JPND One-to-one Stakeholder Consultation

Introduction and background

EU Joint Programme - Neurodegenerative Disease Research (JPND) is a European Union member state-led initiative to tackle the societal threat posed by NDD as effectively as possible and accelerate progress in the search for solutions, by taking a co-ordinated action and undertaking an innovative research initiative. The development of a Strategic Research Agenda (SRA) is central to the JPND initiative, establishing a platform for future EU-wide activity and a reference point for developing national and organisational strategic plans. The SRA has been developed in an iterative manner reflecting the recommendations identified by the Scientific Advisory Board (SAB) and, wherever possible, stakeholder priorities. To provide a basis for this, thematic meetings were held with key opinion leaders in neurodegeneration (ND) research during the first half of 2011. In order to collect the perspectives of key stakeholder groups who did not engage with the previous questionnaire-consultation exercise and stakeholder workshops, a series of targeted teleconference consultations were held in August-October 2011. Individuals representing Europe-wide organisations or initiatives from the categories listed below were approached for their perspectives on the key issues relevant to their area:

- Assisted-living

- Information and communications technology (ICT)

- Medical devices

- Healthcare providers and professionals

Perspectives obtained through the one-to-one consultations have been fed into the development of the JPND strategic research agenda (SRA), and made publically available through the JPND website.

Summary of responses

Stakeholders from the fields of ICT, assisted-living and medical devices largely provided perspectives on provision of support for patients in the home environment with the aim of extending home stay/maintaining independent living for as long as possible. The views expressed across these fields were more or less in alignment, albeit with slightly different emphases. As might be expected, the views of the medical professionals interviewed under the healthcare providers category were mostly focused on clinical care of patients with neurodegenerative disease.

Across the stakeholder categories the need for improved dissemination of information between stakeholders and in particular to patients and carers was stressed. Similarly, preventing isolation or encouraging social inclusion was considered to be important across all groups and several consultees highlighted the need to educate the public and/or destigmatise disease. Lastly, at least one person from each category emphasised the importance of co-operation and co-ordination between the different sectors. In particular, several people highlighted the current lack of effective co-ordination between the health and social care

sectors and the impact this has on patient care and for development or implementation of new technology.

Diagnosis, treatment and care

Stakeholders from all categories agreed that early/earlier detection of neurodegenerative diseases was vitally important, with the two individuals from the medical device sector emphasising the role their industry could play in delivering this.

Individuals from across stakeholder categories also noted the need for clear, standardised, evidence-based guidelines and pathways for patient assessment, management, care and support to reduce decision making and save time. Within the individual responses, the following points of interest were noted:

- Individual aspects of health and social care systems inadequately address certain aspects of disease at present.

- Care models need to address polymorbidity and reduce the emphasis on pharmacological interventions.

- There is an ongoing need to assess the evidence for use of treatments.

- Healthcare [and social care] staff need to be better trained to deal with people affected by neurodegenerative disease.

Supporting technological development by industry

Both academic and industry stakeholders from the ICT, assisted-living and medical device sectors highlighted that new resources and products are needed to support people with neurodegenerative disease. Though some suitable products exist, and are possibly underused, the general consensus was that insufficient products specifically relevant to neurodegenerative disease are available or being developed. Several consultees highlighted that markets are underdeveloped (e.g. e-health and e-care) and/or fragmented (e.g. ICT/assisted-living solutions), possibly due to the range of cultures, systems, and needs across Europe and a lack of co-operation, information exchange and standardisation across sectors. Collectively, these forces negatively impact, both quantitatively and qualitatively, on the development of new technology. This negative impact is particularly detrimental to the production of technology that caters for the full range of patient needs and to the ability of devices manufactured by different companies and sectors to interact with, and compliment, each other ("interoperability").

Though it was recognised that development in this area largely falls on private industries it was suggested that the public sector and society as a whole could do more to support this effort. Firstly, there needs to be greater co-operation and information exchange between the various stakeholders. For example, more could be done to foster interaction between patients and industry to enable industry to more fully understand the needs of people with disease; the importance of obtaining patient and carer perspectives and determining their needs when using technology (e.g. testing to make design 'person-centred') was raised by multiple consultees.

