lahiri A, Steptoe A. (2012). Cortisol responses to mental stress and the progression of coronary artery calcification in healthy men and women. *PLoS One*, 7, e31356. Hamer M, Venuraju SM, Lahiri A, Rossi A, Steptoe A. (2012). Objectively assessed physical activity, sedentary time and coronary artery calcification in healthy older adults. *Art Thromb Vasc Biol*, 32, 500-505.

Hjemdahl P, Rosengren A, Steptoe A. editors (2012). *Stress and Cardiovascular Disease*. New York: Springer.

Jackowska M, Dockray S, Endrighi R, Hendrickx H, Steptoe A. (2012). Sleep problems and heart rate variability over the working day. *JSleep Res*, 21, 434-440.

Jandackova VK, Paulik K, Steptoe A. (2012). The impact of unemployment on heart rate variability: the evidence from the Czech Republic. *Biol Psychol*, 91, 23 8-244.

Messerli-Bÿrgy N, Molloy GJ, Wikman A, Perkins-Porras L, Randall G, Steptoe A. (2012). Cortisol levels and history of depression in acute coronary syndrome patients. *Psychol Med*, 42, 18 15-1823.

Molloy GJ, Randall G, Wikman A, Perkins -Porras L, Messerli-Bÿrgy N, Steptoe A. (2012). Type-D personality, self-efficacy and medication adherence among acute coronary syndrome patients. *Psychosom*



Med , 74, 100-106.

Seldenrijk A, Hamer M, Lahiri A, Penninx BWJH, Steptoe A. (2012). Psychological distress, cortisol stress response and subclinical coronary calcification. *Psychoneuroendocrinology* , 37, 48-55.

Steptoe, A. (2012). Stress, inflammation, and coronary heart disease. In *Stress and Cardiovascular Disease*, Eds. Hjemdahl, P., Rosengren, A., and Steptoe, A. London: Springer-Verlag. Pp 111-128.

Steptoe, A. (2012). Socioeconomic status, inflammation, and immune function. In *The Oxford Handbook of Psychoneuroimmunology*, Ed. Segerstrom, S.G. New York: Oxford University Press. Pp 234-253.

Steptoe A, Kivimäki M. (2012) Stress and cardiovascular disease, *Nat Rev Cardiol*, 9, 360-370. Steptoe A, Wardle J. (2012). Enjoying life and living longer: A prospective analysis from the English Longitudinal Study of Ageing. *Arch Intern Med*, 172, 273-275.

Steptoe A, Demakakos P, De Oliveira C, Wardle J. (2012). Distinctive biological correlates of positive psychological well-being in older men and women. *Psychosom Med*, 74, 50 1-508.

Steptoe A, Wikman A, Molloy GJ, Kaski J -C. (2012). Anaemia and the development of depressive symptoms following acute coronary syndrome: Longitudinal clinical observational study. *BMJ Open*, 2, e00055 1.

Wikman A, Messerli-Bÿrgy N, Molloy JG, Randall G, Perkins-Porras L, Steptoe A (2012). Symptom experience during acute coronary syndrome and the development of posttraumatic stress symptoms. *J Behav Med*, 35, 420-43 0.

## Grants

ESRC (Kumari, PI)	Conducting a GWAS in the English Longitudinal Study of Ageing	£1,988,177	2012-2013
ESRC (Park, PI) (co-investigator)	Understanding inequality in elderly well-being in China and the UK	£99,261	2011-2012
National Institute on Aging (Steptoe, PI)	Objective physical activity in the English Longitudinal Study of Ageing	\$107,854	2011-2012
ESRC: (Banks, PI) (co-investigator)	Measuring time and risk preferences in the laboratory and the field	£156,659	2010-2011
British Heart Foundation (Steptoe, PI)	Psychophysiology of coronary heart disease	£1,240,094	2011-2015
British Heart Foundation (Steptoe, PI)	Core support for BHF Chair	£930,000	2010-2015
National Institute on Aging (Marmot, PI) (co-investigator)	English Longitudinal Study of Ageing	\$7,831,992	2010-2014
UK Government Departments (Marmot, PI) (co-applicant)	English Longitudinal Study of Ageing	£4,350,000	2010-2014
British Heart Foundation (jointly with Henderson and Thompson)	Cell stress proteins, lymphocyte function, and cardiovascular disease	£239,575	2009-2012
ESRC (Steptoe PI)	International study of biology and positive well-being	£99,387	2008-2009

## FRANS VERHEY

Professor Frans Verhey

Prof. Old Age Psychiatry and Neuropsychiatry at Maastricht University and the founder and head of the first Dutch Memory clinic, in the University Medical Centre in Maastricht.

### Education/ Qualifications

University of Amsterdam University of Amsterdam University of Amsterdam Maastricht

University Bachelor 1976 cum laude, Master 1982 MD, PhD 1993

### Professional history

1978: Tropical course, Cacapavo do Sul, Brazil (dr V. Lang)

1981: Residency of cardiology, University of Amsterdam (prof dr Dunning)

from 1986: University teacher, division of Neuropsychology, neuropsychiatry and Psychobiology, State University of Limburg

from 1992: Consultant of Psychiatry, honorary senior lecturer/associate professor (Academisch Hoofdspecialist) University Hospital of Maastricht

from 2001: Professor of Neuropsychiatry and Old age psychiatry University of Maastricht, the Netherlands

### Selected publications

Elias-Sonnenschein LS, Viechtbauer W, Ramakers IH, Verhey FR, Visser PJ. Predictive value of APOE- $\epsilon$ 4 allele for progression from MCI to AD-type dementia: a meta-analysis. *J Neurol Neurosurg Psychiatry*. 2011.

Jacobs HI, Van Boxtel MP, van der Elst W, Burgmans S, Smeets F, Gronenschild EH, Verhey FR, Uylings HB, Jolles J. Increasing the Diagnostic Accuracy of Medial Temporal Lobe Atrophy in Alzheimer's Disease. *J Alzheimers Dis*. 2011.

Köhler S, van Boxtel M, Jolles J, Verhey F. Depressive Symptoms and Risk for Dementia: A 9-Year Follow-Up of the Maastricht Aging Study. *Am J Geriatr Psychiatry*. 2011.

Bour A, Rasquin S, Limburg M, Verhey F. Depressive symptoms and executive functioning in stroke patients: a follow-up study. *Int J Geriatr Psychiatry*. 2010 Oct 13. [Epub ahead of print]

Jacobs HI, Visser PJ, Van Boxtel MP, Frisoni GB, Tsolaki M, Papapostolou P, Nobili F, Wahlund LO, Minthon L, Frölich L, Hampel H, Soininen H, van de Pol L, Scheltens P, Tan FE, Jolles J, Verhey FR. The association between white matter hyperintensities and executive decline in mild cognitive impairment is network dependent. *Neurobiol Aging*. 2010 Aug 23.

Burgmans S, van Boxtel MP, Smeets F, Vuurman EF, Gronenschild EH, Verhey FR, Uylings HB, Jolles J. Prefrontal cortex atrophy predicts dementia over a six-year period. *Neurobiol Aging*. 2009 Sep;30(9):1413-9.

Visser PJ, Verhey F, Knol DL, Scheltens P, Wahlund LO, Freund-Levi Y, Tsolaki M, Minthon L, Wallin AK, Hampel H, Břrger K, Pirttila T, Soininen H, Rikkert MO, Verbeek MM, Spira L, Blennow K. Prevalence and prognostic value of CSF markers of Alzheimer's disease pathology in patients with subjective cognitive impairment or mild cognitive impairment in the DESCRIPA study: a prospective cohort study. *Lancet Neurol*. 2009.

Wolfs CAG, Dirksen CA, Kessels A, Severens JL, Verhey, FR. Economic evaluation of an integrated diagnostic approach for psychogeriatric patients: Results of a randomized controlled trial. *Archives of General Psychiatry*, 2009 Mar;66(3):313-23. 1.

Jacobs HI, van Boxtel MP, Gronenschild EH, Uylings HB, Jolles J, Verhey FR. Decreased gray matter diffusivity: A potential early Alzheimer's disease biomarker? *Alzheimers Dement*. 2012 May 30. [Epub ahead of print]

Meeuwssen EJ, Melis RJ, Van Der Aa GC, GolŸke-Willemse GA, De Leest BJ, Van Raak FH, Schölzel-Dorenbos CJ, Verheijen DC, Verhey FR, Visser MC, Wolfs CA, Adang EM, Olde Rikkert MG. Effectiveness of dementia follow-up care by memory clinics or general practitioners: randomised controlled trial. *BMJ*. 2012 May 15;344:

[PubMed - in process]

Moniz Cook ED, Swift K, James I, Malouf R, De Vugt M, Verhey F. Functional analysis-based interventions for challenging behaviour in dementia. *Cochrane Database Syst Rev*. 2012 Feb 15;2:CD006929.

Van Vliet D, de Vugt ME, Bakker C, Pijnenburg YA, Vernooij-Dassen MJ, Koopmans RT, Verhey FR. Time to diagnosis in young-onset dementia as compared with late-onset dementia. *Psychol Med*. 2012 May 28:1-10. [Epub ahead of print]

Vos S, van Rossum I, Burns L, Knol D, Scheltens P, Soininen H, Wahlund LO, Hampel H, Tsolaki M, Minthon L, Handels R, L'italien G, van der Flier W, Aalten P, Teunissen C, Barkhof F, Blennow K, Wolz R, Rueckert D, Verhey F, Visser PJ. Test sequence of CSF and MRI biomarkers for prediction of AD in subjects with MCI. *Neurobiol Aging*. 2012 Jan 19.

