



# SEVENTH FRAMEWORK PROGRAMME HEALTH-2009-3.2.2: Healthcare outcomes and cost-benefits

# MANAGED OUTCOMES

Operations management and demand-based approaches to healthcare outcomes and cost-benefits research

# Deliverable 5 – Report on scenarios of health systems



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# I. EXECUTIVE SUMMARY

This report is the final deliverable of the WP4 work package of MANAGED OUTCOMES. It is a substantive update of the interim report published in July 2012 before the work on the scenarios had been completed. Three main elements are reported on:

- Futures workshops, with expert clinical and managerial involvement, to explore potential long term changes relevant to the case study domains
- Operational and economic modelling, to explore further the process management issues highlighted by the comparative analyses of case study and user survey data, and to assess the relative value generated in the case studies in terms of outcomes for patients and the costs of the services in a regional health care setting.
- Scenarios, which pull these strands of work together for each case study on the basis of 'good practice', highlighting important ways in which outcomes for patients could be improved through enhancement of process delivery. We outline those process configurations that can contribute the most to patient outcomes for a given cost; ie those which have the greatest 'value'.

Futures Literacy workshops were held for all but two case instances in five of the six countries which undertook case studies (18 out of a possible 20). Materials, developed by the WP4 project team, were used in translation with local stakeholders in case study areas (including additional experts and lay people). The workshops, undertaken between March and early October 2012, were regarded as very successful by participants in all countries and provided rich data and inputs which supported scenario developments as well as helping to strengthen and develop the use of the Futures Literacy approach in the health service field.

Further development of operational models, following initial work carried out under WP2, was undertaken for three of the four case studies and most advanced for the type 2 diabetes case study. The models can now handle case instance differences and calculate efficiency measures as outputs. Calculation of outputs is now standardized. The models were used to develop materials to support scenario development, and the spreadsheets have been formalised for use as decision-support tools for health service managers and planners.

Economic modelling was undertaken towards the end of the WP4 programme when patient reported outcome data were available from user surveys in all countries to supplement outcome data collected in the case studies. This enabled exploration of the variations in measures of cost and outcome across case instances. Costs reported in case instances were standardised to provide comparable unit costs expressed in Purchasing Power Standards (PPS). Patient reported outcomes included EuroQoL Quality of Life measures (EQ-5D) from which Quality Adjusted Life Years (QALYs) could be calculated. Differences between costs and outcomes were reviewed to identify the extent to which these could be attributed to the underlying differenced in care processes, and formed a starting point for the generation of individual scenarios.

For each case study, two or three scenarios have been developed drawing on the case study data, survey data, and the operational and economic modelling. They are specific to each case study:

• <u>Type 2 diabetes</u>: three scenarios are proposed here. The Low Cost scenario maintains patients as long as possible in early stages of condition. There is an important role for generalist nurses in the community to encourage lifestyle change and help to minimise anti-diabetic drug use. The Diabetic Control scenario envisages active management of patients at all stages of the condition including pre-diagnosis. Maintaining a balanced level of 'glycosylated haemoglobin' (HbA1c) is a key clinical outcome here. Finally, Zero Complications is a scenario which aims to ensure that those diagnosed with type 2 diabetes do not experience a 'raised risk' for stroke, AMI (acute myocardial infarction), blindness and sight problems, and peripheral vascular disease and





amputations. This requires both enhanced monitoring and treatment of hypertension and cholesterol amongst diabetic patients, and also greater focus on health promotion initiatives.

- <u>Stroke</u> Again, two scenarios that represent good value are described. Rapid Access is about ensuring patients can access specialist stroke services as soon as possible after the onset of symptoms is reported. This scenario emphasises that early specialist access may have a greater impact on outcomes than the use of thrombolysis, which is limited more by the speed of patient presentation than the efficiency of emergency services. The *Early Identification* scenario places importance on actions to increase awareness amongst patients (especially those at greatest risk from stroke), carers and the public.
- <u>HipOA</u> Two scenarios are described, One focuses on *Process Quality*'(speeding up the patient journey whilst reducing complications). The *Managed Demand scenario* describes closely tied processes arranged between primary health care and the elective hospital services to manage the thresholds at which patients are treated.
- <u>Dementia</u>: three scenarios are also proposed here dependent on the stage of development of the dementia services in a region. *Full integration* the ideal is about ensuring that all relevant services are available and coordinated, the condition is diagnosed at an early stage and preventive therapies are available, and that carers are fully supported. *Hospital Coordination* describes a scenario in which acute hospitals take a leading role to diagnose dementia where it impacts on care delivery (mainly patients with moderate to severe dementia), and ensure primary and community health services are fully informed. Finally, PHC (primary health care) Coordination is where patients are diagnosed by GPs with subsequent monitoring of symptoms in PHC and referral to and coordination of other services.

Taken together the scenarios identify the importance of the *regional system* in providing the focus for the operations management interventions. This underpins various common features that are likely to be important to future developments of regional health care systems. These include:

- The possibility in EU regions with lower expenditure levels of designing *low cost* processes that nevertheless generate good outcomes in terms of cost per QALY. These focus on developing processes, often nurse led, that reduce usage of hospital and pharmaceutical resources.
- The relevance of taking a 'whole system' perspective. In all of the case studies we found that important insights were gained from modelling and analysing the combined effects of care processes rather than the isolated effects of individual services or processes.
- The key role of the PHC system to ensure the coordination of services at the operational level across the region. PHC is the focus for much future service development to support care closer to home, patient self-management, and support for carers.
- Major development of *information systems* is essential to enable different care professionals and organisations to integrate their operations so they can be more responsive and targeted in providing services for patients and carers.





# 1.1. Deviations from the Description of Work

As necessary preceding activities in WP3 concerned with case studies and the user surveys took longer to complete than originally expected this, in turn, delayed the start of work associated with WP4. However, it was possible to generate more specific scenarios than originally envisaged, highlighting important relationships that may exist between process and outcome. Changes to the original specification of WP4 in the DoW are set out in table 1 below. The two main objectives of WP4 as set out in the Description of Work (DoW) were to develop:

- different scenarios of healthcare systems based on the study made in WP 3 where each scenario describes some combination which optimises various elements and perspectives including discussion of balance of access, variety and asset specificity in healthcare systems. The scenarios will also include consideration of the possible delivery channels and regional structures of the healthcare systems.
- financial and operational models of the healthcare service production systems. These models are based on the scenarios composed in the first part of the work package, as well as on the case studies in WP3. Their main objective is to provide guidance for the creation of healthcare production systems for different environments.

