Giving Voice to Older People

International Meeting 2015

Welcome and Introductions   Day One

Councillor Bob Sleigh formally opened the meeting to welcome all guests who included EASYCare International Network members and local stakeholders. During this presentation the meeting group heard an overview about Solihull, its population and infrastructure. Positioned at the heart of the UK, Solihull has a unique concentration of connected economic assets. Within the context of ageing, Solihull is working to deliver a vision where everyone has an equal chance to be healthier, happier, safer and prosperous.

Professor Ian Philp welcomed attendees and thanked West Midlands Academic Health Sciences Network (WMAHSN) and Galderma for their financial support and also for their contribution of knowledge.

Jack Watters Memorial Prize
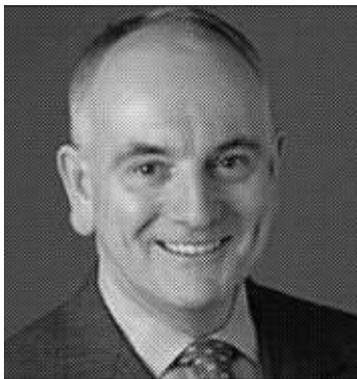
Attendees were informed about the passing of Dr. Jack T. Watters after a short illness. Jack was a friend to many on the international network and a great supporter of the EASYCare Project. In an effort to acknowledge the amazing work that Jack was involved with it was announced that the EASYCare Project would establish an annual prize in Jack's memory. Every year colleagues will be invited to submit their work to a panel of judges who will vote for a project that best represents Jack's values.

EASYCare: A Brief History

Ian Philp explained some of the key development phases of the EASYCare Project against the backdrop of emerging themes in the field of ageing. In 1964, Gerontologist Jimmy Williamson published a key paper in the Lancet. "Old People at Home; Their Unreported Needs," described that over two thirds of older people's needs were unknown to their clinician. Assessments did help to identify these needs however they were often developed for specialist use and too disease specific. There was a gap in primary care for a simpler approach that would help to treat the complexity rather than the condition – EASYCare was introduced and a number of projects developed throughout Europe.

Since 2009 following Ian's return from a National role, the project expanded its research experience to all six WHO regions of the world, establishing EASYCare as a valid and reliable assessment tool with published evidence to describe cost effectiveness and cross cultural comparability.
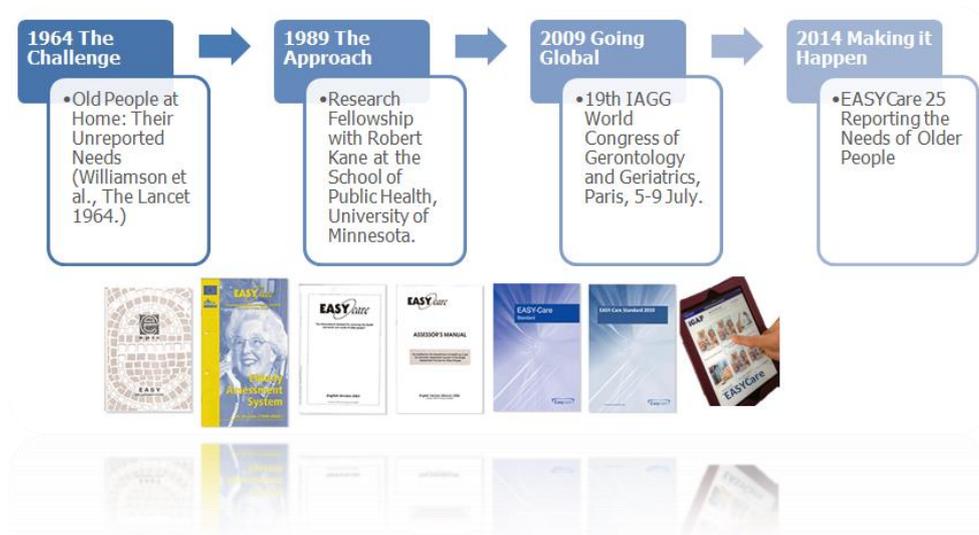
Currently, the project is moving towards a different phase that incorporates a new research direction and a focus on the quality assurance associated with implementation in practice. The research agenda has two main areas:

1. Population studies (reporting needs and priorities of older people around the world).
2. Evaluation/impact studies (cost and benefit).

