JPND Healthcare Research Workshop: London, 31 March 2011

Final Report

1. Introduction and background to the JPND

The EU Joint Programme on Neurodegenerative Disease Research (JPND), in particular Alzheimer's disease, has been established by 23 European countries to address the growing societal challenge presented by age-related neurodegeneration. This initiative spans the biomedical, healthcare and social science agendas, and seeks to improve the scientific understanding of neurodegenerative disorders, provide new approaches for their prevention, diagnosis and treatment, and ensure effective provision of health and social care and support, so that individuals can receive optimum care at all stages of their illness.

The first goal of the initiative is to establish a joint 'Strategic Research Agenda' to guide research activity and investment over the coming decade. To provide a basis for this, three thematic meetings were held with academic opinion leaders in neurodegeneration (ND) research during March 2011, with the aim of providing a Europe-wide view of the research opportunities and needs of the field, and highlight priorities for action in the near and longer term. The outputs of the thematic meetings will be further developed through consultation with key stakeholder groups, for example industry and organisations representing patient/carer groups and healthcare professionals, and integrated to provide a holistic view of the research landscape and a roadmap for future research activity. This will be achieved through a further opinion leader workshop in June, spanning the three themes, and continued consultation with stakeholder groups and policy makers. The JPND Strategic Research Agenda will be published at the end of 2011.

2. Aim and output of the Healthcare Research scientific workshop

This report provides a summary of the key outputs from a workshop held in London on 31 March 2011 with academic opinion leaders in health and social care research pertinent to neurodegeneration. The following sections provide a brief overview of the current 'state-of-play' in this research domain, and highlight the consensus view of research opportunities as well as the key requirements for progress, leading to some recommendations to be considered under the JPND strategic research agenda.

Information on the 'state of play' for clinical research into neurodegenerative diseases was supplied by the workshop 'theme leaders' (see Annex) and integrated with the gaps identified during the workshop. For the sections on 'Opportunities' and 'Needs', points identified during the workshop were integrated and context added by the theme leaders where appropriate.

3. State of play and gaps in our knowledge

Introduction

Neurodegenerative disorders have major impacts on individuals with these diseases, on their families and on the wider society. How individuals and communities perceive and react to neurodegenerative diseases (NDD) also influences the course of the disease and its consequences. Each of a number of disciplines – for example the social sciences (such as sociology), behavioural sciences (such as psychology), economics and health services research - has important roles to play in developing, conducting and interpreting research that has the potential to prevent or delay NDD, to improve their treatment and management, to improve the quality of life of patients/users and carers (unpaid family caregivers), to change the societal response to NDD, and to secure the better and more cost-effective use of individual and societal resources. 'Healthcare research', as the term is used in this JPND initiative, encompasses a wide range of research areas, including disease aetiology, prevention, epidemiology, need, disability, independence and autonomy, social participation, healthcare services, social care, housing, informal (unpaid) care, financing and economics more generally, policy and decision-making. Throughout this report we therefore use the term healthcare research in a much broader way than might conventionally be the case.

The following section sets out our current level of understanding and highlights the critical gaps in our knowledge that should be addressed. Gaps were considered by participants within a series of discussion groups, further details of which can be found in the Annex to the report.

Disease aetiology

Public health is about harnessing the best evidence on prevention, treatment and management of health conditions to optimise population health. Public health research concerns the generation, assembly and integration of evidence to achieve this on a continuous basis. Epidemiological research is a key part of this, and provides the contextual base for understanding research outputs. Epidemiological research can include population cohorts, populations at particular risk (e.g. occupational), case control studies, population-based case series and studies which can identify a denominator population. Population studies can also provide a base for bolt-on multidisciplinary studies with other designs, including qualitative methods, which add value in ensuring the findings are more generalisable.