In practice, however, there are differences between the content of this deliverable and that envisaged at the start of the project. This is an inevitable product of the life cycle of an ambitious piece of research such as this is, and reflects the exigencies of the scientific approach adopted to testing methods and results on the basis of actual circumstances including the need to incorporate new and interesting findings and methodologies on the way.

These differences in the WP4 deliverable are summarised in figure I-1 below. Note that this table has been updated to incorporate changes since the interim version of this report published in July 2012. Note, too, that work has been undertaken which is additional to that originally anticipated in the Description of Work including:

- The development and application of a more rigorous methodology (Futures Literacy) for harnessing local expertise in revealing and detailed the anticipatory assumptions that generate different images of the future than had been originally envisaged. This participatory methodology, Futures Literacy workshops, provides an action research foundation that exploits collective intelligence to develop scenarios of the future.
- A more detailed and extensive engagement with practitioners from the case instance sites than initially expected which, as a result, has provided a more rigorous verification of WP3 case instance findings in each country.
- More detailed development of operational and financial models as a means to identify the components of the scenarios.

The overall effect of these additional activities is to move closer to the achievement of quantified statements of the value of individual scenarios, where the term *value* is used to describe the *outcomes* of health care processes relative to their costs:



Figure I-1. Relationship between costs, clinical processes and outcomes

As summarized in this way we can think of the operational modelling as way to explore different configurations of processes ('inside the box') and the financial modelling as a means to quantify the 'external' relationships that those processes create between costs and outcomes. Thus the scenarios provide a high level summary of the combinations of processes that can deliver best value (ie greatest outcome relative to costs) on the basis of the evidence and assumptions generated by the case studies, futures workshops and subsequent operational and financial modelling.

This represents a substantial enhancement to the level of detail of scenarios originally envisaged, where the models were to be used to quantify scenarios already developed from expert opinion. Instead the models allow us to identify best practice in terms of value based on the evidence collected through the project (see table I-1).



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Table I-1. Changes between this report and as originally envisaged in DoW

	How this element was implemented	How implementation differed from originally envisaged in the DoW	Reasons for the deviation
Obtaining data on scenarios from local/ expert opinion	Case instance-specific 'futures literacy' workshops in each partner country (except Germany) and with the involvement of additional local stakeholders and experts.	Originally proposed as a 'Delphi' exercise; instead a 'Futures Literacy' approach has been used. This takes full advantage of world-leading consortium expertise in this field (Riel Miller, Xperidox). Not solely based on WP3 materials.	Futures Literacy is a more rigorous, focused and content-rich methodology than Delphi. More revealing of potential futures. Better able to be completed within project time constraints. Further develops the Futures Literacy technique for health applications.
Analysis of Futures Literacy workshop findings	Partner country analysis with subsequent translation into English	Not originally envisaged in DoW.	More rigorous specification of anticipatory assumptions used for imagining the future (scenario modelling).
Operational modelling	As set out in WP2.		
Economic modelling	As set out in WP2.		
Developing and documenting different scenarios	WP4 project meetings with relevant partners to identify and align common elements.	Not clear this was a requirement at project start; this need was subsequently identified.	More substantive material was generated than originally expected to support specific scenarios.



In addition to the extra work outlined above which has enabled an enhanced approach to modelling, there were coincident and unanticipated delays outside the control of work package managers due to the approval processes required to undertake patient outcome surveys. The issue of patient confidentiality has been rightly taken as a matter of paramount importance in MANAGED OUTCOMES and these issues required careful consideration and more extensive negotiation than originally expected. For example, as none of the project team members were clinical practitioners or employees of the case instance locations, this precluded direct patient contact. This meant that instead of patient surveys being administered centrally by a single partner (the University of Bamberg), all patient outcome surveys had to be conducted through local partner organisations within each country in conjunction with local project partners and were then subject to time pressures and capacities of those local partner organisations. The extent and complexity of these arrangements varied considerably across the different case instances; not only from country to country, but also within countries.

The approval and compliance regimes imposed by various national ethics guidelines were not straightforward and also varied considerably - even within countries. For example, it took nearly one year to obtain approval for the diabetes survey in the UK, and nearly as long to come to a satisfactory position for undertaking the UK dementia survey. These procedures and negotiations were time-consuming and diverted project resources to an unexpected extent.

This, in turn, had a knock on effect on the timing of the analyses of outcome data and for undertaking the futures workshops which needed to be scheduled at dates for which it was known that sufficient case study data and inter-country comparisons were available.

However, despite these problems the work package has successfully concluded with more substantive findings and a greater detail in the identified scenarios than originally anticipated in the DoW.



# II. INTRODUCTION

# 2.1. The MANAGED OUTCOMES project

The project explores the assumption that healthcare outcomes and costs are affected by the efficiency of service production, the time and location constraints within a regional healthcare delivery structure and the degree to which people are empowered to participate in the co-production of their care. These relationships are insufficiently understood but are important to study in order to meet the objectives of the new European health strategy.

All EU countries are experiencing the same problems in healthcare: ageing populations giving rise to an increasing demand for healthcare services; pressures on funding; availability of trained personnel; more expensive medical treatments. In order to address these constraints, European healthcare systems need to improve the value they obtain from the resources used in terms of improvements to patient health outcomes and not health system outputs. The interconnectedness of EU countries means that studying healthcare issues on a regional level is useful to give policy makers tools to deal with health related challenges on all levels from the EU level down to national, regional and local levels.

Although European health systems are diverse, optimal models can be created on the basis of comparative analysis of treatment practices. Within the MANAGED OUTCOMES project, this has been explored through the development of different stories about the future. These imaginative scenarios have helped us to identify potential opportunities for improving health systems in the present the aim is to provide policy and decision makers with a range of insights on health system reform.

#### 2.2. Structure of this deliverable

This report has the following structure:

In the remainder of section II we summarise the relationship between Work Package 4 and the other project work packages, and describe the involvement of consortium partners in the process.

In section III we provide a brief overview of modelling and workshop approaches explored, and describe the methodological challenges and practical solutions adopted for this work package.

In section IV we describe the three principal components in our scenario modelling: the 'futures literacy' workshops; operational modelling; and economic modelling.

In section V we describe the scenarios emerging from our findings.

# 2.3. Relationship with other deliverables, reports and work packages of the project

The MANAGED OUTCOMES project has two key thematic work packages: work package 3 (Inventory of European practices: case studies), and work package 4 (Scenarios and Models of European Healthcare Systems). These were supported by work package 2 (Methodology and Guidance of Data and Information Collection) which set out methodological guidelines. Work package 5 focuses on dissemination.

The relationship between the two key work packages is visualized in Figure II-1.