In order to better support the above developments, a social enterprise company is being created; EASYCare Health. Any money generated will be reinvested into the programme and will serve the following main purposes:

1) Licence the assured use of the EASYCare approach around the world.
2) Manage the international database.
3) Establish a global partnership for training in person centred care.
4) Assume the coordinating role of the EASYCare Project.

Attendees summarized their backgrounds and links to the EASYCare project - more of which is described in the **'World Café'** session.

Session One: Standardised Changes Review

The last review was undertaken in 2010. Group discussion agreed some suggested changes to the content of EASYCare Standard, the 2015 draft will be made available and network members should look to using this version in future. In this session it was a useful reminder to think about <u>why</u> we want to ask the question we include and <u>what will we use the end data for?</u> Highlighted changes summarized as follows:

Demographics

- Include term assisted living – with local adaptation for this.
- Need to better reflect financial and employment status. Suggest re-conceptualisation of **q8** as economic resources and economic contributions. Francien Scholten, Arvind Mathur and Du Peng to develop.
- Extension of categories for **q9** and **q10**.
- Ethnographic information can be included at the discretion of the country using the tool; it will not be included as a standard.

Medical conditions checklist: now optional

Core questions

Q1.4 Can you use the telephone? This needs updating to reflect change in technology and removing from the independence score. Stephen Johnson, Lisa Black and Kevin Rudge to work on a replacement question. E.g.:

"Are you able to communicate with others using modern technology (e.g. mobile phone, internet)?
Yes, without help / Yes, with some help / Unable". Work will be undertaken to re-calibrate the independence score accordingly.

Q2.13 will now come before **Q2.11**

Q6.2 additional pre-question of Do you drink alcohol?

Q7.2 will now move to the end of section 7

Follow-up evaluation questions

An evaluation section will be introduced as part of the core standardised use of EASYCare in all future implementation to be able to demonstrate some measurement of change in health status and for analysis of cost impact. For clarification, these evaluation questions are for when EASYCare is used as a primary purpose with assessment, within population studies this is not a requirement.

Supplementary Questions

In EASYCare there is space for additional questions, not in the core assessment but as supplementary questions and network members can identify their own short supplementary assessment questionnaires. There are now also recommended supplementary skin health questions.

Scoring

Further discussion led the group to consider if there was enough inclusion in the assessment tool around social and emotional aspects as often this has a direct impact on health status. It was agreed that in addition to the independence score, EASYCare should include a well-being measure and Osaretin Oviasu would assist in developing a ratio scale from wellbeing questions. Furthermore, Stephen Johnson would put us in touch with colleagues at UCLA with regards to their work on the loneliness scale.

Action Points:

- J Long to update version of EASYCare Standard

- F Scholten, A Mathur, D Peng to update demographic question 8

- S Johnson, L Black, K Rudge to work on q 1.4

- All future use of EASYCare in implementation must include follow-up questions

- O Oviasu, I Philp to develop a well-being score and update the independence score

Session Two: Transforming Systems of Care

Think Piece; Improving the Lives of Older People.
Opportunities for Healthcare, **Mike Hodin presentation (slides available).**

Often the media is generally negatively focussed on older people as a burden to society. This presentation reframed the ageing 'challenge' as an opportunity.

This change in attitude can filter through education about the EASYCare approach; in EASYCare's communications we should make the societal opportunities clearer in our narrative.

- EASYCare is intended to describe the older person's voice, in partnership with family and carers
- EASYCare focus is on older people as an asset in their communities
- EASYCare is a disruptive innovation but one that can remove barriers

If people can buy into the value of the EASYCare holistic approach it will more likely gain interest from business, pharma and policy-makers.

The discussion panel shared thoughts on how EASYCare could appeal to businesses and pharma with experiences described for how EASYCare can be applied in rich, middle and poor income countries.

- Business recognises that there is a strategic opportunity in targeting the mass market available of older people who have more disposable income. There is increasing emphasis on healthy active ageing which links to innovations in healthcare delivery and EASYCare could be seen as a useful tool to leverage new technologies. Even in resource poor countries, older people still make significant economic contributions through being part of the general workforce and through their roles as unpaid carers.