## **Management experience**

Head of the outpatient department of the department of Psychiatry, University Hospital of Maastricht  
Deputy head (Opleidsplaatsvervangend opleider) of the residence training for psychiatry MUMC/ PMS  
Vijverdal/azM Leader of Research Division Cognitive Neuropsychiatry & Clinical Neurosciences of research institute Mental health and neurosciences (MHeNS)

**MYRRA VERNOOIJ-DASSEN**  
**PhD**

Prof. Myrra Vernooij-Dassen (PhD) is principal investigator in the Nijmegen Centre for Evidence Based Practice and director of Nijmegen Alzheimer Centre. She has a chair on psychosocial aspects of care for frail elderly people. She is affiliated to the scientific Institute of Quality of healthcare and the department of primary care the Radboud University Nijmegen Medical Centre and to the Kalorama Foundation. She is trained in sociology and research methodology and has performed a large body of research on quality of care, especially on dementia care and palliative care and on care transitions. She has a 30 PhD students and published more than 130 international articles. She is involved in several European Union funded projects, including the Implementation of quality indicators in Palliative Care Study (IMPACT). She is chair of Interdem, a pan-European research group on detection and timely INTERvention in DEMentia and is honorary visiting professor of the School of Health of Bradford University. She is a member of the Scientific Advisory Board of the European Joint Programming Initiative for Neurodegenerative Diseases. Myrra Vernooij received the Dutch royal honor to be promoted to officer in the order of Orange-Nassau.

## PRIDE References

- Abraham, C., Michie, S. (2008). A taxonomy of behavior change techniques used in interventions. *Health Psychology*, 27, 379-387.
- Acheson, H., Annerberg, R., Dammert, R., Klusacek, K., Kraus, W., Lock, J. (2012). *Review of the Joint Programming Process, Final Report of the expert Group*. EU Joint Programme- Neurodegenerative Disease Research.
- Albarracin, D., Gillette, J. G., Earl, A. N., Glasman, L. R., Durantini, M.R., Ho, M.H. (2005). A test of major assumptions about behavior change: a comprehensive look at the effects of passive and active HIV-prevention interventions since the beginning of the epidemic. *Psychol Bull*, 131:856–897.
- All-Party Parliamentary Group on Dementia. (2012). *Unlocking Diagnosis: The key to improving the lives of people with dementia*. London: House of Commons.
- Almeida, O.P., Yeap, B.B., Alfonso, H., Hankey, G.J., Flicker, L., et al. (2012). Older Men Who Use Computers Have Lower Risk of Dementia. *PLoS ONE*, 7(8): e44239. doi: 10.1371/journal.pone.0044239
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental health disorders*, 4th ed. Washington DC: APA.
- Angevaren, M., Aufdemkampe, G., Verhaar, H.J., Aleman, A., Vanhees, L. (2008). *Cochrane Database Syst Rev*, 16 (2): CD005381.
- Ball, K., Berch, D.B., Helmers, K.F., Jobe, J.B., Leveck, M.D., et al. (2002). Effects of cognitive training interventions with older adults: a randomized controlled trial. *JAMA*, 288: 2271–2281.
- Bandura A. (1997). *Self efficacy: the exercise of control*. New York: Freeman.
- Banks, J., Marmot, M., Oldfield, Z., Smith, J.P. (2006). Disease and disadvantage in the United States and in England. *JAMA*, 295: 2037-45.
- Banks, J., O'Dea, C., Oldfield, Z. (2010). Cognitive function, numeracy and retirement saving trajectories. *Economic J*, 120: F381-F410.
- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education & Counselling*, 48, 177–187.
- Barlow, J. (2001). How to use education as an intervention in osteoarthritis. *Best Practice Research Clinical Rheumatology*, 15, 545–558.
- Barnes, D.E., Yaffe, K. (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurol*, 10(9): 819—28.
- Beard, R.L., Fox, P.J. (2008). Resisting social disenfranchisement: Negotiating collective identities and everyday life with memory loss. *Social Science & Medicine*, 66, 1509-1520.
- Beecham, J. & Knapp, M. (1992). *Costing psychiatric interventions*. In *Measuring Mental Health Needs* (eds G. Thornicroft et al), pp.163-183. London: Gaskell.

- Borrelli, B. (2011). The assessment, monitoring and enhancement of fidelity in public health clinical trials. *Journal of Public Health Dentistry*, 71(s1): 52-63.
- Bostock, S., Steptoe, A. (2012). Association between low functional health literacy and mortality in older adults: longitudinal cohort study. *BMJ*, 344: e1602.
- Bucks, R.S., Ashworth, D.L., Wilcock, G.K., Siegfried, K. (1996). Assessment of Activities of Daily Living in Dementia: Development of the Bristol Activities of Daily Living Scale. *Age and Ageing*, 25: 113-120.
- Byrne, L.M.T, Wilson, P.M.A., Bucks, R.S., Hughes, A.O., Wilcock, G.K. (2000). The sensitivity to change over time of the Bristol Activities of Daily Living Scale in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 15, 7: 656-661.
- Cane, J., O'Connor, D., Michie, S. (2012). Validation of the Theoretical Domains Framework for use in behaviour change and implementation research. *Implementation Science*, 7, 37.
- Charlesworth, G., Shepstone, L., Wilson, E., Reynolds, S., Mugford, M., Price, P., Harvey, I., Poland, F. (2008). Befriending carers of people with dementia: randomised controlled trial. *BMJ*, 336:1295-1297
- Clare, L., Rowlands, J. M., & Quin, R. (2008). Collective strength: The impact of developing a shared social identity in early-stage dementia. *Dementia*, 7; 9–30.
- Corbett, A. and Ballard, C. (2011). Information provision services in dementia care. *International Journal of Older People Nursing*, 6: 217–226.
- Courtney, C., Farrell, D., Gray, R., Hills, R., Lynch, L., Sellwood, E., Edwards, S., Hardyman, W., Raftery, J., Crome, P., Lendon, C., Shaw, H., Bentham, P.; AD2000 Collaborative Group.(2004). Long-term donepezil treatment in 565 patients with Alzheimer's disease (AD2000): randomised double-blind trial. *Lancet*, 26; 363:2105-15.
- Crimmins, E.M., Kim, J.K., Langa, K.M., Weir, D.R.(2011). Assessment of cognition using surveys and neuropsychological assessment: the Health and Retirement Study and the Aging, Demographics, and Memory Study. *J Gerontol B Psychol Sci Soc Sci*, 66 Suppl 1: i162-71.
- Department of Health. (2009). Living well with dementia: a national dementia strategy. <http://www.dh.gov.uk/en/socialcare/deliveringadultsocialcare/olderpeople/nationaldementiastrategy/index.htm>
- EuroQoL Group. (1990). EuroQoL: A new facility for the measurement of health related quality of life. *Health Policy*, 16:199-208
- Forbes, D., Forbes, S., Morgan, D.G., Markle-Reid, M., Wood, J., Culum, I. (2008). Physical activity programs for persons with dementia. *Cochrane Database of Systematic Reviews*, Issue 3. CD 006489.
- Fratiglioni, L., Qiu, C. (2011). Prevention of cognitive decline in aging: dementia as the target, delayed onset as the goal. *Lancet Neurology*, 10(9): 778-779.

Gillies, B. (1995). *The subjective experience of dementia – a qualitative analysis of interviews with dementia sufferers and their carers and the implications for service provision*. PhD thesis, University of Dundee, UK.

Goldberg DP, Hillier VF: A scaled version of the General Health Questionnaire. *Psychol Med* 1979, 9:139-145.

Hardeman, W., Michie, S., Fanshawe, T. et al. (2008). Fidelity of a physical activity intervention: predictors and consequences. *Psychology & Health*, 23(1): 11-24.

Hodge S, Doncaster E, Moniz-Cook E, Purandare N, Orrell M (2011) Two sides of the same coin? patients' and carers' experiences of UK memory services. *Aging Health* (in press)

Hogervorst, E. (2012). Prevention of dementia with sex hormones: a focus on testosterone and cognition in women. *Minerva Med*, 103(5):353-9.

Hughes, C., Berg, L., Danziger, W., Coben, L.A., Martin, R.L. (1992). A new clinical scale for the staging of dementia. *British Journal of Psychiatry*, 140:566-72.

Hyde, M., Wiggins, R.D., Higgs, P., Blane, D.B. (2003). A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model (CASP-19). *Aging Ment Health*.7:186-194.

Hulko (2009) From 'not a big deal' to 'hellish': Experiences of older people with dementia. *Journal of Aging Studies*, 23, 131–144; 2009.

Katsuno, T. (2005). Dementia from the inside: how people with early-stage dementia evaluate their quality of life. *Ageing and Society*, 25, 197–214.

Laakkonen, M. L., Hölttä, E. H., Savikko, N., Strandberg, T. E., Suominen, M., & Pitkälä, K. H. (2012). Psychosocial group intervention to enhance self-management skills of people with dementia and their caregivers: study protocol for a randomized controlled trial. *Trials*, 13(1), 133.

Langa ,K.M., Llewellyn, D.J., Lang, I.A., et al. (2009). Cognitive health among older adults in the United States and in England. *BMC Geriatr*, 9: 23.

Langdon, S.A., Eagle, A., & Warner, J. (2007). Making sense of dementia in the social world: a qualitative study. *Social Science & Medicine*, 64, 989-1000.

Llewellyn, D.J., Lang, I.A., Langa, K.M., Huppert, F.A.(2008). Cognitive function and psychological well-being: findings from a population-based cohort. *Age Ageing*, 37: 685-9.

Llewellyn, D.J., Lang, I.A., Langa, K.M., Naughton, F., Matthews, F.E. (2009). Exposure to secondhand smoke and cognitive impairment in non-smokers: national cross sectional study with cotinine measurement. *BMJ*, 338: b462.