Epidemiological studies have a role to play in the continuing search for risk and protective factors across disease life-course, including understanding the causality and natural history of relevant risks from biological and pathological perspectives. A comprehensive knowledge of risk and protective factors for all NDD is key if future prevention and intervention strategies are to be successful. Current knowledge of risk factors is limited in relation to the natural course of disease, especially the 'middle' phase, while the influence and impact of comorbidities in relation to NDD remains unclear. We also need to know more about the protective function of both an active social life (including social contacts) and use of physical and cognitive abilities in mitigating the risk of developing NDD. Lastly, the roles and influences of cohort effects are not well understood, including environmental characteristics (physical, supportive etc) and cultural issues. Overall, and particularly in relation to comorbidities, there is a need to better understand experience and coping strategies of the person with the disorder and their paid and unpaid carers.

Outcome and outcome measures

Some NDDs, especially dementia, carry a stigma and have a negative public image in which the person is often portrayed as being totally incapacitated. In reality, capacity is not 'all or nothing' but is domain-specific and fluctuates throughout any one day and throughout the course of the disease. Understanding the relationship between

functional measures or readouts and the underlying components of disease-associated disability is needed. It is crucial to have a good understanding of what individuals and societies want, as this should structure the relevant target end-points for policy and practice, and therefore help to define the outcomes pertinent to patients, users and carers. It is not clear that sufficient research has been done to gain such an understanding of preferences, with the historical focus having been on (externally defined) measures of need. Today it is widely recognised that outcomes should be - but have still generally *not* been – defined and measured so as to be consistent with the well-established emphasis on person-centred care and the growing emphasis on self-directed support. In turn this requires research that reconciles the differences in conceptual framework between patient/user, carer and clinical perspectives. There has been enormous progress in recent years in the development and validation of outcome measures in psychosocial dementia care. These include measures of needs assessment and quality of life (QoL). However, not all outcomes are sensitive enough to change to enable measurement of the effects of person-centred care and self-directed support on the key stakeholders: patients/users, carers, care practitioners and clinical professionals.

Progress has also been made in relation to the description of care systems across Europe. A logical next step should be to invest in the further development of conceptual frameworks to include the full range of influences on a person's quality of life. This will require that we include the perspectives of patients/users, carers and practitioners in order to better understand their roles in the process of NDD and to better describe the influence of different care systems across Europe on outcomes and costs. Outcome measures need to be seen in their social context, influenced by comorbidities, the actions of others, human and social capital.

Most people involved in the care and treatment of people stress the importance of QoL, but there remain numerous methodological challenges in its measurement. One task is to move away from sole reliance on deficit-dominated approaches to the interpretation of QoL to approaches that give more weight to broader (less pathological) interpretations of well-being. Another task is to invest in generic measures that allow cost-effectiveness comparisons to be made, not only between different treatments for one specific disorder, but also between treatments of different disorders. This implies a need for both disease-specific and generic QoL instruments. The best known of the latter is the Quality Adjusted Life Year (QALY), but its use is not without conceptual and methodological difficulty in the NDD field, and further developmental work is needed. The measurement of other outcomes, such as functional and cognitive dimensions, could also be improved.

Another 'outcome' measure in need of more attention is the cost of care and support. There is little quantitative evidence on the resources needed and used by people with various NDDs, or the associated costs. Outcomes and costs are defined and measured at an individual level but are influenced, perhaps heavily, by care and support systems and by wider contextual factors. There is a need for a better understanding of these influences across the European landscape. Since most NDD are progressive and long-term conditions, both formal care systems (particularly medical and social care) and informal care are involved and interact in complex ways. It would be very helpful to discuss and if possible to harmonise key concepts (such as the meaning of 'long-term care') across countries in order to facilitate comparative research and improve the transportability of evidence.

Interventions and disability

One of the key research gaps that needs to be addressed regarding interventions in this area is how health, social care and related systems can ensure that interventions are matched to needs in a context where the individual with an NDD has the opportunity to exercise choice and perhaps control. Empowering people to help themselves (health education and self-management) has been increasingly

emphasised in many European countries in recent years, yet the evidence base on which such policies and practices can be constructed remains very limited.

