The ROADMAP project an EU consortium to improve care in Alzheimer's disease

Introduction

The ROADMAP communications team carried out an interview with one of the leaders of Work Package 5 (WP5), Prof. Alastair Gray from the University of Oxford. As director of the University's Health Economic Research Centre (HERC) he co-leads the team carrying out ROADMAP's activities in this area. We spoke to him about real-world evidence (RWE) and its importance for achieving ROADMAP's goals, as well as finding out in detail more about the work that the health economic research team has been doing for the project. Finally, we asked him about the impact of his team's work and his vision for ROADMAP phase 1 as we look towards the final year of the project.

Meet the ROADMAP WP5 co-leaders

Alastair Gray has more than 20 years of experience in health economics, including measurement and valuation of health outcomes, disease and decision modelling, and economic evaluation of healthcare technologies. His research on dementia costs and disease progression has been extensively used by NICE in technology appraisal, and his work on dementia research spending in the UK and Europe featured in British general election commitments to increase the dementia R&D effort.

Antje Tockhorn-Heidenreich, has a Master of Science in public health from the University of Applied Sciences in Neubrandenburg (Germany) and has worked at the German affiliate in PRA before moving to the regional Health Technology Assessment (HTA) group covering Europe and Canada for biomedicine products for the past 5 years. Her role involves leading RWE projects and developing cost-effectiveness economic models for HTA submissions.

Could tell a bit what RWE is and why you're doing research that involves it?

RWE refers to non-experimental evidence. It's pretty much anything that hadn't been obtained, for example, in the setting of a randomised controlled trial (RCT) or a carefully conducted case control study, virtually anything else from large cohorts, registry information, routine data sources, electronic health records and ad hoc surveys as well as cohort studies. I would put all of them in the category of RWE.

I think that ROADMAP provides the opportunity to identify sources of information, particularly for myself with respect to modelling dementia that we may not otherwise have been aware of. In addition, I think it's very important that we identify all the sources of information that are available in terms of collecting evidence both on quality of life, resource use, and disease progression. From the point of view of the economic analysis, having RWE is really the best kind of evidence for many aspects of this.

Normally economic analysis relies on two types of information. One would be information on effectiveness of particular interventions, and in that case normally the gold standard would be information from RCTs, because that minimises the chance of bias in the information one has.

But many other things to do with, for example, patient pathways through the health and social care system, the levels of quality of life the people affected may experience in different health states, the resource use generally that they require at different stages of disease progression, are probably best sourced in a more naturalistic way because that gives us the best measure of what happens in real world practice.

The aim of ROADMAP is to improve health outcomes, how would you define a health outcome and what do you focus on?

I would take a fairly standard health economics type approach to this and say broadly we're interested in the duration of life, which would be survival or life expectancy, and quality of life. Ideally, we would use a composite measure of these things in the form of some type of quality adjusted survival. When it comes to dementia there are several aspects where one might have to broaden that even more;

- Firstly, in order to look at the quality of life experience (not only of patients but also of their carers). That's likely to be particularly important in AD and dementia, where a large burden of care often falls on informal carers.

- Secondly, I think there is some argument that standard measures of quality of life don't necessarily capture all the aspects of somebody's ability to live a normal life if they have dementia. In addition to this, we need to consider another important issue, if you ask people with dementia to rate their quality of life it often doesn't deteriorate very much as the disease progresses, but if you ask the carers to rate the quality of life of the patient, they place it at a much lower level.

Could you tell us a little bit more about the aims of WP5, and your activities within it?

In WP5 we're trying to make sure that we've got a systematic view of what has gone before and prepare a route ahead. The systematic review area of WP5 has expanded considerably since we started.

We're now in the process of completing three systematic reviews:

- on quality of life,

- on resource use and cost as the disease progresses, and

- on previous studies that have looked at cost effectiveness and the use of economic models in particular.

These are all important aspects of WP5, the other main thing that we're doing is reaching out to the rest of the economics community and other interested parties; for example, reimbursement bodies so that we understand what everyone else in the research community is currently doing and is planning to do. Further, we are building towards, hopefully, a ROADMAP phase 2 where we can actually have the time and resources to develop these research themes in a much more comprehensive way.

What are your expectations on the impact that your work is going to have in this ROADMAP phase 1?

I hope that the work that we're doing will be impactful. We're certainly trying to make sure that we can publish as much as we possibly can, so we would hope from the systematic reviews to have six publications: three which are reporting the three different methods that we've used to conduct the reviews – the protocols, two have already been published and one is in progress; and then three papers reporting the results.

In addition we're hoping that we can publish other material publicising what we've been doing. So from that point of view we're hoping to generate quite a lot of awareness of the systematic review part of things, but we're also engaging with the wider research community in the area of dementia and AD.

We also held a workshop in Paris, a very good opportunity for us to understand what other researchers are doing, and also to let them know what we've been doing, as well as what our plans are for the future.

Is there something particular you would like to mention about your work on ROADMAP?

There's a lot of synergy involved in ROADMAP that would not be possible without work across several different dimensions at the same time.

One of them is the international dimension. I think having so many countries involved in this enterprise is really good, and something we don't always get so much opportunity to pursue. We're working in a much more international way than many researchers do routinely.

I think it's also much more interdisciplinary, in WP5 we're a bunch of health economists mainly, but we are interacting with many other people. There are people more interested in epidemiology and clinical aspects, there are people interested in machine learning, and there are people interested in the reimbursement side of things, amongst others. I think having that interdisciplinary dimension is very important.

The third thing is that it's also providing quite a unique environment in that it's allowing us to work across the academic / non-academic / public sector / industry dimension in a way which is quite unusual for most research activities. Normally when we interface with industry, it's because they're funding a piece of research which we are doing. Here I think it's going a long way beyond that and I find that quite exciting.