Lorencatto, F., West, R., Seymour, N., Michie, S. (2013). Developing a method for specifying the components of behaviour change interventions in practice: the example of smoking cessation. *Journal of Consulting and Clinical Psychology*, In press

Manthorpe J Samsi K Campbell s Abley C Keady J Bond J Watts S Robinson L Warner J and Iliffe S (2013) From forgetfulness to dementia: clinical and commissioning implications of diagnostic experiences *British Journal of General Practice* January e69-e75

MacQuarrie, C. R. (2005). Experiences in early stage AD: understanding the paradox of acceptance and denial. *Aging & Mental Health*, 9(5), 430-441.

Martin, F., Turner, A., Wallace, L., Choudhry, K., Bradbury, N. (2012). Perceived barriers to self- management for people with dementia in the early stages. *Dementia*, 0(0): 1-13.

Mather, L. (2006). Memory Lane Cafe: Follow-up support for people with early stage dementia and their families and carers. *Dementia: The International Journal of Social Research and Practice*, 5, 290–293.

Medeiros, Fde. L., Xavier, A.J., Schneider, I.J., Ramos, L.R., Sigulem, D., d'Orsi, E. (2012). Digital inclusion and functional capacity of older adults living in Florianópolis, Santa Catarina, Brazil. *Rev Bras Epidemiol*, 15(1): 106-22.

Michie, S., Johnston, M., Abraham, C., Lawton, R., Parker, D., Walker, A. on behalf of the Psychological Theory Group. (2005). Making psychological theory useful for implementing evidence based practice: a consensus approach. *Quality and Safety in Health Care*, 14, 26–33. doi: 10.1136/qshc.2004.011155

Michie, S., van Stralen, M.M., West, R. (2011). The Behaviour Change Wheel: a new method for characterizing and designing behaviour change interventions. *Implementation Science*, 6, 42. Doi:10.1186/1748-5908-6-42.

Mountain, G. A. (2006). Self-management for people with early dementia: An exploration of concepts and supporting evidence. *Dementia: The International Journal of Social Research and Practice*, 5, 429–446.

Mountain, G.A., Craig, C.L. (2012). What should be in a self management programme for people with early dementia? *Aging and Ment Health*, 16(5): 576-83.

Muo, R., Schindler, A., Venero, I., Schindler, O., Ferrario, E., Frisoni, G. (2005). Alzheimer's disease-associated disability: An ICF approach. *Disability and Rehabilitation*, 27, 1405–1413.

National Audit Office. (2007) *Improving services and support for people with dementia*. London: National Audit Office.

Noar, S.M., Zimmerman, R.S. (2005). Health behavior theory and cumulative knowledge regarding health behaviours: are we moving in the right direction? *Health Ed Res Theory Pract*, 20:275–290

Orrell, M. (2012). Should we use individual cognitive stimulation therapy to improve cognitive function in people with dementia? *BMJ*, 344:e633

Owen, A.M., Hampshire, A., Grahn, J.A., Stenton, R., Dajani, S., Burns, A.S., Howards, R.J., Ballard, C.G. (2010). Putting brain training to test. *Nature*, 10; 465(7299): 775-8.

Palmer, K., Winblad, B. (2008). Mild cognitive Impairment in the general population: Occurrence and progression to Alzhiemer's Disease. *Am Journal Geriatric Psychiatry*, 16(7): 603-611.



- Podsiadlo, D., & Richardson, S. (1991). The timed" Up & Go": a test of basic functional mobility for frail elderly persons. *Journal of the American geriatrics Society*, 39(2), 142.
- Price, D., Bisdee, D., Daly T, Livsey, L., Higgs, P.(2013). Financial planning for social care in later life: the 'shadow' of fourth age dependency, *Ageing and Society*, 1-23. Available on CJO doi: 10.1017/S0144686X12001018.
- Reamy, A.M., Kim, K., Zarit, S.H., Whitlatch, C.J. (2011). Understanding discrepancy in perceptions of values: individuals with mild to moderate dementia and their familycaregivers. *Gerontologist*, 51(4): 475-83.
- Rosen, W.G., Mohs, R.C. and Davis, K.L. (1984). A new rating scale for Alzheimer's disease. *American Journal of Psychiatry*, 141, 1356 - 64.
- Rowen, D., Brazier, J., Tsuchiya, A., & Alava, M. H. (2011). Valuing states from multiple measures on the same visual analogue sale: a feasibility study. *Health Economics*, 21(6), 715-729.
- Sinclair, L.B, Lingard LA, Mohabeer RN. (2009). What's so great about rehabilitation teams? An ethnographic study of interprofessional collaboration in a rehabilitation unit. *Arch Phys Med Rehabil*; 90(7): 1196-201. doi: 10.1016/j.apmr.2009.01.021; 2009.
- Shankar, A., Hamer, M., McMunn, A., Steptoe, A. Social isolation and loneliness: Relationships with cognitive function over 4 years follow up in the English Longitudinal Study of Ageing. *Psychosom Med*, in press.
- Skirbekka, V., Loichinger, E., Weber, D. (2012). Variation in cognitive functioning as a refined approach to comparing aging across countries. *Proc Natl Acad Sci U S A*, 109: 770-4.
- Smith, S.C., Lamping, D.L., Banerjee, S., Harwood, A., Knapp, M., et al. (2005). Measurement of health-related quality of life for people with dementia: Development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment*, 9 (10): 1-112.
- Spector, A., Orrell ,M.(2010). Using a biopsychosocial model of dementia as a tool to guide clinical practice. *International Psychogeriatrics*, 22:6; 957-965.
- Sperling, R., Johnson, K. (2012). Dementia: new criteria but no new treatments. *The Lancet*, 11: 4-5
- Steel, N., Bachmann, M., Maisey, S., Shekelle, P., Breeze, E., Marmot, M., Melzer, D. (2008). Self reported receipt of care consistent with 32 quality indicators: national population survey of adults aged 50 or more in England. *British Medical Journal*, 337a:957.
- Steptoe, A., Breeze, E., Banks, J., Nazroo, J. Cohort profile: English Longitudinal Study of Ageing. *Int J Epidemiol*, in press.
- Stock, J., Clifford, A. and Hogervorst, E. (2012). Exercise interventions to improve cognitive performance in older adults- potential psychological mediators to explain variation in findings. *European Neurological Review*, 7(2):107-12

- Teague, G., Bond, G., Drake, R. (1998) Program Fidelity in Assertive Community Treatment. *Am J Orthopsychiatry*, 68, 216-33.
- Van der Wardt, V., Bandelow, S. & Hogervorst, E.(2011). Cognitive Abilities, well-being and internet search performance in older people. *Alzheimers & Dementia*, 7(4), p. 494.
- Van Doorslaer, E., Koolman, X. (2004). Explaining the differences in income-related health inequalities across European countries. *Health Econ*, 13: 609-628.
- Vergheze, J., Lipton, R.B., Katz, M.J., Hall, C.B., Derby, C.A., et al.(2003). Leisure activities and the risk of dementia in the elderly. *N Engl J Med*, 348: 2508–2516.
- Wagstaff, A., Paci, P., van Doorslaer, E.(1991). On the measurement of inequalities in health. *Soc Sci Med*, 33: 545-57.
- Weir, D.R., Faul, J.D., Langa, K.(2011). Proxy interviews and bias in cognition measures due to non-response in longitudinal studies: a comparison of HRS and ELSA. *Longitudinal and Life Course Studies*, 2: 170-84.
- Willis, S. L., Tennstedt, S. L., Marsiske, M., Ball, K., Elias, J., & Koepke, K. M. (2006). Long-term effects of cognitive training on everyday functional outcomes in older adults. *Journal of the American Medical Association*, 296(23), 2805–2814.
- Woods, B., Aguirre, E., Spector, A.E., Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database SystRev*, 2:005562.doi:10.1002/14651858.CD005562.pub2.

31<sup>st</sup> January 2013

Prof Martin Orrell  
Research Department of Mental Health Sciences  
UCL  
Charles Bell House, 2nd Floor  
67-73 Riding House Street  
London W1W 7EJ

Dear Professor Orrell

### **Age Concern Havering & PRIDE Dementia Support Proposal**

I wish to confirm the commitment of Age Concern Havering to act as a project partner in the PRIDE Dementia Support proposal.

As a significant provider of information, advice and support to those with dementia and their carers within the London borough of Havering for nearly 20 years, this organisation entirely supports the objectives and method of the research proposal.

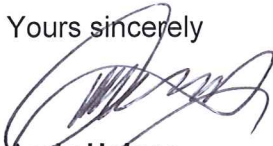
ACH's Dementia Advisory Service and allied activities serve around 1200 people with dementia and their carers each year. The goal of the proposal to better understand the social consequences of dementia and to develop an effective social intervention for people with early stage dementia and their carers will potentially directly benefit the people receiving these services.

ACH works in partnership with memory services, GP's, other agencies and self referring individuals to support those with early stage dementia both pre and post diagnosis. The experience of key staff gained from service provision and as a collaborating agency on the Shield Project, could allow the organisation to effectively support the involvement of individuals and groups participating in relevant elements of the randomised controlled trial for any part of the cohort that resides within Havering. These staff might also provide relevant training and support to colleagues within the project developing the social intervention directly with people with dementia and their carers.

Apart from the proposal being immediately relevant to ACH's services, involvement in the research will allow lessons from emerging outcomes and findings to be applied in the enhancements and extension of increasingly holistic services for the benefit of those with dementia and their carers served by this organisation.

All of us at ACH wish you and the team success in your application and we look forward to both contributing to and supporting this exciting and much required project in any way that is deemed assistive.