Research is needed on how to improve the timeliness of interventions, considering both impairment and abilities and avoiding side-effects. Linked to this is our limited understanding of how health and wellbeing promotion strategies are adopted, and the barriers to them. There is also a need to assess the effectiveness of interventions and the best way to implement them on a *broad scale*, i.e. beyond the unreal confines of trials. Many studies have found that proxy respondents' replies (acting on behalf of users/patients) to questionnaires and rating sales vary quite markedly from responses given by the individuals with NDDs. Research is needed to understand and reconcile these differences. A linked gap is our understanding of the appropriate or ideal unit for measurement: is it the individual with an NDD, their household (thereby incorporating the effects on the QoL of carers) or some wider context such as the community? More generally, there needs to be better recognition of the relevance of carer and community QoL in some types of research.

4. Opportunities and needs

Introduction

Research opportunities and priorities were highlighted in the discussion groups throughout the day, and have been collated under broad headings that provide the most coherence to the emerging themes. While the focus of the meeting was very much on research, it was notable that some of the identified opportunities were linked to the structure of, and potential changes to, health and social care systems across Europe, where there exist quite marked national and regional differences in the ways that treatment, care and support are financed, commissioned, delivered and regulated. The various discussions also emphasised the need to ensure the effective translation of research outcomes and best practice into policy and practice across the breadth of the EU.

Health and social care systems and linked policy approaches

In order to respond to the needs and preferences of populations that are aged and ageing, existing health and care services will need to be re-engineered ideally so that they are more patient/user-friendly and provide individualised care and support. Reducing segmentation of the care sector and evaluating alternatives for long-term care are two priorities that could help improve service effectiveness, cost-effectiveness and efficiency in the long-term. While long-term care facilities such as hospitals and care homes are important for some people at some stages of their lives, there is a need to evaluate and encourage alternatives (e.g. more home/community-based support). Additionally, the established systems should aim to implement (and evaluate) integrated healthcare programmes to ensure a joined-up approach across domains. To support this approach, a 'map' of care and support systems across Europe should be established.

In the broadest sense it was proposed that underlying illness and disability should be tackled earlier and the commonly reported lack of care and intervention after diagnosis addressed. One possible way of facilitating the latter is to encourage greater involvement of relatives and carers. Similarly, individuals could be empowered by utilising assisted living and other technologies. Overall, models of engagement need to be improved and systems need to recognise that dealing with NDD is only one part of a person's needs. Translating recognised classifications systems, such as WHO's International Classification of Functioning, Disability and Health (ICF), into the context of NDD might help address this.

From a policy perspective, improved ethical frameworks for issues relating to end-of-life decisions in NDDs are required, as is the better implementation of new technologies. Within this, policy makers should look to increase cooperation with

technology developers to ensure that there is real consideration of individual use of (everyday) technology. In this context, educating businesses and encouraging them to release the sizeable NDD 'Euro' by thinking of ways to enable large numbers of increasingly elderly patients/users and their families to remain in the community would have the dual benefit of improving QoL and contributing to local economies (e.g. through increased buying of goods and services).

In terms of implementing change, it was considered that there can often be resistance to the 'tyranny of the new' and that incremental 'nudging' should be encouraged as the best way to move the field forward. Potentially, promotion of funding mechanisms that encourage inclusion of novelty (funding for 'high-risk, high-gain' studies), health economic components and implementation strategies could be used as a driver.

Training and education

A recurring theme throughout the workshop was the need to de-stigmatise dementia and other NDDs, which could be aided through the delivery of pan-European studies and networks. This in turn could help participation rates in research, which are currently declining, making the aspiration of population representation difficult in many countries. Overall it was felt that improving public awareness through better education of society would ultimately aid disease prevention and facilitate social inclusion of individuals with NDD and their carers. Developing tools to facilitate communication to and from 'stakeholders' (e.g. individuals with dementia, their families and carers, plus healthcare professionals, care service providers etc) will be essential if successful integration into the wider community is to be achieved.