Secondly, many consultees, both from industry and academia, identified the need for new business models to encourage the development, piloting and delivery of new technology and solutions and to enable them to be financially viable in the long-term. Public-private partnerships to help reimburse R&D costs and economic support via indirect revenue were among the suggestions made. Further to this, it was suggested by several consultees that a more holistic view of costs and cost management for medical technology was required. Approaches incorporating social and economic factors into cost calculations would favour solutions that are cost-effective across the whole health and social care system; however, for this

to work, co-operation between health and social care organisations and industries is essential.

Individual responses

Consultees were asked for opinion and priorities in three areas:

- Healthcare and social care
- Quality of life
- Policy, organisation and infrastructure

Name	Category	Organisation
Benjamin Knapp	Assisted-living	Centre for Affective Solutions for Ambient Living Awareness (CASALA)
Feng Li	Assisted-living/ICT	Newcastle University
Silas Olsson	Assisted-living	Ambient Assisted Living JP
Marcus Merne	Assisted-living	Everon
John Wilkinson	Medical devices	EUCOMED
Hans Hofstraat	Medical devices	Philips
Silvio Bonfiglio	ICT	FIMI/BARCO – OASIS Project
Marc Lange	ICT	European Health Telematics Association (EHTEL)
Laura Pastor	ICT	Universidad Politecnica de Madrid – PERFORM Project
Richard Hughes	Healthcare providers	European Federation of Neurological Societies (EFNS)
Desmond O'Neill	Healthcare providers	European Union Geriatric Medicine Society (EUGMS)
Jacques Van der Vliet	Healthcare providers	Standing Committee of European Doctors (CPME)
Carl E Clarke	Healthcare providers	Association of British Neurologists (ABN)

Reports summarising the full set of 1:1 stakeholder consultation teleconferences are listed below; two include details of relevant European initiatives the consultee is involved in.

Dr Ben Knapp – Assisted-living   **23ʳᵈ August 2011**

Organisation: Centre for Affective Solutions for Ambient Living Awareness (http://www.casala.ie/); Netwell Centre (http://www.netwellcentre.org/) and BRAID Project (http://www.braidproject.eu/)

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Dr Knapp provided comments from the perspective of assisted-living

Healthcare and social care

The Netwell centre is looking at how home environment can be used to support individuals as they age taking into account the specific requirements at different stages i.e. an adaptive AAL home environment.

Specific challenges in relation to neurodegenerative disease are memory loss and mood.

Wandering interventions can be used to address issues relating to memory loss transitioning through three levels as disease progresses: i) alerts to the individual; ii) alerts to informal carers; iii) alerts to formal carers/care structures. Alerts need to be socially acceptable and not cause panic or worry.

Attempts to address mood in relation to neurodegenerative disease are less developed and more research needs to be conducted relating to how the home environment influences mood and what can be done to elevate it. Mood and (lack of) sleep are interlinked; furthermore, research has shown that people affected by Alzheimer's disease have shorter sleep cycles. Interventions in the home aimed at influencing circadian rhythms and improving sleep could be used to elevate mood and potentially reduce memory loss; altering food, music, decor and lighting could all have an impact.

Quality of life

One approach or strategy is to find a way of naturally assessing/self-assessing disease; a 'light touch' approach to assessment should be favoured. Devices in the home can be used to facilitate this in early or moderate disease states; however, design of devices is important in relation to data collection and interaction. Netwell/CASALA has been surveying potential users to work out what is important and how long people are prepared to spend answering questions. Design should be person-centred and must incorporate how individuals feel and assessment of emotional wellbeing and social interaction. Users often need to be encouraged to fill in questionnaires/undertake assessment and this can be facilitated by providing feedback to individuals and intervention where appropriate. Feedback should avoid making individuals feel nervous about their health; for example, fear of memory loss, as opposed to actual memory loss, can often have a significant impact in early stage disease. Assessment can potentially feed into intervention - steps could be taken to improve social interaction in early stage disease and to improve care in mid-stage disease.

Policy, research organisation and infrastructure

Technologists would answer that platforms and standards are required including devices that easily interact with each other.

People with disease or carers often ask what they can do. Accordingly, there is a need to increase awareness of possibilities by improving dissemination of information. Tools such as wikis or web-based discussion fora can potentially be

used to improve communication with stakeholders; BRAID has developed a wiki to address this issue (http://wiki.braidproject.eu/).

Similarly, information relating to companies involved in developing technology/devices in this area is currently fractured. Accordingly, it is difficult to have an accurate idea of what technology is available or being developed and how good it is. A central point of reference (e.g. a portal) and a (standard) set of ratings for available technology would potentially be useful in this regard.