Figure II-1. Time-period focus of the work packages 3 and 4 of MANAGED OUTCOMES

Case studies undertaken in work package 3 provided a basis for the development of future healthcare system scenarios in this work package. These images of the future, generated through a collaborative process engaging practitioners and researchers, addressed a range of issues that play a role in the dynamics of each case study. These dynamics are themselves relevant for discussions about healthcare policies, such as the governmental role, public-private partnerships, various funding models, and division of tasks between primary care and specialized care. Each scenario considered one or more combinations of different perspectives (such as equal accessibility, service variety, asset specificity, and alternative delivery channels and structures).

#### 2.4. Partners involved in the work

The following partners of the MANAGED OUTCOMES project consortium have contributed to this work package:

Partner	Responsibilities	Contributors
Tom Bowen Associates	WP4 project leaders	Tom Bowen
(Balance of Care)	<ul> <li>Authoring WP4 deliverable</li> </ul>	Paul Forte
	<ul> <li>Development of Futures Literacy materials</li> </ul>	
	Preparing local case study presentations	
	Running futures workshops for each case instance	
	Reporting back on futures workshops	



	Scenario development	
Xperidox	<ul> <li>Lead development of Futures Literacy materials</li> <li>Support for pilot Futures Workshops in UK</li> </ul>	Riel Miller
Erasmus University Rotterdam	<ul> <li>Operational modelling for scenarios</li> <li>Preparing local case study presentations</li> <li>Running futures workshops for each case instance</li> <li>Reporting back on futures workshops</li> </ul>	Sylvia Elkhuizen Mahdi Mahdavi Jan Vissers
Ethniki Scholi Dimosias Ygeias Eidikos Logariasmos Erevnon	<ul> <li>Economic modelling for scenarios</li> <li>Preparing local case study presentations</li> <li>Running futures workshops for each case instance</li> <li>Reporting back on futures workshops</li> </ul>	Apostolos Dolgeras Eleftheria Karabli John Kyriopoulos Maria Liatsou Elpida Pavi
Otto-Friedrich-Universität Bamberg	<ul> <li>Inter-country survey analyses</li> <li>Support for operational and economic modelling</li> </ul>	Uwe Konerding
Aalto University	<ul> <li>Preparing local case study presentations</li> <li>Running futures workshops for each case instance</li> <li>Reporting back on futures workshops</li> <li>Editing the final version</li> </ul>	Ari-Matti Auvinen Paul Lillrank Tomi Malmström Paulus Torkki Antero Vanhala



Universidad Valencia	Politecnica	de	Preparing local case study presentations	Raquel Faubel Teresa Meneu
			<ul> <li>Running futures workshops for each case instance</li> </ul>	
			<ul> <li>Reporting back on futures workshops</li> </ul>	



# III. SETTING THE SCENE

3.1. Scenario methodology overview

A key objective of the MANAGED OUTCOMES project has been to identify opportunities for improving health service operations in Europe, and the scenario analyses have supported this by:

- Detailing and refining the specifications of models that identify variables and possible explanatory hypotheses regarding the links between resource usage and health outcomes as revealed by the different health systems case studies.
- 'Using the future' to explore potential implications for current health service operations management decisions in the present through the medium of expert stakeholder engagement with the issues.

Case studies in the MANAGED OUTCOMES project are illustrative; they are not - nor were ever intended to be – *representative* of the national health systems of the countries in which they are situated. However, in so far as analyses have been undertaken at regional health service provider network levels and depict different operational models and operations management practices in the respective partner countries, they expose many of the more general anticipatory assumptions that play a major role in shaping current decision making and operational practices in those countries.

The MANAGED OUTCOMES WP2 deliverable (2010) has a more extensive discussion on scenario methodology approaches, but a reminder here of a definition of scenarios is helpful<sup>3</sup>:

'descriptions of fundamentally different future states of an organization's environment considering possible developments of relevant interdependent factors'

The process by which the descriptions of 'future states' are arrived at is important. A common distinguishing feature<sup>4</sup> is that scenarios are not predictions aimed at getting the future 'right' or focused on a single point in time but, rather, concerned with creating a range of 'stories' about the future; especially those which challenge existing thinking and world views. In this respect scenario development can support the efforts of a 'learning organisation' to gain a better understanding of existing and emergent systems and factors in its environment. With this goal in mind managers can use scenarios to consider the way potential future states influence what their organisation perceives and acts upon in the present. This can potentially result in significant reappraisals of an organisation's core functions and structure if pursued with serious intent. An effective organisational learning process<sup>5</sup>, is one which enables the mapping, challenging and improving of mental models of an organisation and its purpose – crucial into today's economically challenging environment.

It is important to recognise that the methodologies for thinking about the future have advanced since the initial work on scenario planning in the second half of the 20<sup>th</sup> century. The method adopted for this project takes as its starting point the lessons learned from the work of people like Schwartz<sup>6</sup> and van der

<sup>3</sup> Brauers, J. and Weber M, (1988) A new method of scenario analysis for strategic planning, Journal of Forecasting, 7, pp. 31-47 quoted in (p23) Markham I, and Palocsay W, (2006) Scenario Analysis in Spreadsheets with Excel's Scenario Tool. INFORMS Transactions on Education, 6, 2, pp 23-31.

<sup>4</sup> Chermack T, Lynham S, Ruona W, (2001) A Review of Scenario Planning Literature. Futures Research Quarterly (Summer), pp7-31.

5 Senge P, Kleiner A, Roberts C, Ross R, Smith B, (1994) The Fifth Discipline Fieldbook: Strategies and Tools for Building a Learning Organisation. (New York: Doubleday)

<sup>6</sup> Schwartz P, (1991) The Art of the Long View. (London: Doubleday)



Heiden<sup>7</sup> that highlight the role of the process of scenario construction for achieving certain cognitive goals such as the identification by a group of people of:

- specific phenomena ('trends', events, organizations, patterns)
- shared discourse (ways of making sense of phenomena)
- values (hopes, aspirations for the future)

The approach to thinking about the future adopted for the MANAGED OUTCOMES project uses rich insights provided by the case studies and participants in the case study who also engaged in the Futures Literacy workshops to analyse how different operations models and management practices might function in an imaginary future.

# 3.2. Role of scenario methodology in the Managed Outcomes project

The MANAGED OUTCOMES project aimed to produce twenty-four case instances derived from the analysis of health service operations management practices for four distinct health conditions in six Member States. Results and analyses from these case studies was to provide input for the scenario development process, which sought to establish and test out the characteristics of 'successful' operational processes; particularly with respect to health outcomes (remembering, of course, that scenarios do not offer national-level comparisons between countries and their systems of health care, but can only be seen as providing comparisons between site-specific regional health care systems).