Improving education and skills training of health and social care practitioners, and in particular their knowledge of the complexity of NDDs and how to offer support that is effective and acceptable, would facilitate earlier and better diagnosis and management of disease. This could bring numerous benefits to the individual and society as a whole. From a research prospective, building capacity in areas of future need, for example in health economics and statistics, will be essential if decisions are to be based on accurate and up-to-date information. Lastly, developing systematic networks that cross disciplines and involve among others clinicians, health service researchers and health economists would encourage cross-fertilisation of ideas, improve overall knowledge and facilitate data-sharing.

One issue is that it is apparent that health and social care research currently has a Northern European emphasis. To address the disparity across the member countries of the JPND, there is a need to ensure outreach from the areas of highest critical mass to help build research capacity and capability across all regions of the EU. This in turn might provide direct benefit in enabling the diversity in healthcare systems and cultures across Europe to be more effectively utilised in the research agenda.

Health and care services research

With respect to the overall research strategy, accessible evidence/analysis-based policies informed by people with NDD and carers, and which incorporate evaluation, should be the benchmark. A key aim should be to ensure that evidence is effectively and efficiently translated into practice so that research affects day-to-day health and social care services. In addition there needs to be effort to improve integration across the full breadth of relevant disciplines (including ethics and sociology) and between different communities (researchers, industry, patients/users, carers etc). Potentially, interdisciplinary research spanning biomedical, social, economics through to ICT, smart-home technologies and engineering could be encouraged through a convergent and flexible infrastructure, as encapsulated in the notion of the 'community-based lab'. There is a clear need to investigate and contrast the effectiveness of different health and social care models and approaches throughout Europe, and determine if an integrated public health framework is the best option. Within this context it was proposed that research into the contribution of the voluntary sector and of volunteers

should be promoted. Research should aim to concentrate on the experiences of people with NDD and could explore not just problems but enabling factors (technologies and social approaches). This could involve studies of the dynamics or interaction between patient/user (and carer) and physical environment. To gain a fuller understanding of the existing situation, population-based QoL studies to assess people who may be outside standard 'care pathways' need to be conducted, ensuring that as far as possible research reaches across cultures, covers potentially stigmatising conditions, and takes account of gender and other important social dimensions. It would be similarly helpful to assess QoL and capability across age groups; middle-age people can be recruited to studies to identify the baseline as they may be easier to focus on than older people who may have other disabilities or be unwell. One major aim of such research should be to narrow the gap between disability and the unmet needs for care, support and help. Related to this, there is a need to further investigate the impact of assisted living interventions on QoL, using a fully integrated, platform-based approach capable of field-testing existing technologies – in other words they need to be investigated in real life settings with all their complexities. Underlying these requirements is a need to develop a systematic understanding of cross-cultural issues and diversity across Europe to facilitate the development of better instruments and implementation of interventions. Similarly, the importance of determining how effective links can be made between evidence and policies was emphasised.

Throughout the workshop the importance of health economics was mentioned, with a need to better understand the cost-effectiveness of pathways to diagnosis, intervention, care and support highlighted. In a broad context there is a natural link between diagnostic procedures and the treatment, care planning and support that follows. Thus it is important to highlight the purpose of diagnostics and determine how to design cost-effectiveness studies with links to treatment. To inform our understanding of the pathways of cost-effectiveness, there is also a need to identify the hidden costs of informal and long-term institutional care (impact on carers etc). The costing of informal care is complicated (because of the difficulties of identifying the hours of support, and then estimating their opportunity cost) but essential. With respect to long-term care (LTC), it is difficult to make comparisons between countries due to the heterogeneity between and within countries. More data are needed on the patterns of informal and long-term care across Europe, particularly from Eastern Europe. As LTC is a major cost driver in NDD care, multinational cost-effectiveness studies (often designed in order to add statistical power) are necessary; however, it will be crucial to use harmonised and simplified LTC concepts. Beyond direct determination of expenditure, cost-effectiveness studies are important to support decisions about resource allocation and priorities. However, the parameters for inclusion in such studies need to be identified, including costs and outcomes, comparative treatment options, and whether outcomes such as QoL or disease burden should be linked to family members and informal carers in addition to patients/users.