More generally, it is apparent that a number of initiatives at the European level have a degree of overlap and awareness of this within individual projects may be limited; action to 'join up' these activities and avoid unnecessary overlap is to be encouraged. Furthermore, in the past there has been a certain amount of naivety regarding what research, technology etc already exists thus reducing the impact and effectiveness of any findings or recommendations.

Feng Li – Assisted-living/ICT   **7th September 2011**

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Healthcare and social care

The care of older people with neurodegenerative disease is part of a broader societal challenge relating to aging and assisted-living. In the assisted-living field three major issues can be identified:

1. Understanding the problems that occur within existing health and social care systems and how to improve them.

Specific issues are:

- a shortage of funding - additional sources of funding, e.g. from charities or donations, or from commercial revenue streams, will be necessary; however, additional funding will not in itself be sufficient to provide adequate assistance and resolve the problem.

- lack of effective co-ordination between health and social care systems.

- insufficient availability and large scale use of effective solutions involving telehealth, telemedicine and telecare. New digital technologies will have a key role to play in extracting more value out of the existing health and social care systems.

2. Developing a sustainable market

The private and voluntary sectors have a key role to play in developing novel resources and innovative products and services for assisted-living to supplement state provision.

Needs:

- Identify sustainable and scalable ways to improve wellbeing and quality of life. It is important to evaluate the economic dimension of the solutions available when understanding how to deliver a new product or service. Companies and charities are trying to develop sustainable revenue streams to facilitate effective use of pilot products that are not currently financially viable at large scales.

- Identify new business models through which hospitals could save money and companies could earn revenues enabling further investment in new product development and delivery.

3. Determine patient, carer and family perspectives on the technology currently available and in use. Much of the existing care technology and provision is based on assumptions that have not been correctly evaluated from the user and carer perspectives, and as a result some of the available technologies, products and services are insufficiently used.

Quality of life

Near term priorities:

- Develop a common understanding of the nature of the problems and challenges.

- Explore sustainable and scalable business models (commercial models) to enable new ways of delivering services and solutions, especially by innovatively using new digital technologies.

Long term priorities:

- A co-production approach – bringing health and social care organisations and industries together to work out sensible solutions that could save money by distributing costs and sharing services, and develop workable solutions that will benefit the system as a whole.

- Promote new market development around state provision in health and social care, by encouraging private and third sector organisations to develop and deliver new products and services that address social objectives but in financially sustainable fashions.

Policy, organisation and infrastructure

- Different organisations have different priorities and budgets. Policy should encourage organisations to develop solutions that could save money at the level of the entire system and open up new opportunities for them to provide high quality services to people in financially sustainable fashions.

- At a clinical level there is the need to reform the way assistance is provided utilising digital technology and to understand how best to implement new technologies in way that is financially sustainable and commercially viable.

Silas Olsson – Assisted-living   **12th September 2011**

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The views expressed by Silas Olsson are in line with those of the AAL JP but derive from his own knowledge and experience.

Healthcare and social care

People affected by neurodegenerative disease would like to retain their independence and function within society for as long as possible. Support for independence and functioning needs to be addressed by offering a suitable home environment, at least at the beginning of disease, and appropriate social support; home care should be organised in a way that also supports informal carers. In order to assist both patients and carers, there is the need to:

- train informal carers about disease;

- provide remote support for patients and carers - ICT solutions potentially allow healthcare professionals to remotely monitor the status of patients and enable patients and carers to ask for advice and receive feedback from healthcare professionals.

- provide social support i.e. facilitate interaction between patients and their friends, relatives, neighbours and society as a whole.

Quality of life

A need that could be addressed in the near term is improving social support, helping patients to keeping functioning within society for as long as possible.

Finding cures/treatments is ultimately key to improving quality of life but will require a much longer timeframe.

Policy, organisation and infrastructure

First of all there is the need to educate the public about disease progression and how to interact with people affected by neurodegenerative disease in order not to exclude them from society.

There is also a need to interact with and support healthcare industries in developing assisted-living technologies. Currently, there is a growing interest within healthcare industries to learn more about the precise needs of people with disease. Industry should do more in this regard, but society should also ask what it can do to help industry.

- Industry needs profits in order to survive and for this reason hesitates to invest in new or unknown markets. The market for assisted-living solutions is fragmented across Europe - the available solutions address local market needs meaning that scaling-up treatments/solutions across a wider area is difficult. In order to facilitate the scaling-up of new products there is a need for more efficient and cheaper solutions than the ones currently applied in local markets. Furthermore, different categories of patients have different needs - facilitating interaction between industries and patients will enable industries to better understand what they can do to provide suitable support. Authorities, policy makers, public institutions and researchers should encourage this interaction.