- Pharma recognises ageing is a strong trend and are keen to see how this population breaks down for example; those who are ageing well / those who are more dependant or those who need prevention and those who need to be brought back. EASYCare can be used to help pharma better target and develop their resources by articulating the needs of older people.

The collection of impact data will be instrumental in helping to evidence the usefulness of EASYCare when approaching business/pharma for support. EASYCare should ensure that as well as describing the direct impact on improving the lives of older people, that it also clarifies the wider social and economic benefits.

Development of the EASYCare Project through the European Institute of Innovation and Technology. Paddie Murphy presentation (slides available).

The WMAHSN's mission is to lead and catalyse co-operation, collaboration and productivity between its members and accelerate adoption of innovation in order to improve health, care and wealth promotion for stakeholders. This links to the European Institute of Innovation and Technology (EIT) who support, promote and share a range of models, products, training etc. across a large network of more than 140 leading organizations spanning key areas of healthcare such as Pharma, MedTech, Payers, Research Institutions and Universities.

Priorities and themes include promoting healthy living, supporting active ageing and improving healthcare which correspond well with the EASYCare approach. The EIT also has an ambition to articulate the citizen's voice in order to better describe the needs of people and EASYCare could be the tool to deliver a measurable impact.

Through joining the EIT network the benefits for EASYCare include; access to elite partnerships throughout Europe, higher profile through the EIT network, support for innovation at pace and scale, funding opportunities, access to well established systems to promote training and education (EASYCare dissemination) and access to partners for research and development.

Action Point:

- Start-up funds competition application for 50,000 euros. EASYCare Health will apply for funding to develop the new social enterprise company and to create demonstration videos of EASYCare in practice.

Welcome and Introductions   Day Two

Councillor Ken Meeson gave a presentation about Solihull's Health and Wellbeing Board and described some of the impact that the ageing population and described plans for the re-design of their delivery of services. Working towards a more integrated model they use the motto "Alone I go faster **Together** we go further."

Session Three: Implementing the EASYCare Approach

Assured Use: Training & Implementation. Graham Beaumont presentation (slides available)

EASYCare is developing a social enterprise company (EASYCare Health) together with another social enterprise company Health Exchange. Health Exchange is a values-based company committed to building the capacity of individuals, voluntary organisations and communities to take control of their health and wellbeing. They already have experience in developing systems for data collection, measuring impact and are also using EASYCare in a local Community Navigation Project.

EASYCare Health will work to deliver a more structure framework for the standardised delivery and implementation of all EASYCare projects, including licensing for assured use. This is a not for profit company that will see any income generated reinvested back into the project.

What EASYCare Health will do for Network members:

- Licensing the EASYCare tool (with training and data commitment)

- Developing support tools and resources to underpin your work

- Facilitating pilots through access to sponsorship

- Maintaining and managing the database (and producing reports and analysis)

- Growing awareness of EASYCare and the International Network

- Developing and disseminating best practice in community support/asset building

World Café event Feedback - additional paper to follow

Session Four: Research

Population Studies & Impact Evaluation. Du Peng (slides available)

In 2014, the China Longitudinal Aging Social Survey (CLASS) introduced EASYCare into their assessment of self-care ability and health needs of the elderly for the first time in China. The sample is 11,511 elders and next year participants will receive the first follow-up. Analysis so far indicates that use of EASYCare in the questionnaire has good internal consistency.

A panel session discussed the variety of settings in which EASYCare is applied around the world, highlighting the use of different models around the network. It was agreed that as well as undertaking longitudinal studies the next phase of research focus aims to undertake intervention studies in parallel, which will help to demonstrate impact and benefits.

Since policy makers will find it difficult to advocate large scale implementation without evidence through published data and in order to better support network members in approaching policy makers, funders etc. it was acknowledged that the EASYCare project will need to develop a portal of easily accessible information, including data and case studies.

A paper is currently planned using unpublished data of 11 countries, to describe general overview of needs of older people. It could also look at how independence varies in relation to living arrangements using the Chinese dataset for comparisons.

Action Points:

- Research focus on impact studies and longitudinal studies

- Develop publication for 2010 datasets

- Build a shared portal for data collection and dissemination of project activities

- Ideas about knowledge transfer to be directed to Nicola Burgess at Warwick Business School

- Develop a monograph of EASYCare following IAGG Thailand