Research methodologies

In the broadest sense, workshop participants considered that existing research has a strong theoretical basis and uses appropriate methodology. However, it was emphasised that improved or enhanced techniques and methodologies will be required to enable better understanding of what factors are associated with good outcomes and ensure research is optimally effective in the long-term. For example, to evaluate psychosocial interventions and health service and care pathways, improved qualitative methodologies or mixed methods will be required. Similarly, improved modelling techniques are needed to enable studies of association structures, and qualified methodologies to study person/environment interactions. Participants in the workshop thought it was particularly important to develop alternative QoL scales/measures, given that current Quality of Life Adjusted Year (QALY)-generating tools do not adequately capture all the relevant dimensions of health-related QoL for people with NDD. A second development that would be particularly welcome across the research spectrum is enhanced modelling techniques that facilitate integration of health

economics with other datasets. Due to the limitations of RCTs to capture long-term effects of the treatment of NDDs, problems with generalisability and representativeness, simulation modelling is often used in health economics to supplement trial-based evidence. At the European level it will be essential to ensure (as far as possible) the transferability of models and their results from one country to another.

Standardisation and/or harmonisation of approaches and methods will be necessary to encourage data-sharing across centres and cohorts in order to ensure adequate power and study replication. Of course, while there are significant benefits to a common approach in a number of areas, competition is healthy in others. Accordingly, a strategic approach to achieving the necessary level of standardisation/harmonisation is required. Efforts should focus on the need for clearer definitions for NDD to improve clinical phenotyping, as well as identifying agreed outcome measures for disease that are person-, carer- and family-centred and factor in QoL. Where possible, defined or standardised tools, outcome and cost measures should be made relevant to health economic analyses.

Population and cohort studies

Maximising the potential of existing resources through better and more widespread data collection, record-keeping and data-sharing is likely to be a cost-effective way of delivering research benefit. For example, the relevance of existing cohorts that are not disease-focussed could be evaluated to determine if they could be utilised for NDD research. Secondly, the frequency and quality of data collection could be increased and existing data sets integrated, especially across countries. Population studies should be strengthened by including more sophisticated clinical biomarkers and phenotyping and should also aim to include natural history after onset to allow disease course and determinants to be more carefully mapped. The overarching aim should be to produce shared, translatable databases and to fully integrate registry and cohort data as well as social care information. Building research-based registers for all NDD, utilising best models and practice, is of particular importance, although public acceptance of such registers will be required.

In addition, new long-term studies for generational and cultural variation are needed to account for lifestyle changes in the last 30 years and to investigate novel risk factors. New cohorts could incorporate interventions, and existing cohorts could be used as platforms to trial interventions on well phenotyped participants. New studies should consider the design most appropriate for measuring person-centred care and, wherever possible, seek to capture additional or non-standard data and integrate other disciplines. In future, researchers should ensure that studies are representative of the 'real' population (socio-economically and ethnically diverse etc) and incorporate an understanding of cultural differences into design. In the absence of a representative sample, problems occur when extrapolating results. For example, results from studies that are not population-based run the risk of overestimating costs, while long-term effects on mortality are often underestimated because of the restrictive exclusion criteria employed in many clinical studies. The interrelationship between biology, clinical phenotype and disability needs to be considered as the relationship between QoL and underlying pathophysiology is not always straightforward. Lastly, there is also a need to better understand what motivates participation in studies across the whole spectrum, and then to work to improve participation.