Markus Merne – Assisted-living   **29th September 2011**

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Healthcare and social care

The major issues that surround the care of elderly people with ND are:

- Non use of existing solutions, such as devices to prevent wandering.

- Categorisation of patient needs.

- Harmonisation within and between countries - Some countries have a complicated path between suppliers and users. Users need to know both about solutions and payment terms including available reimbursement. Countries handle payments differently, thus negotiation with national authorities is required and individual solutions must be found.

A less major issue surrounds competition between the public and private sectors in certain countries.

Quality of life

Technical solutions that preventing frequent and problematic issues relating to patients, such as falls and wandering, offer carers the chance to live more normal lives. Housing patients is a more complex issue that requires socio-economic evaluation and involves emotional and social aspects*.*

Policy, organisation and infrastructure

- Harmonisation between countries (see point 3, *Healthcare and social care* section).

- An individual has the right to choose how their disease is managed.

- Organisations need defined pathways for patient management as this reduces the decision making process and saves time.

- Policies need to take into consideration projections of aging when allocating resources.

Dr John Wilkinson – Medical devices/e-health   18th August 2011

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Dr Wilkinson provided comments from the perspective of medical technology.

Healthcare and social care

- There are three areas where medical technology could contribute:
  - Development of diagnostic tools to facilitate intervention or management of disease
  - Development of specific interventions for disease. For example neuro-stimulatory devices for people affected by Parkinson's disease
  - Technology addressing broader or more general aspects of disease including symptoms that are generic for old age or infirmity. For example technology to treat incontinence.

- In relation to care, both patients and carers can potentially become isolated. Technology that helps prevent this and/ or improves the input of patients or carers would be beneficial. However, such technology is not necessarily seen as commercially viable and public funding might be required to encourage it to be developed.

Quality of life

- In a general sense technology that ameliorates the onset or decline of a patient will improve quality of life. While stopping disease is most desirable, benefit can also be gained by limiting its impact.

- The needs of carers should be considered and technology that directly or indirectly helps them should be investigated.

Policy, organisation and infrastructure

- Industry has traditionally relied on the opinions of clinicians to drive technology forward. Increasingly there is a move towards a broader focus with greater input from patients and carers. EUCOMED is currently undertaking a strategic review working with the European Patient's Forum to develop a better understanding of patients and carer needs.

- There is lot of scepticism about how industry works from outside the private sector which makes it all the more important to improve the dialogue between different stakeholders and find common ground and mutual understanding. Accordingly, fora where open, bilateral and structure discussions can take place between industry and patient/carer groups should be encouraged.

- Good policy should be informed policy. Therefore a variety of stakeholders should be encouraged to interact with each other to identify areas for joint working.

- Decision-making is insufficiently evidence-based at present and there is a need to take a holistic view of costs and cost management. Social and economic impact factors should be included in evaluation of costing for medical intervention. Research to define these factors and to develop better models in this area should be encouraged.

- Achievement of a better co-ordination of research work across Europe is critical to the well-being of very large numbers of people. (*from e-mail*)

Hans Hofstraat – Medical Devices 26th September

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Healthcare and social care

Moving care outside the hospital setting into the home is important as it enables people to live independently for longer. Many products/solutions focus on bridging the gap between hospitals and the home; for example, smart emergency systems and systems allowing distant surveillance, services for provision of help and assistance e.g. in the case of falls. In future, systems may allow detection and monitoring of specific aspects of lifestyle with information captured through these systems used to provide assistance where required e.g. with management (incl. adherence and compliance) of medication. In addition monitoring will allow prevention of complications and exacerbations through early warning, and – if needed – early intervention. Intelligent sensors may be able to predict elevated risks of falling and provide active guidance of frail elderly. In all solutions envisaged considerations of privacy and ethics should be taken into account throughout the development.

Quality of life

Independent living is a key factor in QoL and enabling this requires personalised solutions to make the environment (home etc) safer by managing and decreasing risk. On a broader scale the increasing number of older people means that solutions must be aimed for at the societal level and also considered to address the wider environment.