Yours sincerely



**Andy Haines**  
CEO

Trust Head Office

Goodmayes Hospital  
Barley Lane  
Ilford  
IG3 8YB

Tel: 0844 600 1298  
Fax: 0844 931 0118

Email: [john.brouder@nelft.nhs.uk](mailto:john.brouder@nelft.nhs.uk)

To Whom it may concern  
Economic and Social Research Council

6<sup>th</sup> September 2012

Dear Sir/Madam

**PRIDE - Promoting Independence in Dementia**

NELFT is satisfied that all NHS Support and Treatment Costs in the application are correct and is prepared to meet these costs.

Yours sincerely



**John Brouder**  
Chief Executive

Progress report on ESRC grant (RES/J002445/1) Start date 2<sup>nd</sup> January 2012

February 19<sup>th</sup> 2013

### **Adult Survivors of Childhood Liver Transplant: Personal Narratives of an Emerging 'New' Ageing Population**

Principal Investigator	Dr Karen Lowton	King's College London	
Co-Investigator	Professor Paul Higgs	University College London	

The study is investigating the psychosocial impacts of liver transplant performed in children who are now adults. In the mid-1980s surgeons at Addenbrooke's Hospital, Cambridge began performing significant numbers of paediatric liver transplants, at that time an experimental treatment for children with end-stage liver disease. This programme was soon joined by one at King's College Hospital, London. Those who survived make up a bounded and identifiable group of around 65 now adult 'pioneers'; Adult Survivors of Childhood Liver Transplants (ASCLT). Of these, around 65 are potential participants for our study as they have passed their eighteenth birthdays. The cohort includes men and women for who it is 20 years or more since their first liver transplant, and around a quarter of the cohort has required more than one liver transplant. Uncertainty, risk and hope are likely to have been key determinants for parents and medical specialists at the time of childhood transplant, and a key feature of life following transplant for the now adult 'patient' and the medical team. The research is interested in the lived experience of these adult survivors and the views of the liver and transplant specialists at Addenbrooke's who continue to have medical responsibility for them.

To date we have completed the majority of data collection.

1. We have interviewed and had transcribed 27 in-depth interviews with adult survivors of childhood liver transplant. We are particularly pleased with this as represents a 50% response rate, and we have included in the study seven more participants than originally planned.
2. We are currently interviewing clinicians who have provided, or continue to provide, clinical care to this cohort. We are pleased to have interviewed two key stakeholders in this field and are currently scheduling interviews with six further clinicians. We anticipate that these interviews will be completed by end of March.
3. We are completing our analysis of the now-adult childhood liver transplant recipient interview data and have begun to focus on key findings from this.

We have a number of early outcomes and outputs arising from this grant:

We have submitted an abstract to the 7th Congress of the International Paediatric Transplant Association, to be held in Warsaw, Poland in July 2013 (abstract acceptance notifications expected in early March 2013):

Understanding 'normal' and different for pediatric liver transplant recipients: a qualitative study of the UK's first now-adult survivors.

We are particularly keen to make links with clinicians presenting in a session entitled 'Is "Normal Life" a Realistic Goal?' as the concepts of 'normal' and 'different' particularly reflects one of our key findings for our cohort and wider sociological debate.

We have submitted three abstracts to the European Sociological Association's (Turin, August 2013):

Sociology of Health and Illness research network: Lowton, Hiley & Higgs. The limitations of biographical disruption approaches: The case of adult survivors of childhood liver transplant  
Sociology of families and intimate lives research network: Lowton, Hiley & Higgs. Family survival strategies and network solidarity in the context of children needing liver transplants  
Sexuality research network: Lowton, Hiley & Higgs. Shark bites and surgery: personal and social meanings of a scar for a 'new' ageing population

We additionally met with Michael Attwell, Managing Director of MAP TV, with a view to making a documentary about this group of survivors. Lowton has worked previously with Attwell and is developing strong links with this documentary production company. However, on this occasion we felt that as the group was so heterogeneous it would currently prove difficult to provide a 'story' for the documentary.

We have begun to sketch out our plans for our end of project seminar, through which we will disseminate our findings to academics, health policy makers and health and social care professionals. We have contacted Shaun Woodward MP who has expressed interest in speaking at this event. Woodward is of particular interest to our project as he was the young journalist on BBC's 'That's Life', a television programme that was instrumental in enabling childhood liver transplants to begin in the UK. We will also invite all our transplant survivor interviewees; a notable finding from our research being that bar two respondents, none of them have met another childhood liver transplant recipient in adulthood and the majority have expressed a desire to do so.

## **PRIDE - Data Management Plan**

WP1: ELSA Study: This project will be integrated into the English Longitudinal Study of Ageing (ELSA), a panel study of a representative sample of men and women aged 50 and over living in England. ELSA involves repeat collection of economic, psychosocial, cognitive, health, and biological data from around 10,000 individuals. One of the primary purposes of this study is to collect data that can be used by other academic and policy analysts. The ELSA study maintains a strict policy of rapid public release of data, and the dataset is typically lodged with the UK Data Archive within a few months of completion of data collection. It then becomes available to registered users to download and analyse. The first 5 waves of ELSA data (2002/3 to 2010/11) plus appropriate documentation from the UK Data Archive (<http://www.esds.ac.uk/findingData/snDescription.asp?sn=5050>). The data are made available in STATA and SPSS formats. Data collection in ELSA is carried out by NatCen Social Research. They have strict procedures for standardisation of data collection and quality control (<http://www.natcen.ac.uk/elsa/> for further details). The research team at UCL will analyse the information and derive summary variables for use in statistical analyses. All data deposits from ELSA are accompanied by technical documentation that is available from the UK Data Archive. All data will be available through the UK Data Archive (<http://www.data-archive.ac.uk/>). We will identify any data repository that is, or will be, entrusted with storing, curating and/or sharing data from the study, where they exist for particular disciplinary domains or data types. Information on repositories is available here.

The UK Data Archive has an established set of data access and sharing agreements, and these apply to users of ELSA data. All new credible users who satisfy UKDA will have access to the new data collected in this study. The data are very suitable for sharing, and the information is structured to facilitate this. ELSA policy involves complete access and data sharing. The statisticians will keep the analysis files created from this database on a secure password protected shared drive, which is managed and backed up daily by UCL. All ELSA publications and outputs indicate how the data can be accessed. The information is also distributed through the UK Data Archive. As part of our commitment to the public funders of ELSA we aim to make data publicly available as soon as possible. The only delays relate to the development of suitable metrics for the public release of data. There are aspects of the ELSA dataset (genetic data, linkage with health and benefit records) that are restricted, and have special rules for access. ELSA is also included in the RAND Survey Meta Data Repository (<https://mmicdata.rand.org/meta/>), and it is likely that the results from this project will be added to that repository in due course.

### **WP2-4: Qualitative components:**

Information on new data: We will gather new data in documentary sources (paper and online), audio-taped semi-structured group and one-to-one interviews, and in written and audio-taped field notes of observations. Interviews and field notes will be transcribed verbatim either by the researcher or professional transcribers already known to the study team and who have experience working with academic material. Field notes will be written up in full. All data will be kept in strict adherence to Good clinical practice (GCP) guidance, which includes storing data in a locked cabinet in a locked room. All documentary and transcribed data will be anonymised and imported into the latest version of the qualitative analysis software, NVivo (currently version 9.2), which allows the storing, coding and organisation of qualitative datasets. Electronic files will be password-protected.

Quality assurance of data: We will ensure the quality and integrity of our data in ensuring that it is accurate, legible, complete and contemporaneous, and attributable to the person by whom it is generated. All transcriptions will be checked for accuracy by the researcher

and field notes will be written up in full soon after observations have taken place so that the quality characteristics of the original data (audio-files, field notes) are preserved. We will ensure that data is collected in accordance with the study protocol and procedures through regular meetings between the PI and researcher. The qualitative research team members will review the quality of interviews and field notes at regular points across the period of data collection to ensure they are of a high standard. Data analysis will be undertaken by the researcher in conjunction with the PI and co-investigators.

**Back-up and security of data:** Physical data (e.g. digital audio-recordings, hand written field notes) will be kept to allow traceability and stored in a locked cabinet in a locked room. All data will be anonymised. All sensitive data held electronically will be encrypted. Data will be backed-up daily as part of routine practice by the computing services at University College London or at the University of East Anglia. All documents will be assigned version numbers which will be presented in headers and electronic filenames. We anticipate this to be in the format N.n, where N represents a new, approved or finalised version of a document and n represents draft versions prior to finalisation.

**Data sharing, copyright and responsibilities:** We do not expect any obstacles in the sharing of newly generated data. Prior to any sharing, data will have been anonymised. Copyright will be owned jointly by University College London, the University of East Anglia and the PI. The PI accepts overall responsibility for data management, data quality and final delivery of data for sharing and archiving. Data will be prepared and documented during the course of the study as described above and according to guidelines set out in the Documentation Processing Procedures (Version 2) of the Economic and Social Data Service (ESDS). Non-sensitive data will be shared with the ESDS on completion of the study. However, the interviews will contain sensitive medical information that would not be suitable for data sharing. The Memory Clinic database could be deposited in the archive if appropriate permissions are sought at the client consent stage

**WP3/4: Data Management:** We propose to use the data management system Red Pill which is built on the open source web platform LAMP (Linux, Apache, MySQL and PHP), hosted on a centralised application server, and accessed through a web browser (eg Explorer). Red Pill provides: 1) contact management for trial sites, investigators, ethics committees, regulatory agencies and other organisations; 2) data collection of CRF data with comprehensive error checking, query resolution and data history; 3) live reporting on all aspects of the database; 4) integration with randomisation services; and 5) role based permissions for users.