In addition, scenario workshops sought to tease out future directions of health, well-being and care and contribute material to the debate over the future structure of health care. (However, it is important to note that neither the definition of the variables nor the collection of the data was undertaken with the sole aim of producing 'scenarios of the future'). A further important aim of the case studies was to enable comparative analysis between processes for the same health condition in different Member States. The main attributes of the cases are, therefore, descriptions of current health service operational practices and the service users' perceptions of the outcomes of experiencing those processes.

The process for using the case study insights in scenario formulation, as envisaged in the WP2 methodological report, is depicted in Figure III-1.

<sup>&</sup>lt;sup>7</sup> Van der Heijden K, (1997) Scenarios: the Art of Strategic Conversation. (New York: Wiley)





Figure III-1. Steps in the comparative analysis

The narrative or scenarios are grounded in data arising from the case instance reports, outcomes survey data and the input from external experts - including clinical professionals, managers and other relevant stakeholders - regarding relevant clinical and policy developments for these conditions.

In view of the scope of the MANAGED OUTCOMES project and its demand based approach, developments regarding the following topics have been explicitly addressed in a series of stakeholder workshops and interviews on future scenarios:

- Changes in perception, expectation and valuation by health service users and providers
- Changes in volumes and nature of demand
- Health service process improvements, particularly regarding development and coordination of care networks
- Health service provider improvements, particularly with respect to organisational development and process operations

With some adaptation to timing and order, this approach served us well. A first process modelling cycle took place under the auspices of WP3 with initial development of three of the operational models (diabetes, stroke and hip OA), and some early comparative case study findings which were used in the first round of feedback sessions with local clinical and managerial colleagues. Their comment and interpretation enabled further case study data refinement and scenario development which was then used in wider futures literacy workshops with stakeholders. These workshops usually included some of the same local key players who had been involved in the first-round of feedback which, in turn, helped to enrich the subsequent futures literacy workshop discussions as they had prior knowledge and understanding of the project aims and objectives.



While feedback sessions and futures literacy workshops proceeded, development of the operational models continued and, with the completion of the patient outcome surveys, there was sufficient material to start the wider economic modelling linking processes and their resource usage to the outcomes (see sections 3.2 and 3.3 below).

3.3. Methodological challenges and rationale of adopted methodology

Both comparative and scenario analysis have to deal with differences and discontinuities across the case studies due to national and condition-specific data definitions, availability, and coverage. Moreover, the nature and extent of the information pertinent to the construction of scenarios also differs across cases and these limitations have important implications for the design of the scenario processes used.

Issues which were encountered and which we took into account included:

- The health outcome surveys especially those for hip OA and stroke measure health status of patients at points in time which lie outside the scope of the operational model boundaries and the process under investigation. Outcome measures which remain meaningful while recognising this issue have been developed as far as possible
- Accounting for variable response rates from patient and carer surveys in the same case study in different countries
- Differences in data definitions and baselines between case studies arose due to our need to use only routinely available data for the case studies and, consequently, this has given rise to some difficulties in explaining differences between case studies



# IV. METHODOLOGY & FINDINGS

#### 4.1. Futures Literacy

Organisations, policy makers and people in general use the future constantly to focus attention on aspects of the world around us and to make decisions. When the use of the future is done in an explicit fashion it usually involves one form or another of a narrative or story. These stories can be called scenarios. A wide variety of methods can be used to generate these scenarios, ranging from probabilistic models for short term phenomena that are assumed to be non-stochastic, to more creative approaches that accept the non-ergodic nature of complex systems characterised by novel emergence. As outlined in the WP2 Methodological Handbook there are different ways of teasing out the material locked in the 'system' (most usually in people's heads), that describes it and the future imagined through the scenario development process. There are a variety of methods for developing scenarios, including models that project the future on the basis of past data to expert validated rounds of scenario development as produced through a Delphi process. With a Delphi process there may be a series of 'rounds', questions that develop iteratively, reflecting and building on insights which have gone before. It is particularly useful when it is not possible to gather expertise together in the same place, and it is a straightforward methodology to apply.

Although considered the most likely methodology that would be employed in MANAGED OUTCOMES at the project proposal stage, further consideration led us to regard it as inappropriate for this study for a number of reasons: first, the highly specific and local nature of the data collected in order to grasp the specificity of the health processes provided a particularly rich foundation for using the local knowledge to generate the images of the future; second the iterative nature of the Delphi process did not fit easily with the lumpy and intermittent flow of results from the case studies; and third, the importance of identifying shared systemic anticipatory assumptions meant that the action research approach of Futures Literacy workshops provided a more robust methodology.

The advantages of the Futures Literacy (FL) method given the nature of the data and analytical aims of the MANAGED OUTCOMES project, as well as the ease of implementation due to the involvement of Riel Miller, an expert in this method, provided a strong case for this approach. FL workshops, conducted around the world over the last decade provided a solid basis for designing and implementing this approach for Managed Outcomes<sup>8</sup>. The adoption of the Futures Literacy methodology allowed Managed Outcomes to more effectively achieve two goals:

- scenarios supporting the project aims,
- testing and extending the utility of the FL methodology in the field of healthcare with new experiences of its application to draw on and the development of prototype materials for subsequent application elsewhere.

A key advantage of the FL approach for this project is that it provides a systematic way to use the information from the case studies as well as the in-depth knowledge of workshop participants and other experts. The significant advantage over a standard Delphi approach is the ability to focus the acquisition of the expertise and condense it into a short period of time using a more targeted and focused group of people (compared to the difficulties of choosing and recruiting participants for a Delphi panel). The FL methodology also enables more immediate and useful direct 'learning feedback' for the participants of the workshop. Another advantage over a Delphi exercise is the ability to take into consideration the different systemic assumptions of the participants even from within a common organisational setting or operating environment. In the context of MANAGED OUTCOMES participants also shared a common set of

<sup>8</sup> Miller R, (2011) Futures Literacy – Embracing Complexity and Using the Future. Ethos, 10, pp23-28.



experiences. By moving the groups anticipatory assumptions from tact to explicit the FL method enables participants to deepen their own understanding of their own procedures and how the future enters into such understanding.

The specific FL technique for both constructing and making sense of the scenarios is a general foresight methodology that works through three levels of reflection and analysis set out in table IV-1 below. The process introduces elements of action-research where the identification and invention of evidence is an explicit part of the foresight process<sup>9</sup>.