The ultimate challenge to improve QoL is to prevent or combat disease, or to take (early) measures that delay its onset. Preventing and treating disease will require more complete knowledge of relevant diseases and 'earlier' measurable observables and endpoints to accelerate feedback. Philips is currently working in partnership with academia to develop imaging and other diagnostic tools for differential diagnosis, and for more accurate and less invasive treatment monitoring and feedback. Imaging procedures have the potential to give a global overview of location, extent, and progression of disease; however, fundamental insights into disease mechanisms and origin will also be needed if effective treatment is to be achieved. This is particularly true for the main non-communicable diseases that impact on our aging society i.e. cancer, cardio-pulmonary diseases, and neurodegenerative disorders.

Policy, organisation and infrastructure

Regulatory processes more apt for home support and a more homogeneous approach to reimbursement across the EC could help accelerate getting increased assistance into personal settings. Reimbursement of R&D via Public Private Partnerships could potentially improve cost-effectiveness of product development and allow treatments/interventions to be available earlier, particularly if all stakeholders participate (not only public and private research partners, but also patients, care providers, payers, regulators, etc). Projects such as the European Innovation Partnership on active and healthy ageing may help facilitate (quicker) patient access to advances and innovations in health care and cure.

Silvio Bonfiglio – ICT   **30th August 2011**

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Healthcare and social care

- Autonomous living (physical and psychological independence)

- What e-health can do to support older people:

  - Slow down the physical and cognitive decay of people (prevention).

  - Once decay appears, mitigate its effects using technology to support physical and intellectual functioning e.g. IT systems to remind people with memory loss to take their medication.

  - Prevent the isolation of older people; keeping them actively bound to society e.g. use of the internet to overcome physical distance.

Quality of life

Priorities to improve QoL (in order of importance):

1. Prevention through remote monitoring of older people's health, 'health coaching' and medical education.

2. Support for daily activities in smart homes.

3. Social inclusion / socialisation.

Policy, organisation and infrastructure

- Despite everyone believing that commercial opportunities related to aging are strong (due to people living longer with a concordant increase in age-related disorders) the e-health and e-care markets are still underdeveloped and there is only one mainstream product on the market (the button for emergency call); other products / solutions / services are still at the prototype stage and/or in trials. Companies participate in research projects and EU initiatives but do not invest significantly, or sufficiently, in e-health / e-care; barriers discouraging companies from investing in this area are outlined below. Accordingly, there is the need to foster awareness and to promote and realise co-operation at all levels (academia, industry, healthcare community etc).

- Issues keeping companies out of the market at present:

  - The market is fragmented due to different cultures, needs (different aspects of aging and age-related disorders) and a lack of standardisation – this makes interoperability of multi-vendor solutions difficult.

  - There is poor co-operation among the various players and lack of sustainable business models.

  - There are difficulties relating to how individuals interact with technology e.g. poor usability of the proposed ICT-based solutions, psychological barriers, benefits of the solution unclear to the older users, lack of personalisation in products.

  - There is cultural resistance to spend on e-health / e-care solutions; older people and their families expect that this kind of assistance will be provided by national healthcare systems.

- Medical professionals and carers sometimes have a sceptical attitude towards technology and do not facilitate the introduction of new, technological approaches.

• From a business perspective new and effective business models have to be identified in order to favour the birth/growth of the market. Business models could be based on a collaborative approach with both public and private partners, including new players inside the value chain (e.g. the service aggregator, the context provider, the sensor data provider, the resource provider), and incorporate economic support via indirect forms of revenue (e.g. contextual advertisement, use of anonymised information etc)

The OASIS project

The OASIS project is a research project partially funded by the European Commission (FP7-ICT) that has developed an open and innovative reference architecture based upon ontologies and semantic web services. This architecture enables plug & play and cost effective interoperability, seamless connectivity and sharing of content between existing and newly developed services thus reducing the individual investment of service providers. The OASIS platform allows aggregation of different services offering the unique benefit of enhancing each of them through a synergic exchange of information. Consequently, each application can be adapted to the specific needs of the user. For example, the 'nutritional service' uses data collected by the 'health monitoring service' to adapt the diet of the elderly user to his or her current health status. The 'nutritional service' shares their information with the 'activity coach' who adjusts the intensity/mode of the patient's physical activity accordingly. By fostering interoperability, standardisation and organizational / business arrangements based on co-operative and aggregating models - OASIS addresses some of the barriers discussed above.

Marc Lange – ICT   **5ᵗʰ September 2011**

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The views expressed by Marc Lange are in line with those of EHTEL but derive from his own experience.