**Quality control:** Compliance with GCP standards is now a requirement of all MRC and NHS R&D funded clinical trials (NHSE, 1999) and this trial will be conducted according to GCP standards as interpreted by MRC guidelines, giving particular credence to guidance on multi-centre trials. Accurate records will be kept, in accordance with the protocol laid out in the investigator's manual for recruitment, randomisation and data collection. Data will be collected and managed in a systematic and verifiable manner. Research staff will be trained, supervised and supported. Data collection will be ongoing with a database designed at the outset, to expedite reporting and enable data quality control. Compliance to GCP, protocol and trial processes will be monitored monthly in the first year and quarterly subsequently. Project management methods will be used including detailed work plans, quarterly meetings of the applicants, monthly local management meetings, and regular supervision sessions.



PRIMENT is a UK Clinical Research Collaboration (UKCRC) registered clinical trials unit (CTU 20) with a mission is to conduct high quality randomised trials and related studies in mental health and primary care. The Trial Management Group (TMG) led by the Chief Investigator (CI) includes the trial statistician, the trial manager and other investigators with trial expertise. The division of responsibilities for the TMG will be filed in the Trial Master File. The day-to-day management of the trial will be co-ordinated through PRIMENT CTU through the trial management team (reporting to the TMG). All trials are run in accordance with PRIMENT's Standard Operating Procedures (SOPs) which include: protocol development; trial initiation, conduct and, management; statistical management and analysis; data management; and trial closure. PRIDE will have a specific monitoring plan (developed by the Trial Management Team and approved by the TMG) based on SOPs adapted to reflect the trial's level of risk and data collection methods. Each trial regularly reviews its risk register at TMT and TMG meetings.

PRIMENT will ensure that careful records of randomisation are maintained via a trial register and that subject confidentiality is assured. Quality control will be applied to a sample of key data items at study sites and during data entry. Each centre (memory service) will return an updated weekly monthly report of enrolled patients with a copy of the signed informed consents to PRIMENT including a sheet confirming each patient meets the eligibility criteria. The original informed consents, and questionnaires will all be forwarded directly to PRIMENT for quality control checks. Questionnaires will be checked upon receipt for accuracy and completeness. All tracking and questionnaire data will be entered onto the secure trials database. Data will be double entered. PRIMENT will monitor the information from each memory service, detailing the outcome of these scheduled contacts, so that the study coordination centre can monitor recruitment and data quality. This is a low risk study with minimal source data to verify. All data obtained in the memory services will be recorded directly onto the CRF, which will be the source data document. Data quality will be audited according to GCP guidelines, and a trail will be maintained of any change or correction to the case report form or the electronic database. Data will be generated, recorded and reported in compliance with the protocol. A proportion of sites will be visited at random, and sites with inconsistent data, or queries about recruitment or data collection will also be visited. Site monitors will check the local study file, CRF and the process of taking informed consent and inform PRIMENT.

The trial statistician will ensure that all data items required for analysis of all outcome measures specified in the trial protocol are accurately captured on the Case Report Forms. The trial statistician will review the database requirement specification to ensure, in collaboration with the trial team, that the design of the trial's main database permits the efficient extraction of data in a format suitable for use in a statistical package (statistical analysis files). The trial statistician will perform extensive range and consistency checks on the variables in the statistical analysis files following data extraction. This is in addition to any checking which is incorporated within the trial database. Any queries arising from these checks will be referred to the Trial Manager for resolution. Once queries are resolved, alterations will be programmed within a single file and include appropriate explanatory annotation. There will be clear documentation of statistical analysis file specification, and procedures for exporting data from the trial database. Write permission to trial-specific statistical directories will be limited to the statisticians working on the trial. The analysis files will be kept in a shared password protected folder allocated to PRIMENT CTU specifically for this trial held in the UCL system and backed up daily. Data will be prepared according to guidelines set out in the Documentation Processing Procedures of the Economic and Social Data Service (ESDS) and will be shared with the ESDS on completion of the study.

## **Proposal for UCL ESRC DTC Studentships aligned to Promoting Independence in Dementia (PRIDE - Orrell)**

### **PRIDE ESRC DTC PhD Studentship (1)**

#### **Evaluating the implementation of a social intervention to improve independence in dementia**

**Base:** Division of Psychology and Language Sciences, University College London (ESRC accredited Doctoral Training Centre)

**Lead Supervisors:** Prof Susan Michie and Dr Ben Gardner (UCL)

**Supervisory team:** Dr Lou Atkins (UCL; experience of relevant theoretical frameworks); Fabi Lorencatto (UCL, completing PhD; expertise in fidelity assessment methods)

**Duration:** Three or four years (3+1), depending on the candidate.

#### **Background**

Complex interventions, such as our proposed social intervention to improve independence in dementia, often face problems of implementation as they typically operate in dynamic, social situations. This results in the delivered intervention deviating from the intervention protocol. Assessing the fidelity of delivery should be part of intervention evaluation since it is critical for the accurate interpretation of intervention outcomes, for intervention optimisation and for improving future implementation. Assessing fidelity can prevent failures to achieve desired outcomes from being erroneously attributed to problems of the intervention design or content rather than to problems of implementation. It can also highlight provider training needs and aspects of intervention delivery that require improvement.

Although the importance of examining fidelity of delivery is widely recognised (e.g. in the CONSORT statement for reporting complex interventions), reviews suggest that it is not frequently assessed or accounted for in analyses (e.g. Borrelli, 2011). Where fidelity of delivery has been assessed, it is often found to be poor (<55%) and rarely uniform (e.g. Hardeman et al, 2008). Factors influencing implementation in healthcare settings include contextual factors, such as time, workload, and staffing; attributes of the intervention, such as clarity of instructions for delivery; and psychological factors of those delivering the intervention, such as lack of motivation and problems of memory and attention.

There is a lack of established procedures for monitoring fidelity of delivery of complex interventions in clinical practice although examples exist (Teague et al., 1998). A reliable method has been developed for behavioural support for smoking cessation as part of doctoral work supervised by SM (Lorencatto et al, in press). In order to improve implementation, it is necessary to both document the problems and to explain them. An integrative framework for understanding implementation theoretically, based on theories of behaviour change has recently been validated: the Theory Domains Framework (TDF; Cane et al, 2012). The TDF has been used to investigate a wide variety of implementation problems including those for treatment of schizophrenia, midwife provision of advice for pregnant women, primary care practitioners' behaviours in relation to HPV, GP treatment of back pain, clinicians' blood transfusion behaviour and hand-hygiene behaviour. The TDF has been used as the basis for designing interventions to increase implementation by linking theoretical domains to specific techniques and to more general intervention functions (Michie et al, 2011).

This studentship will build on this methodological and theoretical work to investigate the implementation of the social intervention to improve independence in dementia developed

as part of PRIDE. It provides an important additional dimension that will help both the interpretation of the trial results and optimisation of future implementation.

## Aims

This studentship will (i) review the relevant implementation literature, (ii) develop a method for assessing the implementation of a social intervention to improve independence in dementia, (iii) assess the extent to which the intervention is delivered as specified in the protocol, (iv) theoretically analyse reasons for non-implementation, and (v) design an intervention to improve implementation, informed by previous studies.

## Methods

**Systematic review:** The review will update and synthesise evidence of assessment methods and theoretical frameworks of implementation. It will draw on both Cochrane methodology and the NICE methods manual for public health interventions, which takes a conceptual approach to evidence searching and synthesis.

**Develop method for assessing implementation:** The most promising assessment method identified in the review will be piloted during the pilot phase of the social intervention, using methods for testing reliability used by Lorencatto et al (in press).

**Assess implementation:** A purposive sample of audio-recorded interventions will be transcribed and coded in relation to the intervention protocol. Implementation will be compared across setting and provider. Associations between implementation and participant engagement will be investigated, with engagement measured by use of the helpline, phone text, web-based support, peer support and optional 3 month review.

**Theoretical analysis of implementation:** A purposive sample of providers will be interviewed, guided by the TDF. Transcripts will be analysed thematically to identify the domains with most explanatory value. Depending on the results, observational data of the intervention may also be collected and analysed.

**Intervention design:** The results of the above studies will inform the design of a prototype intervention to improve implementation, using an intervention design guide being developed by SM's team at UCL. This will be presented to one or more groups of stakeholders and feedback data analysed to inform a refined intervention.

## References

- Borrelli, B. 2011. The assessment, monitoring and enhancement of fidelity in public health clinical trials. *Journal of Public Health Dentistry*, 71(s1): 52-63.
- Cane J, O'Connor D, Michie S. (2012). Validation of the Theoretical Domains Framework for use in behaviour change and implementation research. *Implementation Science*, 7, 37.
- Hardeman W, Michie S, Fanshawe T et al. 2008. Fidelity of a physical activity intervention: predictors and consequences. *Psychology & Health*, 23(1): 11-24.
- Lorencatto F, West R, Seymour N & Michie S. (2013). Developing a method for specifying the components of behaviour change interventions in practice: the example of smoking cessation. *Journal of Consulting and Clinical Psychology*, In press
- Michie S, van Stralen MM, West R. (2011). The Behaviour Change Wheel: a new method for characterizing and designing behaviour change interventions. *Implementation Science*, 6, 42. Doi:10.1186/1748-5908-6-42.

## **Proposal for UCL ESRC DTC Studentships aligned to Promoting Independence in Dementia (PRIDE - Orrell)**

### **PRIDE ESRC DTC PhD Studentship (2)**

### **DE ESRC DTC PhD Studentship (2)**

#### **An exploration of social and cultural contexts of fear of dementia**

##### **Proposed Supervisors:**

- 1. Georgina Charlesworth, Lecturer, Research Department for Clinical, Educational and Health Psychology, UCL**
- 2. Paul Higgs, Professor of the Sociology of Ageing, Unit of Mental Health Sciences, UCL**

#### **Background**

Receiving a diagnosis of dementia has an impact on social identity and affects social relations. Dementia holds a particular negative symbolic role in discourses around ageing and old age, and there is emerging data on the nature and extent of fear of dementia in the 'normal' population, with especial concerns over dependence and 'loss of self'. Early contact with Memory Clinics is encouraged as part of the National Dementia Strategy in order to facilitate access to the potential benefits of such services. Existing studies on the experiences of receiving a dementia diagnosis suggest that the majority of those who have chosen to engage with the diagnostic process have found this broadly beneficial. However, the research is limited in that it is mainly: with family carers rather than people with dementia themselves; taken from a service perspective; and does not consider the potential role of fear-related avoidance for those who refuse service contact.