In general, statistical power needs to be increased, necessitating new cross-centre studies employing consistent concepts, methods and approaches that apply across centres and countries. This is especially true for non-AD disorders where the populations available within any one site are likely to be too small to be adequately powered. A further consideration is that most clinical intervention studies to date have been under-powered for assessment of health economic aspects; resource use data often include many zero values (no events), are skewed and show great variability.

Cross-registry studies could potentially be utilised, although they will most likely be limited to assessment of formal care because important data on resource use, quality of diagnosis, outcomes and informal care are often missing. A third option is to merge large ongoing European epidemiological cohort studies on NDD; diagnostics are often good in such studies and significant background variables are included. By definition, registry and cohort studies are non-controlled and so there is a risk that results will be biased. Nevertheless, as a complement to traditional RCTs, and with an awareness of the limitations, registry and cohort studies may be useful.

Prevention and intervention studies

Positive health trends (such as an active lifestyle) and health promotion activities that reduce known general risk factors (such as obesity, smoking, hypertension) may influence the course of NDDs. However, it is not known whether this is due to a reduction of comorbidities or direct disease-modification effects. Despite this, such positive effects may give opportunities for cost-effective preventive strategies. More broadly, there is a need to undertake research to support or encourage normalisation of health promotion and illness prevention.

As a first step, local intervention studies could be conducted to inform the design of cross-country interventions that will be important for increasing study power and assessing variability. Such intervention studies will need to be anchored in an epidemiological/population context, address carer-based and social inclusion, and factor in QoL. They should also aim to avoid 'side effects' that reduce people's ability to retain dignity, enjoy a normal life and make positive contributions to society. In the future it will also be important to support integrated approaches, given that pharmaceutical and social interventions for NDDs are traditionally conducted separately, meaning that synergistic effects are likely to be missed. However, social care intervention concepts will firstly need to be harmonised across Europe.

6. Broad recommendations

In summary, the following health and social care topic areas were identified as those where concerted action at a European-wide level would provide real impact over the coming decade:

- **Population studies:** There is a need to better exploit existing cohorts, including those that are not disease-focussed, through ensuring that datasets can be integrated and shared. New longitudinal studies will be required that address lifestyle changes over the last 30 years and investigate emerging risk factors, while their design should encompass socioeconomic, ethnic and cultural diversity to ensure representativeness; novel study designs may also be considered. An overarching aim should be to provide an integrated registry of standardised cohort data and social care information at the European level.

- **Intervention studies:** These should ideally be anchored in the context of epidemiological / population studies that provide well-phenotyped participants. Improved qualitative methodologies, or mixed models, are needed to evaluate psychosocial and other interventions, as well as treatment and care pathways, while study designs should seek to address comorbidities, assess carer inputs, needs and outcomes, and take full account of social, economic and cultural contexts.

- **Outcome and outcome measures:** There is a need to develop better outcome measures of relevance to patients/users and carers that are person-, carer- and family-centred and which should help reconcile the existing differences in conceptual framework between patient/user, carer and practitioner perspectives. Measurement of quality of life and disability needs to be improved, coupled to a fuller integration of health economics considerations. The growing emphasis on

person-centred care and self-directed support needs to be taken into account in measuring outcomes and designing studies more generally.

- **Health services research:** Across Europe there is an opportunity to investigate and contrast the effectiveness of different health and social care models and approaches. A systematic understanding of cross-cultural issues and diversity across Europe will be needed to facilitate the development of better instruments and the implementation of interventions. Lastly we need to better understand the cost-effectiveness of pathways to diagnosis, care and support and identify the critical parameters for determining resource allocation decisions.

- **Education and networking:** New approaches are needed to disseminate the research outputs and facilitate communication between the various 'stakeholders' in NDD research, in order to aid disease prevention and facilitate the social inclusion and research participation of individuals with NDD and their carers. There is also a need to provide better training (in research appreciation) for health and social care professionals, and support for inclusive research networks that involve statisticians and health economists (among others).