Healthcare and social care

Patients should be cared for at home for as long as possible and ICT can help facilitate this in the early stages of disease; however, at a certain point technology ceases to be of help (we need to be realistic). Accordingly, efforts should focus on the early stages of disease.

At present, one device relevant to care at home is available; it allows patients to contact a tele-centre through which they can receive social support. The ICT industry is developing tools that will provide health support through monitoring devices and devices to allow patients to contact nurses and doctors; currently, these tools are being developed for people with diabetes, cardiovascular diseases, lung problems etc but not specifically neurodegenerative disease. Other devices/tools under development include secure homes (e.g. locking doors and gas detection) and videoconference devices.

Quality of life

The key priority for improving quality of life for patients and their carers is early detection of the disease. Alzheimer's disease, for example, is generally diagnosed when pathology is relatively advanced meaning ICT is less able to provide effective support.

Policy, organisation and infrastructure

The creation of local organisations to provide home support for patients in their community would be beneficial. For example, these organisations could aim to propose useful devices and ICT tools (e.g. telemonitoring assistance). Local awareness should feed into national agendas with the ultimate aim of creating more political awareness at an international level.

Dr Laura Pastor Sanz – ICT   **6th September 2011**

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Healthcare and social care

Major issues in relation to Parkinson's disease include:

- Standard clinical diagnoses are neither accurate or reliable – currently patients go to hospitals for half an hour once or twice a year and their status is evaluated subjectively based on observation using the Unified Parkinson's Disease Rating Scale (UPDRS) that classifies symptoms on a scale from 0 *(unspecific symptoms)* to 4 *(very severe symptoms).* Rating is based on experience, and interpretation varies from place to place and from doctor to doctor. Furthermore, features such as tremor, rigidity of limbs, speech problems etc fluctuate during the day and depend on treatment intake.

- Need to adapt the timing of the medication intake for each patient – Levodopa is a major treatment for Parkinson's disease and the timing of intake is crucial in relation to patient quality of life due to the state fluctuations across the day (ON-OFF). This is especially important in the phase of Motor Response Complications.

- Need to destigmatise disease

- Lack of information about disease provided for/to patients and carers (often relatives)

- Keeping hospitals, medical centres and doctors informed about patient status and the solutions available

- Need to reduce the costs of disease - in the USA[1], Parkinson's disease affects 2-3% of the population over 65 years old costing ~ $21,000 per patient per year divided into:

    - direct costs: medications, nursing home care

    - indirect costs: loss of productivity, cost to caregivers

Quality of life

Priorities to improve quality of life are:

- Improve disease prevention

- Improve diagnosis

- Predict the evolution of patient status

- Provide optimised/personalised medical procedures – in order to achieve this goal there is the need to stratify patients

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[1] O'Brien JA, Ward A, Michels SL et al*. Economic burden associated with Parkinson´s disease*, Drug Benefit Trends, 2009; 21(6): 179-190

Dengler I, Leukel N, Meuser T et al. *Prospective study of the direct and indirect costs of idiopathic Parkinson's disease*, 2006; 77(10): 1204-1209

- Increase awareness and involvement of patients and carers – organise dissemination events for caregivers, patients, doctors and set up training sessions/materials

- Allow patients to stay at home for as long a time as possible keeping doctors informed about patient status in order to adapt treatments. Patients could be in contact with medical centres through internet/mobile devices/visual contact *(webcam)* and panic/emergency buttons.

- Promote social inclusion

- Develop technological solutions suited to older people e.g. non-invasive, wearable etc:

  - computers should be simple to use and with contrasting colours

  - devices should be waterproof and discrete

- Analyse efficacy of new medications

- Study combinations between different treatments, for example deep brain stimulation (DBS) with the standard treatment (levodopa).

Policy, organisation and infrastructure

Needs:

- Standardise methodology and technological solutions as much as possible [as stated in the Rome workshop]

- Facilitate access to databases of patient data for research purposes. The databases of interest are heterogeneous: movement recordings, imaging, genetic, behavioural data

- Dissemination of project/research results

- Address ethical issues in a systematic way: there is the need to adapt legislation to protect patients and assure them that their data is confidential and that their dignity is preserved.

- Combine the efforts of different types of actors/stakeholders (hospitals: general practitioners/nurses/neurologists, patients, users associations, research centers/universities, pharma industry…). In this regard EU projects are very useful.

- Clinical trials need to be conducted for longer time periods; this would require substantial amounts of funding. Potentially public money could be dedicated to industries allowing them to run clinical trials for longer.