The proposed study would explore the social and cultural context of fear of dementia. Data would be drawn from surveys, the general public, and individual interviews with participants in the wider PRIDE study. Both qualitative and quantitative techniques will be used.

#### **Proposed components**

- review of literature on social construction of dementia (in contrast to the medical diagnosis) as well as emerging work on the concept of the 'fourth age'
- systematic review of impact of receiving a diagnosis of chronic, deteriorating and ultimately fatal illness in general and dementia in particular on the recipient of the diagnosis (especially impact on anxiety)
- explorations of appraisals/attributions by 'normal' populations of (a) memory failures in self & others and (b) impact of a diagnosis of dementia on independence and identity
- cross-sectional and longitudinal modelling of relationship between fear of dementia, perceptions of cognitive deficits and wellbeing using data from the PRIDE Memory Clinic cohort (n=520)



## **Proposal for UCL ESRC DTC Studentships aligned to Promoting Independence in Dementia (PRIDE - Orrell)**

### **PRIDE ESRC DTC PhD Studentship (3)**

**Title: Impact of cognitive function on quality of care**

**Primary supervisor: Prof. Stephen Morris, UCL**

**Secondary supervisor: Dr. Laura Vallejo-Torres, UCL (*to be confirmed*)**

#### **Background and aims**

Improving the quality of health care received by patients, and reducing inequality in that health care, are important concerns for the NHS in England. These issues are likely to be especially pertinent for people with cognitive impairment, who may have difficulties accessing high quality health care services. The aims of this PhD studentship are to investigate:

1. The impact of cognitive function on quality of primary care; and,
2. The impact of cognitive function on socioeconomic-related inequality in the quality of primary care.

#### **Data and main variables**

The main data source for this studentship is the English Longitudinal Study of Aging (ELSA). ELSA provides data from a representative sample of adults aged 50 or more living in private households in England. The sample was drawn from households that had previously responded to the Health Survey for England (HSE) in 1998, 1999 or 2001. Individuals selected for the ELSA survey have been interviewed every two years since 2002. We propose to use data from waves 2, 3 and 4 (run in 2004-05, 2006-07 and 2008-09, respectively) of ELSA, which provide detailed information on the quality of health care received as well as measures of cognitive function as well as health status, demographic and socioeconomic factors. Area level factors may affect the demand for, and supply and quality of health care so we will link these to ELSA using Primary Care Trust (PCT) codes which will be obtained under special license (we have undertaken these linkages previously).

#### *Quality of care indicators*

ELSA contains 35 indicators of quality of care covering 13 medical conditions (see box for examples). These were derived to assess the care of vulnerable older people across a number of conditions (Steel et al., 2008). The conditions were chosen according to their prevalence, impact, effectiveness of available prevention/treatment, importance in older people, feasibility of measurement, and the potential for quality improvement. The indicators were designed to represent processes of care that have been linked to improved outcomes in each of these conditions, and were constructed with input from an expert panel of clinicians, who were asked to review and score the degree to which the indicators reflected good practice in the UK. All indicators were intended to assess the quality of the delivery of care to a minimum acceptable standard, rather than the optimal level (Steel et al., 2008), and are based on individual self-reported by patients.

#### *Cognitive function*

ELSA includes a range of measures of cognitive function memory, executive function, numerical ability, and literacy measured in face to face interviews at each wave.

## Overview of thesis

(A). Systematic literature reviews of studies investigating (i) the impact of cognitive function on the quality of primary care; (ii) the impact of cognitive function on health care use; (iii) factors affecting the quality of primary care.

(B). Develop an theoretical economic model to describe the factors affecting the quality of care and the role of cognitive function.

(C). Assemble data for analysis, including: obtain ELSA data with PCT codes; manipulate these data into an appropriate format for estimation; and, link area level demand- and supply-side variables.

(D). Explore the impact of cognitive function on the quality of care at the individual level by estimating the following relationships using regression analysis:

$$q_{it} = f_1(\delta_i, C_{it}, Z_{1it}, Z_{2jt}) + \varepsilon_q \quad \text{Eq. [1]}$$

where  $q_{it}$  is the quality of care received by individual  $i$  at time  $t$ ,  $C$  is cognitive function,  $Z_1$  and  $Z_2$  are individual and area level factors (respectively) likely to affect quality such as age, gender, schooling, wealth and GP supply (each individual  $i$  is located in area  $j$ ), the  $\delta$ 's are the coefficients to be estimated and  $\varepsilon$  is an error term. We will analyse 32 indicators of quality of primary care recorded in ELSA.

(E). Investigate the impact of cognitive function on socioeconomic-related inequality in the quality of primary care using a concentration index approach (see, e.g., Wagstaff et al., 1991). This will measure the concentration of appropriate quality of care for each of the 32 measures against wealth rank. We will then measure the contribution of cognitive function to the measured inequality by decomposing the calculated concentration index (van Doorslaer and Koolman, 2004), based on the regression model in Eq.[1].

## Examples of quality of care indicators included in ELSA

### Diabetes mellitus

IF a person aged 50 or older has diabetes, THEN his or her glycosylated haemoglobin or fructosamine level should be measured at least annually.

### Urinary incontinence

IF a person aged 50 or older has new urinary incontinence that persists for over 1 month or urinary incontinence at the time of a new evaluation, THEN a dipstick urinalysis and/or mid-stream urine sample should be obtained.

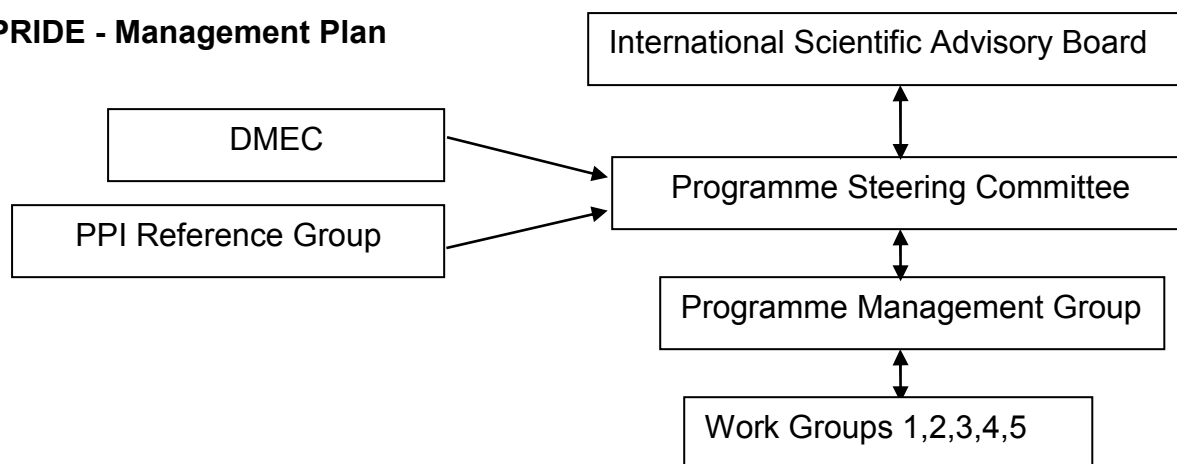
### Pain

IF a person aged 50 or older has a newly reported chronic painful condition, THEN treatment should be offered.

## References

- Steel, N., Bachmann, M., Maisey, S., Shekelle, P., Breeze, E., Marmot, M., Melzer, D. 2008. Self reported receipt of care consistent with 32 quality indicators: national population survey of adults aged 50 or more in England. *British Medical Journal* 337a:957
- Van Doorslaer E., Koolman X. Explaining the differences in income-related health inequalities across European countries. *Health Econ* 2004; 13: 609-628.
- Wagstaff A., Paci P., van Doorslaer E. On the measurement of inequalities in health. *Soc Sci Med* 1991; 33: 545-57.

## PRIDE - Management Plan



**International Scientific Advisory Board** - This will be chaired by Prof Myrra Vernooij-Dassen - also Chair of the European INTERDEM research network and include other INTERDEM representatives. It will meet annually and advise on the overall strategy of the PRIDE programme, management and research methods, and capacity development work.

**Programme Steering Committee (PSC)** - This will oversee the entire programme with an independent Chair and other independent members including carer/PPI representatives, the Programme Lead (MO) and other coapplicants will be invited as appropriate. The Data Monitoring and Ethics Committee (DMEC) will be a subcommittee of the PSC and also have an independent Chair, statistician and two other members plus the Programme Statistician (Rumana Omar). Both the PSC and DMEC will meet biannually.

**Programme Management Group (PMG)** - This bimonthly group will carry operational responsibility for the delivery of the Programme and comprise the programme lead MO, programme manager, Work Group Leads and PPI representatives. As PRIDE progresses other collaborators will attend as needed.

**PRIMENT Clinical Trials Unit** - this provides trial management, data management, quality control, statistics, methodology support, and blinded web based randomisation. We consulted the Research Design Service in the preparation of this proposal.