Futures Literacy	Task	Technique(s)
Level 1 Catalytic Awareness	Temporal awareness, shifting both values and expectations from tacit to explicit – builds the capacity of participants to define and refine the specific topics for the MANAGED OUTCOMES scenario process	A wide range of catalysts (existing scenarios) and processes (group work) generate the discussions and sharing of stories that define the values, expectations and topics for the MANAGED OUTCOMES scenario process
Level 2 Imaginat ive Discovery	'Rigorous Imagining' involves two distinct challenges – imagination and rigour, the former in order to push the boundaries and the latter so that what is imagined is done so in a systematic and intelligible manner.	Escaping from the probable and preferable to imagine the possible demands systematic creativity and creating systematically, non-discursive reflection and social science are essential ingredients
Level 3 Strategic Choice	Strategic scenarios aimed at questioning the assumptions used to make decisions in the present; not as targets to plan by, but to provide new insights into actions that might alter the potential of the present.	Strategic scenarios are constructed using the capacities and stories acquired in developing Levels 1 and 2, by combining values, expectations and possibilities into scenarios that follow clear narrative rules.

#### Table IV-1. The Three Phases of a Futures Literacy Process

In the MANAGED OUTCOMES project, the FL methodology was employed using the Hybrid Strategic Scenario (HSS) method. This action research method provides a design framework rooted in a set of foresight principles<sup>10</sup> that help to guide the customisation of the scenario process at each step in order to construct and then connect imaginative and coherent strategic scenarios to policy options relevant to decision makers. As participants move through a 'FL-HSS' process the comparative analysis from the case studies - together with the expertise of the workshop participants – produces a picture of both current and alternative anticipatory assumptions about the future of managed outcomes in the health care sector.

<sup>9</sup> Miller, R. (2007) Futures literacy: A hybrid strategic scenario method, Futures — the Journal of Policy Planning and Futures Studies, 39, pp. 341–362

<sup>&</sup>lt;sup>10</sup> Miller R, and Poli R, (2010) Anticipatory systems and the philosophical foundations of future studies. Special Issue, Foresight, 12, 3.



Working through the stages of the FL-HSS method initially exposes participant's existing assumptions about values and expectations. The process develops a shared understanding of the anticipatory assumptions, finding common threads and systemic coherence across disciplines.

For each case in the MANAGED OUTCOMES project, the FL scenario process comprised three main phases:

- a preparatory phase using the data from the case studies to provide comparisons between case studies across countries and to develop potential catalysts for discussion
- a workshop phase for engaging in Level 1 and 2 exploration and co-creation of rigorously imagined futures that can be used to sketch strategic scenarios
- an analysis phase which examines the fit between existing operational models and operations management and the 'systemically distinctive future states of an organization's environment' evoked by the strategic scenarios

The preparatory phase was executed by each the workshop team in each partner country and included the assessment and interpretation of the case data in line with the developments identified in the preliminary phase. This was presented to participants partly to report back to them initial analyses of the case study data which they had not seen before this point, and also to help stimulate their thinking for the FL sessions which followed immediately afterwards.

During the workshop phase the scenario analysis team began with a 'Level 1' exercise to co-create a framework for workshop participants' future expectations and aspirations. This gave a basis against which participants could project their current assumptions, ideas and values of the future.

In 'level 2' the session moved into a more explicitly creative, but still rigorously structured, phase. Here, the picture was deepened to create the parameters for imagining distinctive and detailed scenarios. These scenarios avoid the pitfalls experienced by many other methodologies by excluding futures that take the forms of 'high vs. medium vs. low'. Level 2 strategic scenarios are descriptive (not causal) and on a common basis of comparison; solely differentiated on the basis of operational (institutional, behavioural, cultural) grounds. So the session tries to get participants to explore 'within' and 'without' influences on their system of interest and how these might interact with each other in the future. The effects of substitution (eg of one technology for another); complementarity (eg new technologies working in complement with existing ones); and emergence (where a new technology radically alters the environment of the existing system in ways not easily prefigured) are all important concepts here.

'Level 3' continued this refinement process and was designed to evoke innovative propositions about the ways in which the questions 'what do you expect?' and 'what do you desire?' influence what is imaginable and feasible. The extent to which it was possible to engage stakeholders at this level was more variable than with stages 1 and 2; this is discussed further in section 3 below.

The third phase of work after the futures workshops brought together the material from the futures workshops with that of the operational and economic models and contributed to identifying potential management practices which best address health service demands in each of the formulated scenarios. The FL workshops enabled the scenario teams to present robust and innovative research findings regarding the resilience of health service provider networks to the scenarios likely to unfold in future decades.

#### 4.1.1. Futures Literacy Workshops

In some partner countries (Finland, Spain) case studies were all undertaken at the same location while in others (Greece, England, Netherlands) they were carried out in several different locations. Futures



workshops were carried out at nearly all of the case study sites with some exceptions table IV-2. Due to lack of cooperating institutions the FL workshops were not organized in Germany.

	Stroke	НірОА	Diabetes	Dementia
England	Yes	Yes	Yes (expert meeting)	Yes
Finland	Yes	Yes	No	Yes
Greece	Yes	Yes	Yes	Yes
Netherlands	Yes	Yes	Yes	No
Spain	Yes	Yes	Yes	Yes

#### Table IV-2. Futures Literacy Workshops held and case study location

Out of a total of 20 potential futures literacy workshops (four in each of five partner countries), 18 workshops (one of which was a smaller-scale 'expert meeting') focused on scenarios were held with relevant stakeholders. Only in two cases were scenario workshops or meetings not able to be held at all (due principally to availability constraints of stakeholders). Workshops ran for half or full days; the expert group meeting in Tower Hamlets was a shorter session held in lieu of a full workshop. Appendix I provides a summary commentary, grouped by case study, based on material from all of the workshop reports held, and appendix II provides accounts of the individual workshops, grouped by country.

# 4.1.2. Structure of the workshops

Futures Literacy workshops are usually designed to run over a single day but it became clear as the first workshops were being organised - and with the experience of the first workshop (which was designated as a pilot and was held in England on the stroke case instance) - that having attendance of clinicians for this length of time would be the exception rather than a rule in most partner countries. Where a full day was not available, therefore, the workshop was designed to fit a 5-hour schedule which had the following general pattern:

- Lunch and introductions to other participants, the MANAGED OUTCOMES project, the scope of the particular case instance, and the futures literacy workshop process.
- An overview of initial comparative case study and outcomes findings across partner countries plus any interesting country-specific findings from the data.
- The Futures Literacy workshop process focusing on introductory explanations and scene-setting, group working sessions and plenary discussions.

See appendix III for an example of a workshop agenda and schedule. Where more time was available (for example, a whole day was possible for the hip OA workshop in England), the same general structure applied, but with more time available for presenting and discussing comparative case study material. It also enabled more time available for group working in the Futures Literacy sessions.