PERFORM project

Patients affected by Parkinson's disease experience a high frequency of falls; the PERFORM project. (www.perform-project.eu) monitored the motor status of patients with sensors endowed with accelerometers put on their limbs. Participant status was monitored in their home for a week with data download and transmitted to the centre on a daily basis. The system was evaluated in three different pilots: Navarra (Spain), Modena (Italy) and Ioannina (Greece) with a total number of 112 patients.

Professor Richard Hughes – Healthcare providers   22nd August 2011

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The views expressed by Richard Hughes are his own and do not represent those of EFNS.

Healthcare and social care

Brain disorders are the major diseases affecting the elderly and tend to be debilitating and progressive in nature. Causes are largely unknown and treatments generally ineffective. Collectively these factors mean that brain disorders constitute around 35% of the total cost burden of all diseases in Europe (Andlin-Sobocki *et al*., European Journal of Neurology 2005, 12)*. Currently a far smaller proportion of the research budget is allocated to this area and this needs to be addressed ideally making funding allocation proportional to overall cost.

*EFNS are sponsoring a paper to re-assess this figure.

Quality of life

In addition to broadly applicable issues that can be applied to all debilitating diseases, specific issues surrounding quality of life exist for each neurodegenerative disease. For example, reducing/reversing memory loss and improving social functioning would be key objectives for patients affected by Alzheimer's disease while slowing the progression of immobility is important in people affected by Parkinson's disease.

Policy, organisation and infrastructure

A major problem for researchers concerns obtaining funding for studies comparing existing treatments and for assessment of more 'simple' interventions including non-pharmaceutical treatments such as physiotherapy and exercise. These kinds of studies are "clinically useful but not Nobel Prize winning" and should not be overlooked as they can have significant impact.

There is an ongoing need to assess the evidence for use of existing treatments and more money and resources need to be allocated to appropriate studies. An essential first step is to perform a systematic review and there is a need to provide funding for such reviews which are themselves time consuming. The Cochrane Collaboration is the most notable source of such reviews and needs broader financial support.

Clinical guidelines need to be based on systematic reviews. The EFNS are in the process of funding and producing evidence-based guidelines for neurological disorders; these guidelines incorporate standardisation of assessment measures and have generally been well received to date [Of interest in relation to some of the workshop recommendations].

Professor Desmond O'Neill – **Healthcare providers 24th August 2011**

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Desmond O'Neill provided comments from the perspective of Geriatric Medicine.

Alzheimer's disease and the dementia syndrome are the most important causes of significant acquired disability in older people, and the knowledge, skill and attitudes required for the prevention, assessment and management of these very important syndromes are a core part of the practice of geriatric medicine.

Healthcare and social care (of older people)

Three major issues surround care of older people with neurodegenerative disease:

Gerontological and dementia illiteracy – Many healthcare staff are insufficiently trained to deal with people affected by neurodegenerative disease (ND) both in terms of assessment and management of disease. Gerontological training is best placed in this regard and is particularly important in relation to managing comorbidities – a form of horizontal integration of gerontology, dementia care, general medicine, rehabilitation and palliative care. As such more and better (i.e. specifically) trained staff are required, particularly in areas such as nursing, but also in medicine, therapies and care support staff.

'Neurological nihilism' - Belief that nothing can be done for people with dementia is an issue in some circles possibly partly due to ageism and a failure to appreciate neuroplasticity and the role of comorbidities in disease. To overcome this there is a need to show that people with ND can be helped. Broadening out the focus of care from an over-emphasis on the effectiveness of pharmacological treatments may help as non-pharmacological interventions can have a great impact.

Oversimplification and stigmatisation of dementia – dementia is a complex disease with a diverse range of symptoms and severity of manifestation; for example, Alzheimer's disease is often treated as a unitary disease and is assigned by diagnosis of exclusion. Furthermore, quality of life for individuals with neurodegenerative disease does vary – very many people progress very slowly and even with significant degrees of dementia maintain high quality of life[2]. Disseminating this information is important and there is a need to let people know that life with dementia continues.

The complexity nature of neurodegenerative disease requires that a biopsychosocial model (i.e. covering biological, psychological and social factors) should be adhered to by different healthcare providers involved in the treatment and care of patients. For example, hospital treatment is too focused on the biological, while nursing homes are too focused on dealing with psychosocial aspects of disease while failing to provide adequate diagnosis and assessment[3].