**Work Groups** - Each work group will be responsible for one work packages and be led by a senior applicant(s), and include the programme manager, a PPI representative and the specific research team. These will meet regularly during the course of the specific work packages. Project management methods will include detailed work plans, weekly management meetings, and regular supervision sessions. Teleconferences will be used to coordinate progress across sites. (applicants/researchers - initials)

WP1: Longitudinal changes in lifestyle, cognition and ageing (ASt,EO,RO,EH,SMo)

WP2: Social and personal constructs of dementia (FP,PH,GC,UH,DP)

WP3: Development and piloting of the social intervention (SMi,EA,EMC,GM,DC,AX,EH)

WP4: Randomised controlled trial of social intervention (RO,SMo,SMi,DP,GR,RH,DC,MO)

WP5: Career development and capacity building (FV, MO, ASp, EMC)

### **Public Patient Involvement (PPI) Reference Group (FP/UH/DP/AH/EA)**

This biannual group will oversee all aspects of carer/user involvement and report directly to the PSC. It will be chaired by Fiona Poland (FP) the coapplicant lead for PPI, who has extensive experience working with users and the voluntary sector. FP wrote the PPI policy for the SHIELD programme. FP and EA plus the carer coapplicants (David Prothero/Ula Htay) will ensure involvement of carers, people with dementia and members of the voluntary sector (Andrew Haines) in study planning and implementation to encourage input, to enhance experiences of participants in the study, and to maintain relevance to stakeholders and policy. People with dementia and carers will be consultants (opinions on information sheets/consent forms, focus groups) and collaborators (pilots of training packages, training project staff). We work closely with DENDRON PPI, Age Concern UK and Dementia UK. Dr Elisa Aguirre worked for 5 years with the Alzheimer's Society.



## **Dementia: prevention, intervention and care**

### **Additional costs proforma: NHS support and treatment costs**

This form is used to clarify costs you are requesting from the NHS and the Department of Health (DH) as part of your application for ESRC and NIHR funding. Any funds you wish to receive from the NHS or DH should be entered on this form and not in the Resources or Costs section of your Je-S application. Entering NHS costs in these sections of your Je-S application could invalidate your proposal.

Justification for the costs detailed in this form must be clearly provided in your **Justification of Resources** document. Please also note that any award from the ESRC will not include NHS Support costs or NHS Excess Treatment Costs/Savings. These will be paid directly from the NHS/DH.

Applicants should read the guidance documents referred to in the Guidance notes for applicants [www.esrc.ac.uk/dementia](http://www.esrc.ac.uk/dementia)

#### **Section 1: NHS costs in context**

*This section is designed as a form cover-sheet for reviewers and may be completed after the subsequent sections.*

1.1 Please state the value of funding you are seeking from each source at 100% FEC.

Research costs £	4964421
NHS Costs £	227240
Total Value £	5191661

## Section 2: NHS Support Costs

2.1 Please complete the following table

Description of expected additional procedures/resource requirements	Cost per patient	Year 1 £	Year 2 £	Year 3 £	Year 4 £	Year 5 £	Overall Total £
Contact with NHS staff and meetings for ELSA cohort interviews x 60	40	300	900	900	300	0	2400
Contact with NHS staff and meetings for memory services cohort interviews for x 60	80	600	1800	1800	600	0	4800
Screening for memory services cohort, meetings, discussions with NHS staff, checking clinical records x 1500	60	10000	70000	10000	0	0	90000
Consenting and registering memory services cohort x 600	80	4000	41000	3000	0	0	48000
Screening and consent to social intervention trial, meetings, checking clinical records x 450	60	0	10000	17000	0	0	27000
<b>Total NHS Support Costs</b>	<b>0</b>	<b>14900</b>	<b>123700</b>	<b>32700</b>	<b>900</b>	<b>0</b>	<b>172200</b>

2.2 Have you discussed these costs with your proposed NHS funding partner? Yes

### Section 3: Estimated Treatment costs

Provide an estimate of the treatment costs involved in the research (and which would continue assuming that the patient care service in question continued after the research activity has stopped), along with the costs of the usual standard treatment of the condition. These costs should be determined in conjunction with your NHS Trust partner(s) and their commissioners

3.1 Please complete the following table

Description of expected resources required or released	Cost per patient	Year 1 £	Year 2 £	Year 3 £	Year 4 £	Year 5 £	Overall Total £
Social interventions provided by dementia advisors, assessment, planning, travel, support, follow up staff training x 260	211.69	0	10000	40000	5040	0	55040
	0	0	0	0	0	0	0
	0	0	0	0	0	0	0
	0	0	0	0	0	0	0
	0	0	0	0	0	0	0
<b>Total NHS Treatment Costs</b>	<b>0</b>	<b>0</b>	<b>10000</b>	<b>40000</b>	<b>5040</b>	<b>0</b>	<b>55040</b>

3.2 Is the patient care being provided different from the usual standard treatment for the condition? Yes

If you answered 'Yes' to 3.2 please complete Section 4: Estimated Treatment costs (continued).

## Section 4: Estimated Treatment costs (continued)

4.1 Please complete the following table only if you have answered 'Yes' to 3.2.

Usual Treatment Costs Description of expected resources required or released	Cost per patient	Year 1 £	Year 2 £	Year 3 £	Year 4 £	Year 5 £	Overall Total £
Information and support from memory services x 450	20	2000	3000	3240	2000	0	10240
	0	0	0	0	0	0	0
	0	0	0	0	0	0	0
	0	0	0	0	0	0	0
	0	0	0	0	0	0	0
<b>Total NHS Unusual Treatment Costs</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>

Em atendimento ao solicitado pela COPROJ informo que não existe uma cópia impressa original assinada pelas partes porque a minuta de convênio foi originalmente assinada em vias separadas por cada uma das dez partes (dez Universidades em países diferentes), em seguida as folhas assinadas foram reunidas em um único documento enviado por email para todas as partes, tendo validade legal, conforme a cláusula 24.1 (regras para assinatura do convênio):

24.1 This Agreement may be executed in any number of counterparts, and by the Parties on separate counterparts, each of which so executed and delivered shall constitute one and the same instrument. Each party agrees that the delivery of this Agreement by email shall have the same force and effect as delivery of original signatures and that each Party may use such PDF/JPEG signatures as evidence of the execution and delivery of this Agreement by all parties to the same extent that an original signature could be used.

24.1 Este Contrato pode ser assinado em qualquer número de vias e pelas Partes em vias separadas, cada uma das quais após ter sido assinada e entregue constitui um e o mesmo instrumento. Cada Parte concorda que a entrega desse Acordo por e-mail deverá ter a mesma força e efeito que a entrega de assinaturas originais e que cada Parte poderá usar tais assinaturas em PDF/JPEG como evidência da assinatura e entrega desse Acordo por todas as Partes da mesma medida que uma assinatura original poderia ser utilizada.

Florianópolis, 06 de fevereiro de 2017



Eleonora d'Orsi

## PRÓ-REITORIA DE PLANEJAMENTO E ORÇAMENTO

## EXTRATO DE CONVÊNIO Nº 2016/0120

UNIVERSIDADE FEDERAL DE SANTA CATARINA - UFSC e a UNIVERSITY OF NOTTINGHAM - NOTTINGHAM. Objeto: Execução do projeto "Promovendo a Independência na Demência" Vigência: O presente instrumento entrará em vigor em 01 de março de 2014 e terminará em 28 de fevereiro de 2019. Data de assinatura: 03/11/2016. Valor: 139.000,00 LIBRAS ESTERLINAS. Convênio UFSC: 2016/0120. Processo SPA: 23080.056328/2016-17.

## EXTRATOS DE REGISTROS DE PREÇOS

Processo: 23080.056943/2016-15. Modalidade: Pregão Eletrônico 018/2017. Vigência: 22/02/2017 a 21/02/2018. Objeto: Registro de preço para a eventual aquisição de materiais elétricos para atender as demandas de manutenção elétrica.  
Fornecedor: 09.548.709/0001-09 - HBJ Comércio de Materiais de Construção Eireli - ME. Valor total registrado: R\$ 530,00.

Fornecedor: 04.176.836/0001-00 - RC Teive Comércio e Distribuição Ltda - EPP. Valor total registrado: R\$ 7.190,50.  
Fornecedor: 25.329.901/0001-52 - MGS Brasil Distribuidora Ltda - EPP. Valor total registrado: R\$ 3.311,00.  
Fornecedor: 85.392.678/0001-10 - Nacional Comércio de Ferragens Ltda - ME. Valor total registrado: R\$ 10.251,00.  
Fornecedor: 26.507.653/0001-55 - Volt Materiais Elétricos Eireli - ME. Valor total registrado: R\$ 6.891,50.

Processo: 23080.041753/2016-01. Modalidade: Pregão Eletrônico 364/2016. Vigência: 22/02/2017 a 21/02/2018. Objeto: Registro de preço para a eventual aquisição de materiais diversos para atender ao Campus Curitibaanos.  
Fornecedor: 08.255.734/0001-23 - PH Mídia Informática Ltda - EPP. Valor total registrado: R\$ 5.962,00.  
Fornecedor: 05.999.532/0001-06 - Condufibra Distribuidora de Cabos e Conectividade Ltda. Valor total registrado: R\$ 15.650,00.  
Fornecedor: 59.378.174/0001-35 - YT Bortholin Comércio e Distribuição Ltda - ME. Valor total registrado: R\$ 3.425,80.