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A mix of participants was sought for those attending the workshops with contributions from a variety of spheres including: clinical (comprising a potentially wide range of medical, nursing and other clinical staff); managerial (from different organisations within the regional health care setting as appropriate); and other stakeholders (for example, relevant voluntary organisations such as the Alzheimer's Society in connection with dementia). While participants could include expertise drawn from outside the case study location, in practice they were mostly drawn from organisations in those areas which had been central in providing access to data or supporting the patient surveys.

## 4.1.3. Experience of running the Futures Literacy workshops

The FL workshops were led by project team members from each partner country and held in the local language (in the Netherlands they were run in both English and Dutch as the workshops held here were partly supported by Paul Forte from the UK project team). The process began in January 2012 when all partners involved in the workshops held a project meeting to develop materials for the MANAGED OUTCOMES application of Futures Literacy. This led to the first workshop - the UK stroke case study - being held in March and run as a pilot. – It was led by Riel Miller and all project partners also attended to observe and participate at first hand and consider any aspects that needed adapting for local application in other partner countries.

In all workshops, initial summary case study comparative material from WP3 was presented locally as an introduction to the MANAGED OUTCOMES project and to offer a basis for futures discussion. The Futures Literacy sessions then followed, based on materials produced by Riel Miller with support from Paul Forte, and with subsequent changes made in the light of the pilot workshop experience (and language as necessary). These materials were then used as the basis for all case instances although local adaptation was encouraged as necessary. In practice, though, there was little variation employed from the original slides and working notes.

The structure of the workshop (presentations interspersed with group work and plenary discussion sessions) was also adaptable and there was more variation across partner countries in this. In Spain, for example, the four case studies were run on the same day within the same overall workshop with parallel group sessions (organised by case study) and common plenary discussion sessions. In the Netherlands a similar approach was adopted for the stroke and hip OA workshops which were run together. This way of working was useful where the case studies themselves involved the same local institutions.

Flipchart and other notes from all group and plenary sessions were retained and written up (see appendix II) and, in Greece and Finland, sessions were also voice-recorded to support subsequent write-up of material.

One aspect in particular emerged, however, that merits further note is the extent to which typical locallevel workshop participants were able to fully engage with some of the policy issues which were raised in the course of discussion. Participants were, for the most part, more closely involved in operational aspects of services and even those in more senior clinical or managerial roles have a relatively low input to significant policy decisions when looking at regional-level health care networks. Previous experience of FL methodology outside MANAGED OUTCOMES use has been more commonly with people operating at a policy-making level, and there can be something of a disconnection between policy aspirations and their decision-making space, and that within which operational stakeholders can shape and influence matters. This helps to explain similar reports from different workshop settings of some overlap in the type of responses which participants gave to the questions posed at levels 1 and 2; with more difficulty in moving issues from 'level 1' discussion of their everyday experience to 'level 2' where more consideration of policy and control in the future could be implied.

There were also some difficulties encountered in using the material for the dementia case study in particular which confronted the question of how a postulated 'Learning Intensive Society' could contribute to the needs of people with deteriorating cognition, and the consequent need for patients to be accepted for who they were and what matters to them now, with important implications for the way that care was integrated across both formal service providers and informal carers.





The overall opinion of the FL workshops, from both those running them and those participating, was that they were a success. All workshops resulted in good engagement with some workshops running well beyond the end of the scheduled sessions due to the enthusiasm of the debate and discussion. Unprompted feedback at several sessions remarked on the usefulness of having time to reflect with local colleagues on issues to do with the future direction of services in a way which is normally not possible in the day to day working environment. Despite initial unfamiliarity with the materials, partners in all countries where workshops have found the FL approach robust and relatively straightforward to understand and apply, and several commented that they would consider using it again outside the MANAGED OUTCOMES project. This implies that there is good potential to develop and apply the material as a workshop tool in health planning and scenario development beyond the scope of this project.

4.1.4. Key themes on health over the next 30 years arising from the workshops

There were some common broad themes which emerged from across the workshops and partner countries:

- A big increase in the role of ICT in health care was seen as inevitable in most countries. This was linked to an increase in 'personalised medicine' and the rise of genetic screening. This extended to service provision as well and the role of telehealth (particularly for people with dementia and their carers) was frequently mentioned.
- A decrease in overall levels of health status (ageing, economic factors) or, in some cases, an increase in the disparity of health status between different socio-economic groups.
- The 'hospital of the future' could increasingly be the home of the patient with hospital facilities becoming increasingly specialised and care professionals within them handling complex care only. The emphasis on community-based service provision was noted across both case instances and across all case study sites.
- The extent of cultural variation within countries as well as across them. This included more philosophical points of view around societal acceptance of dementia ('now at the point of acceptance that cancer was 20 years ago' (UK), but also thresholds of pain, and attitudes to death and end of life care. Patient expectations of health care in all countries were seen as increasing as well as a shift towards health as an 'absolute' rather than 'relative' condition.
- Importance of integrated care and of primary care team management of conditions particularly for diabetes and stroke was a common perspective across all workshops.
- More self-help and management, with nurses taking on a greater 'health counsellor' role. This coresponsibility and patient empowerment was characterised across all case instances and seen as a positive move away from paternalism by the medical profession.
  - 4.1.5. Relating workshop findings to draft proposals for a new WHO European Office health policy: 'Health 2020'

There are notable alignments between emerging FL workshop findings and some of the main features of the 'Health 2020' draft recommendations WHO Regional Office for Europe<sup>11</sup>. One of the six main goals of 'Health 2020' also gives particular importance to the concept of 'patient-centred' health systems by promoting the idea of increased participation:

<sup>11</sup> WHO Regional Office for Europe, (2012) The New European Policy for Health – Health 2020: Vision, Values, Main Directions and Approaches [DRAFT]. (Copenhagen: WHO Regional Office for Europe).



'Empower the people of the European Region to be active participants in shaping health policy through civil society organizations, to respond to the health challenges facing them as individuals by increasing health literacy and to ensure their voice is heard in person-centred health systems.'

Similarly, increasing the innovative and adaptive capacities of the health care systems - which arose frequently in workshops across partner countries and case studies (eg increasing the use of ICT; developing community-based services) is another strategic aim of 'Health 2020':

'Increase the knowledge base for developing health policy and addressing the social determinants of health, by enhancing the capacity of health and other professionals to adapt to the new approach to public health and the demands of person-centred health care in an ageing and multicultural society, and by making full use of the technological and managerial innovations available to increase impact and improve care.'

In terms of values discussed in the FL workshops these, too, are in line with WHO policies, particularly with respect to greater personalisation of health care and information to support greater individual responsibility:

'Further increase the number of years in which people live in health, improve the quality of life of people living with chronic disease, reduce inequities in health and deal with the impact of demographic change.'