- **Policy:** Effort should be focussed on identifying and overcoming the barriers to the adoption of health and wellbeing promotion strategies, and on enabling the empowerment of affected individuals through, for example, the utilisation of assisted living technologies. Finally there is a need to ensure effective outreach to enhance research capacity and capability across all regions of Europe, and provide routes to effective translation of existing evidence into health and social care services.

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Annex

Workshop location and agenda

Institute of Physics, 76 Portland Place, London, W1B 1NT

Time	Item	Note
10.00h	Introduction	*Chair (Martin Knapp)*
10.10h	JPND and the SRA	*Rob Buckle*
10.20h	EU landscape of neurodegeneration research	*Rob Buckle*
10.40h	Thematic presentations (x4) - 5 minutes	*Theme leads*
11.20h	Introduction to break-out groups (1)	*Chair*
11.30h	Parallel discussion groups (Dimension 1)	*Chaired by theme leads*
12.45h	Report to plenary	*Chaired by theme leads*
13.15h	Lunch	
14.00h	Introduction to break-out groups (2)	*Introduced by chair*
14.10h	Parallel discussion groups (Dimension 2)	*Chaired by theme leads*
15.30h	Break	
15.45h	Report to plenary	*Theme leads*
16.15h	Summary and conclusions	*Discussion lead by chair*
17.00h	End of meeting	

Dimension 1 theme	**Theme leader**
Health and social service research	Jill Manthorpe – King's College London
Epidemiology	Carol Brayne – University of Cambridge
Sociology/community-based research	Myrra Vernooij-Dassen – UMCN
Health economics	Anders Wimo – Karolinska Institute
Dimension 2 theme	**Theme leader**
Prevention	Martin Knapp – London School of Economics
Interventions	Martin Rossor – UCL Institute of Neurology
Disability and quality of life	Thomas Gasser – University of Tübingen & DZNE

Format

The workshop revolved around two structured discussion sessions, with participants allocated to one of three or four break-out groups. The morning and afternoon discussions addressed different topics, related to methodologies and outcomes, with membership of the break-out groups changing between the two sessions to encourage discussion from different perspectives.

Meeting attendees

Gian D Borasio	Centre Hospitalier Universitare Vaudois
Lena Borell	Karolinska Institute
Carol Brayne	University of Cambridge
Alistair Burns	University of Manchester
Brian Caulfield	TRIL & UCD
Jesús De Pedro Cuesta	Institut de Salud Carlos III
Murna Downs	Bradford University
Harriet Finne-Soveri	National Institute for Health and Welfare, Finland
Thomas Gasser	University of Tübingen & DZNE
Claire Goodman	University of Hertfordshire
Susanne Iwarsson	Lund University
John Keady	University of Manchester
Martin Knapp	London School of Economics
Jill Manthorpe	King's College London
Pablo Martinez-Martin	Fundación Reina Sofia
Alain Paraponaris	INSERM
Kaisu Pitkälä	University of Helsinki
Matthias Riepe	University of Ulm
Martin Rossor	Dementia Research Centre, UCL Institute of Neurology
Alberto Rovetta	Politecnico di Milano
Jan Sørensen	University of Southern Denmark
Gerold Stucki	University of Lucerne
Myrra Vernooij-Dassen	Radboud University Nijmegen Medical Centre (UMCN)
Anders Wimo	Karolinska Institute
Bob Woods	Bangor University

JPND staff and observers

Rob Buckle	JPND Management Board, MRC UK
Adriana Maggi	JPND Management Board, MIUR Italy
Sean Greatbanks	JPND WP2, MRC UK
Catherine Moody	JPND WP2, MRC UK
Alexander Pemberton	JPND WP2, MRC UK
Micol Zappa	JPND WP2, MIUR Italy
Marlies Dorlöchter	JPND WP3, BMBF Germany
Petra Pütz	JPND WP3, BMBF Germany
Derick Mitchell	JPND WP4, HRB Ireland
Manuel Romaris	European Commission, DG Research and Innovation