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[2] Hurt CS et al, J Neurol Neurosurg Psychiatry. 2010 Mar;81(3):331-6.

[3] Challis D et al, Age Ageing. 2000 May;29(3):255-60.

This should be addressed and could be aided by individual sectors learning from each other.

Quality of life

Key priorities to improve quality of life in people with neurodegenerative conditions:

- Increased numbers of specialist trained staff – care staff, nursing, therapists, medical etc

- Patients and carers would appreciate, and benefit from, more home assessment.

- Early diagnosis with a clear pathway for assessment and support. Within this area there is a need for/that:

  - more consensus between the different specialisms involved in managing dementia across Europe as to the optimum care pathway.

  - standardised/common pathways for assessment, management and support with delineation of clear care standards.

  - patients and carers should deal with as few agencies as possible; care/case management for individuals could be dealt with by a specialised broker/advocate.

Policy, organisation and infrastructure

- There is a need for specific national dementia strategies supported by the European community and which aim to co-ordinate all relevant activity including research, public health etc

- Research budgets needs to include funding for more specific projects relating to aging and neurological diseases of later life.

- There needs to be more focused and targeted incentivisation for health and social care structures to deal appropriately with patients with dementia and comorbidities.

- National registers of patients would be very beneficial on a number of levels.

Dr Jacques Van der Vliet – **Healthcare providers   28th September 2011**

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Healthcare and social care

- Access to proper services and care

- Early and accurate diagnosis of the problem will enable older people and their carers to understand what is happening to them

- Access to appropriate help (meeting patient needs) and the necessary treatment

- Community multidisciplinary teams must be established. Keywords are partnership and effective communication. Examples: primary and acute care, social services, governmental departments, NGOs, patient and carers

- Concentrate on what people can still do, instead of what they cannot do

Quality of life

- Participation and social inclusion - staying active in society as long as possible, preventing people from getting isolated or become lonely; people are entitled to a meaningful place in society for as long as possible. Social services and formal and informal carers play important role in maintaining people place in society social inclusion e.g. through physical support (vacuuming the house, doing repair work, other support) or helping with transportation or cooking meals etc.

- Within families it is important to organise care - younger carers can help older people.

- Organise and develop places where people who are affected by disease can go to engage in suitable activities e.g. hobby-like activities.

Policy, organisation and infrastructure

- National medical associations should be encouraged to actively stimulate awareness and support good practice initiatives. The elements mentioned in the sections above should be stimulated through education of doctors, social workers and other stakeholders in this area (NGOs and others)

- Co-operation and co-ordination of care between different professionals is important. Elements like threat to status, clashes in culture and priorities in the different sectors (public, private, voluntary) must be taken very seriously. Training to ensure optimal co-operation, mutual respect and understanding is needed.

- Integrated care models around polymorbidity (chronic medical conditions including mental health disorders) can address the growing complexity of patient needs by responding to the multiple conditions of people in need.

Final remark on work aspects

In the future people will have to work longer. This means good working conditions/working environment will be more important; these conditions should be adapted to senior employees. Early detection of mental disorders is very important, meaning that supervisors should be trained to notice when something

is wrong. They should then seek help from experts to achieve proper advice or referral.

Professor Carl E Clarke – Healthcare providers   10ᵗʰ October 2011

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The ABN is fully supportive of the aims of the JPND initiative. However, the respondents felt that the three specific questions related more to service provision than to research into neurodegenerative conditions.

Healthcare and social care

The major issues that surround clinical research relating to neurodegeneration are:

- Exclusion of the elderly from clinical trials, commercial studies and research in general. Trials should be more pragmatic to overcome this and reflect how health services are run in individual European countries.

- Lack of knowledge or existence of research networks across different European countries.

- Lack of research into rehabilitation interventions, nursing homes (e.g. falls prevention) and non-motor problems in Parkinson's disease (e.g. dementia).

Quality of life

- Finding disease modifying treatments is the most important long-term goal; tracking disease progression will require suitable biomarkers.

- Interventions that can readily be implemented in the short-term include exercise, physiotherapy, and rehabilitation which may reduce the incidence of hospital admission and nursing home placement and thus improve patient quality of life.

Policy, organisation and infrastructure

There is a need for:

- Co-ordinated research on neurodegeneration across Europe.

- Research nurse support for clinicians conducting trials.

- Research networks that help people to join trials.

- Speeding up simplification of EU regulations relating to clinical trials.