'Empower the people of the European Region to be active participants in shaping health policy through civil society organizations, to respond to the health challenges facing them as individuals by increasing health literacy and to ensure their voice is heard in person-centred health systems.'

As the supporting WHO report documentation notes, societal values underpin everything and health systems reflect as with any other social organisations.

#### 4.2. Operational modelling

Further development of operational modelling was undertaken as part of WP4. The case instances made already use of a first version of the operational model derived from the model as described in the methodology handbook and developed during the pilot phase of each case. This first version was used to collect the data for the operational model in the case instances in a standardised way, during WP3.

In WP4 the objective was to develop the operational model further. By taking the experiences with the operational models into account we have developed a specific operational model for each case that can handle case instance differences and that is able to calculate efficiency measures as output of the model. The advantage of this redeveloped model is that now also the calculation of outputs from the model is standardized. This is also important for using the specific model for what-if analysis following from the scenario modelling in WP4.

The purpose of this further modelling was to integrate our experiences with the operational models in the new versions and to make it possible to use the models developed for use outside the context of MANAGED OUTCOMES. For type 2 diabetes, stroke and hip osteoarthritis a spreadsheet model was developed that enables the description and analysis of regional service delivery networks studied. The models include a short introduction and are, in combination with information provided, self-explanatory<sup>12</sup>. For the dementia case study it was not possible to develop a similar spreadsheet model as the case instance studies performed did not make use of an equivalent operational model.

We describe in Section 4.2.1 the main structure of the models developed and reflect in Section 4.2.2 on the possibilities to use the models in new settings.

<sup>&</sup>lt;sup>12</sup> The spreadsheet versions of the models will be made available through the Managed Outcomes website: <u>www.managedoutcomes.eu</u>



#### 4.2.1. Developing specific models for each case

The generic model for regional health service delivery as described in the Methodology Handbook of MANAGED OUTCOMES has been the basis for the specific models per case. Figure IV-1 shows the main structure of the operational model.



Figure IV-1. The main structure of the operational model

The demand for the patient group studied, as arising from the population in the region investigated, is described in terms of demand location and demand segment. Distinguishing demand locations in a region provides the possibility to take into account differences in demand in different parts of the region investigated. Demand from more urban areas may for instance differ from more rural areas. Distinguishing demand segments makes it possible to differentiate between different target groups for specific services. For instance the target group for prevention and the target group for treatment.

The driver of the model is the new users that enter the system each year. The model follows the new users, identified by demand location and demand segment, through the health service delivery system. The first stage is the demand for services distinguished in response to the demand arising from the users. The list of services may contain a prevention program, a diagnostic program, a treatment program and follow-up services. Such a service consists of service elements, which are the individual activities that need to be performed to deliver the service. As follow up services are also considered we can describe the complete use of services generated by the demand arising from the new users.

The user journey connects the demand for services with the supply of resources for services, and describes the journey of the user through the service delivery system. As patients require often services from different providers, the user journey describes the way the user makes use of the network of providers from the perspective of the user. For the journeys in the stroke case and hip osteoarthritis case this is more or less straightforward, but for the type 2 diabetes case we had to model the journey over the patient career as diabetes is a chronic condition that progresses in time.

Table 5 presents the five demand segments distinguished for type 2 diabetes. DS2-5 describes the different health states which a patient can be in during their lifetime. In stage 1 and 2 the patient can be treated with lifestyle advice and oral medication. In stage 3 the patient becomes insulin dependent and



needs insulin injections to control the blood sugar levels. In stage 4 complications may arise that need specialized care often provided in a hospital.

Number	Name	Description of target group
DS1	Prevention	Population that is at risk for developing diabetes type II
DS2	Diabetes care stage 1	Patients with diabetes type II needing lifestyle advice.
DS3	Diabetes care stage 2	Patients with diabetes type II needing lifestyle advice and oral medication.
DS4	Diabetes care stage 3	Patients with diabetes type II needing lifestyle advice, oral medication and insulin injections.
DS5	Diabetes care stage 4	Patients with complicated diabetes type II needing specialized care.

#### Table IV-3. Type 2 Diabetes demand segments

Once a patient is diagnosed as having diabetes the patient can either move in time from DS2 to DS3, DS4 and DS5, or alternatively the patient can move directly to one of the higher stages. We decided to model only the most common flows, which are shown in Figure IV-2.



#### Figure IV-2. Service user journey for diabetes patients

Figure IV-2 shows that the diabetes patients move after maximum three years from DS2 to DS3. While patients are in DS2, a small percentage (1.2%) leaves the model, either by dying or by moving to a house in another region, and another small percentage (0.5%) moves due to complications to DS5. Patients stay maximum 9 years in DS3, with again small percentages leaving the model or moving to DS5. Patients stay maximum 10 years in DS4, with larger percentages leaving the model or moving to DS5. Patients stay maximum 10 years in DS5, before they die. While staying in a DS each year an equal fraction moves to the next stage, resulting in all patients in a next stage after the maximum term in a demand stage. The data are example data from one of the case studies, based on expert estimates and supported by data from diabetes registers. The model is called in mathematical terms a semi-Markov model as only limited states and transfers are distinguished.

The user journey also determines the amount of resources required from each service provider in the service provision points (SPP's) that are used by the service provider. A service provision point is a physical location where resources are available to deliver the service. A service provider may operate in different



SPP's. It is also possible that different service providers use the same SPP. The actual coupling between service and resource takes place at the level of each service element required for the service. The resource requirements can be translated to costs using the unit price at the level of each service element.

The different components of the operational model allow to describe the operations for delivering services in a systematic way, and to arrive at a calculation of the costs of a service. The systematic description and the use of a spreadsheet model with these components also uniforms the way the data are collected in different settings. It enhances therefore the quality of the data collection and facilitates the comparability of descriptions of different regional delivery systems.

For the operational models of stroke and hip osteoarthritis we made use of the same modelling approach as for the diabetes model, but it was possible to model the patient journey in a simpler way. As the demarcation of the stroke case is confined to the diagnostic and treatment phase (the chronic phase is outside the demarcation), modelling the patient journey is straightforward: Ambulance - Emergency Department - Stroke unit - Ward. For hip osteoarthritis modelling the patient journey is also straightforward: GP referral – Diagnosis – Admission – Surgical Procedure – Rehabilitation.

#### 4.2.2. Possibilities for applying the models

The three models developed can be used for a number of purposes. First of all the models can be used to describe type diabetes care, stroke care and hip osteoarthritis care in new settings. A limitation is the demarcation used in each case, which was set out at the start of the MANAGED OUTCOMES project. Use of the models in different case instance settings would make it possible to compare the results with findings from this study.