Fornecedor: 85.093.524/0001-27 - Nitrosem Produtos Agropecuários Ltda - EPP. Valor total registrado: R\$ 12.450,00.  
Fornecedor: 18.995.383/0001-40 - Thaline Huyer da Roza - ME. Valor total registrado: R\$ 5.250,00.  
Fornecedor: 12.903.455/0001-04 - Licitamix Materiais de Escritório Ltda - ME. Valor total registrado: R\$ 1.650,00.  
Fornecedor: 14.790.131/0001-24 - Intelix Tecnologia Eireli - EPP. Valor total registrado: R\$ 1.264,80.  
Fornecedor: 15.807.911/0001-00 - Master Comércio de Tapetes Ltda - ME. Valor total registrado: R\$ 60.000,00.  
Fornecedor: 13.993.669/0001-73 - Embala Tudo Indústria e Comércio de Embalagens Eireli. Valor total registrado: R\$ 614,40.  
Fornecedor: 07.174.735/0001-80 - Oxigênio Joaçaba Comércio de Gases Atmosféricos E Produtos para Saúde Ltda EPP. Valor total registrado: R\$ 5.700,00.

## UNIVERSIDADE FEDERAL DE SANTA MARIA

EDITAL Nº 24, DE 17 DE FEVEREIRO DE 2017  
HOMOLOGAÇÃO DE CONCURSO PÚBLICO

O VICE-REITOR DA UNIVERSIDADE FEDERAL DE SANTA MARIA, no exercício da Reitoria e no uso de suas atribuições legais e estatutárias, considerando o Parecer exarado pela Comissão de Legislação e Normas e a decisão "Ad Referendum" do Conselho de Ensino, Pesquisa e Extensão em 10/02/2017, resolve divulgar que o seguinte Concurso Público para Docente foi homologado:

Edital de Abertura de Concurso Público N. 162, de 21 de dezembro de 2015, publicado no DOU de 24 de dezembro de 2015.

Edital de Divulgação de Resultado N. 007, de 16 de janeiro de 2017, publicado na imprensa local e no sítio da UFSM dia 18 de janeiro de 2017.

Processo N. 23081.012397/2015-10

PROFESSOR ADJUNTO A

Departamento de Defesa Fitossanitária/Centro de Ciências Rurais

Área: Matologia (Herbologia/Plantas Daninhas)

Candidato classificado	Nota final	Classificação
André da Rosa Uguim	8,32	1º lugar
Keli Souza da Silva	7,62	2º lugar

O prazo de validade do Concurso Público é de um ano a contar da publicação da homologação no Diário Oficial da União, conforme legislação vigente.

PAULO BAYARD DIAS GONÇALVES

EDITAL Nº 25, DE 20 DE FEVEREIRO DE 2017  
CONCURSO PÚBLICO PARA DOCENTES DO MAGISTÉRIO SUPERIOR

O VICE-REITOR DA UNIVERSIDADE FEDERAL DE SANTA MARIA, no exercício da Reitoria e no uso de suas atribuições legais e estatutárias, considerando o disposto no Art. 37 e Art. 207 da Constituição Federal, o Art. 11 da Lei N. 8.112, de 11/12/1990, o Decreto N. 3.298, de 20/12/1999, o Decreto N. 6.944, de 21/08/2009, a Súmula N. 45/2009, da Advocacia Geral da União, a Portaria MEC N. 243, de 03/03/2011, o Decreto N. 7.485 de 18/05/2011, a Resolução N. 019/2012 da UFSM, a Lei N. 12.772, de 28/12/2012, a Lei N. 12.863, de 24/09/2013, a Resolução N. 030/2013 da UFSM, a Lei N. 12.990, de 09/06/2014, e o Decreto N. 8.368, de 02/12/2014, torna pública a abertura de inscrições para Concurso Público destinado ao provimento de cargos da Carreira de Magistério Superior da Universidade Federal de Santa Maria, nas classes de Professor Adjunto A e Professor Assistente A, nas cidades de Palmeira das Missões e Santa Maria, nas condições previstas neste Edital e demais instrumentos reguladores do concurso.

## 2. QUADRO DE VAGAS

Nº de vagas	Campus de lotação do Docente/Cidade	Depto de realização do Concurso Público/ Centro	Área	Cargo/ Classe/ Nível	Regime de Trabalho	Requisitos	Valor da inscrição	Remuneração
1	Palmeira das Missões	Ciências Econômicas/ Campus de Palmeira das Missões	Economia Monetária e Fiscal/ Teoria Monetária e Financeira	Professor Adjunto A, Nível 1	Dedicação Exclusiva	Graduação em Economia e Doutorado em Economia ou Desenvolvimento Econômico ou Economia Regional e Urbana ou Economia da Indústria e da Tecnologia ou Economia Aplicada	R\$ 239,00	R\$ 9.570,41
1	Santa Maria	Artes Cênicas/ Centro de Artes e Letras	Teatro (Teoria Teatral)	Professor Adjunto A, Nível 1	Dedicação Exclusiva	Graduação em Artes Cênicas ou Teatro ou Teoria Teatral ou Licenciatura em Teatro e Mestrado em Letras ou Teatro ou História e Doutorado em Letras ou Teatro ou História	R\$ 239,00	R\$ 9.570,41
1	Santa Maria	Direito/ Centro de Ciências Sociais e Humanas	Direito Público/ Direito Administrativo	Professor Adjunto A, Nível 1	Dedicação Exclusiva	Graduação em Direito e Doutorado em Direito ou áreas afins	R\$ 239,00	R\$ 9.570,41
1	Santa Maria	Documentação/ Centro de Ciências Sociais e Humanas	Ciências Sociais Aplicadas/ Ciência da Informação/ Arquivologia	Professor Assistente A, Nível 1	Dedicação Exclusiva	Graduação em Arquivologia e Mestrado nas áreas de Arquivologia ou Patrimônio Cultural ou Ciências da Informação ou Administração ou História ou Educação ou Letras ou Engenharia de Produção ou Sociologia ou Comunicação ou Sistema de Informação e demais áreas afins	R\$ 164,00	R\$ 6.586,66
1	Santa Maria	Engenharia Sanitária e Ambiental/ Centro de Tecnologia	Engenharia Hidráulica	Professor Adjunto A, Nível 1	Dedicação Exclusiva	Graduação em Engenharia Civil ou Engenharia Sanitária ou Engenharia Sanitária e Ambiental ou Engenharia Ambiental e Sanitária ou Engenharia Hídrica e Doutorado em Engenharias ou áreas afins	R\$ 239,00	R\$ 9.570,41
1	Santa Maria	Estruturas e Construção Civil/ Centro de Tecnologia	Engenharia Civil/ Construção Civil	Professor Adjunto A, Nível 1	Dedicação Exclusiva	Graduação em Engenharia ou Arquitetura e Doutorado em Engenharia	R\$ 239,00	R\$ 9.570,41

## 3. DAS INSCRIÇÕES

3.1. Modalidade: via internet, exclusivamente no endereço eletrônico [www.ufsm.br/concurso](http://www.ufsm.br/concurso).

3.2. Período e horário (observando o horário oficial de Brasília): Início: 09h do dia 22 de fevereiro de 2017 (quarta-feira). Término: 23h59min do dia 23 de março de 2017 (quinta-feira)

## 3.3. Procedimentos para inscrição

a) acessar o endereço eletrônico [www.ufsm.br/concurso](http://www.ufsm.br/concurso), no período previsto no subitem 3.2;

b) clicar sobre o link "Inscrições em andamento";

c) acessar a página do Edital, ler atentamente o Edital do Concurso Público e demais orientações;

d) clicar no link "Inscrições On-line";

e) selecionar, dentre as opções de inscrição, aquela para a qual deseja concorrer;

f) selecionar a cota para a qual deseja concorrer (ampla concorrência ou vagas reservadas a deficientes ou vagas reservadas a negros);

g) preencher adequadamente os dados do candidato no requerimento de inscrição, observando o preenchimento obrigatório dos campos marcados com um asterisco (\*);

h) clicar em "Finalizar";

i) se a inscrição for finalizada corretamente, aparecerá na tela "Inscrição solicitada". Nesta mesma tela, aparecerá o link "Gerar GRU". Clicar sobre a figura para gerar e imprimir a Guia de Recolhimento da União (GRU) para pagamento.

j) Em caso de solicitação de isenção de taxa de inscrição, proceder conforme item 3.4.;

k) Valor da inscrição:

- Adjunto A, Nível 1 (Dedicação Exclusiva): R\$ 239,00 (duzentos e trinta e nove reais);

- Assistente A, Nível 1 (Dedicação Exclusiva): R\$ 164,00 (cento e sessenta e quatro reais);

l) O pagamento da inscrição deverá ser efetuado no Banco do Brasil até o dia 24/03/2017 (sexta-feira), conforme expediente bancário;

m) O valor da inscrição, uma vez pago, não será restituído em hipótese alguma por solicitação do candidato;

n) São considerados documentos válidos para a inscrição: carteira de identidade; carteiras expedidas pelos Comandos Militares, pelos Corpos de Bombeiros Militares; pelos órgãos fiscalizadores de Exercício Profissional (órgãos, conselhos); passaporte; carteiras funcionais do Ministério Público e as expedidas por órgão público que, por Lei Federal, valem como identificação; carteira de trabalho e carteira nacional de habilitação (dentro do prazo de validade);

o) A UFSM não se responsabilizará por solicitação de inscrição não recebida por motivos de ordem técnica dos computadores, falhas de comunicação, congestionamento das linhas de comunicação, bem como outros fatores que impossibilitem a transferência de dados;

p) Os requisitos básicos para investidura no cargo serão exigidos por ocasião do provimento, de acordo com o que dispõe o Art. 5º da Lei N. 8.112/90, o Art. 207 da Constituição Federal, a Lei N. 9.515/97 e a Lei N. 12.772/2012.

q) A inscrição somente será efetivada após a confirmação do pagamento da inscrição. O comprovante de inscrição do candidato estará disponível para impressão na página [www.ufsm.br/concurso](http://www.ufsm.br/concurso), após a compensação bancária, que ocorrerá em até cinco dias úteis após o pagamento da GRU ou após a divulgação do deferimento do pedido de inscrição.