A second possibility for using the models is to test the sensitivity of the models for variations in inputvariables. For each of the models one could distinguish a number of scenarios using variations in input as main driver. One could for instance vary demand (incidence, length of stay in a demand segment), services (mix), resource requirements, et cetera. This could be for further research beyond the current project.

Another option could be to use the models for doing what-if analyses for the assumptions used in the scenarios proposed for each of the cases. This would again be a recommendation for follow-up research.

# 4.3. Economic modelling

Within the framework of the WP4, economic modelling aims at complementing the operational modelling in formulating scenarios which provide guidance for the creation of healthcare service production systems for different environments.

Methodologically, economic modelling was based on the economic evaluation in healthcare principles and methods, and used data produced in WP3 (case studies and questionnaire survey). This approach allowed a better understanding of the efficiency of each healthcare services production system of each partner country, in order to draw comparative conclusions and formulate future scenarios effectively.

#### 4.3.1. Methodological considerations

Economic evaluation is a tool which allows decision makers to allocate resources rationally, so that efficiency of the healthcare system is increased. Usually, the question is whether to put more resources in one medical intervention or in another, so what is sought to be answered is: what is the additional (incremental) cost of intervention A over intervention B, relative to the additional effect (outcome) of intervention A over intervention B.



Thus, economic evaluation examines the relationship of costs (resources, inputs) on the one side and outcomes on the other, when comparing to competing allocation of resources. In healthcare research, four types of economic evaluation are mostly used. In all types costs are measured in monetary units. What differs is in what units the outcomes are measured:

Cost-minimization analysis (CMA): outcomes are measured in natural units and assumes that outcomes are identical or very similar in the two interventions compared (e.g. for blood pressure reduction after two medical interventions, same reduction was achieved by both interventions which is measured in mmHg). So, for the similar outcomes, we examine which intervention was the less costly.

Cost-effectiveness analysis (CEA): outcomes are measured in natural units. The two interventions compared must be such, so that they are measured in the same natural units even though they have different magnitude of effect (e.g. for blood pressure reduction after two medical interventions, one achieved greater reduction than the other, but both outcomes are measured in mmHg).

Cost-utility analysis (CUA): outcomes are measured in units which encompass the concept of utility, like the Quality Adjusted Life Years (QALYs). Utility is a theoretical construct of the satisfaction derived by the consumer of a health service. Usually, utility is measured with the use of generic or disease specific Health Related Quality of Life Questionnaires. In Managed Outcomes the widely used generic tool EQ-5D has been used, together with other specific quality of life (QoL) questionnaires/scales incorporated in the questionnaires of the survey conducted in WP3.

Cost-benefit analysis (CBA): outcomes are measured in monetary terms (after employing specific procedures for the valuation of health outcomes). This is the most demanding and least used type of economic evaluation in the medical literature.

In conducting economic evaluation analysis, the methodology is very strict as to the comparability of the medical interventions, which means that there are strict criteria. From all the above it is evident that:

Within the framework of the purposes of MANAGED OUTCOMES, we could not fully apply any of the four types of the economic evaluations, because the design of the project was not to compare two exactly same treatments or health services in order to find out which one is more efficient. Indeed, the very essence of MANAGED OUTCOMES was to build on the differing processes and procedures in each of the health systems of each partner country/case study. The data we had from WP3, allowed us to adopt basic only features of:

- cost-effectiveness analysis (CEA): resources/costs and outcomes in physical units
- cost-utility analysis (CUA): resources/costs and outcomes in QALYs (using in particular the Dolan index of EQ-5D scores as explained in the WP3 final report)

Based on the methodology of WP3, the following assumptions were adopted:

- Given that costing data have been collected according to the study demarcation for each case study, outcomes used for the comparison of costs and outcomes should also be related to the outcomes achieved within the study demarcation.
- Whenever required and possible, quality of life outcome indicators were considered as stable during a study period, that is, one year, so the EQ-5D score can be considered equal to 1 QALY (quality adjusted life-year).
- There have been no major reforms in the health systems under study between 2009 and 2010, so, cost data which were collected during 2009 could be related to patient reported outcomes data which were collected from patients treated in 2010.

Apart from the costs being expressed in euros, the Purchasing Power Parity (PPP) index was used, so that all costs were also reported in a more comparable form. PPP transformation takes into account the differing purchasing power in each country (e.g. differing level of salaries, differing consumer price index, etc.). For this reason, the PPP coefficient for 2009 (at aggregate GDP level) as calculated and reported



by EUROSTAT was used. So, by using each country's PPPs, euros were transformed into PPS (purchasing power standards) the comparable (equivalent) imaginary monetary unit.

In terms of outcome measures, for all indicators the mean standardised values were used. Standardisation was done by using the main (statistically significant) characteristics of the entire (from all countries) study population. The figures used are those reported in the questionnaire survey results.

See appendix IV for a more detailed economic analysis by case study.



# V. SYNTHESIS

#### 5.1. Introduction to scenarios

In succeeding sub-sections we present a range of scenarios for each case study but, as there are some features and terms in common to all of them, we begin by describing and defining them.

Each case study can itself be viewed as a scenario in that it describes a particular set of processes and associated outcomes. However we are aiming more particularly to develop 'good practice' scenarios which we define as 'descriptions of configurations of services and process that deliver the best outcomes for a given cost' (refer again to figure 1 above). Note that 'good practice' here is not the same thing as 'best clinical practice'; rather it is about taking a wider view and setting clinical practice in the context of the most efficient use of resources and most effective outcomes for patients.

All of the scenarios make extensive use of various data sources accessed and developed during the course of the project: case study data (including local routinely available data sources); user surveys; and outputs from the Futures Workshops materials. We have produced two or three scenarios for each case study which have arisen from these sources and our investigations, modelling and discussions. All scenarios encompass some widely familiar issues and trends, but are given added weight by virtue of varying degrees of support from the project findings. However, it is important to remember that the scenarios are not validated in any technical sense and should be regarded as 'considered expert opinions' drawing from the experiences of the MANAGED OUTCOMES project.

#### Regional healthcare systems

An important aspect of MANAGED OUTCOMES has been a focus on 'regional health care systems'. These can be - but not necessarily - defined administratively; service population catchment areas can also define a 'healthcare region'. Individual case studies are products of the national health systems (often with additional locality-specific influences). The case studies were not chosen to be representative of the countries they are sited in and comparisons between them should not be taken as national comparisons. However, although we normally use the case study organisation site names in this section to emphasise their uniqueness, we also use the country name as a short-hand descriptor on occasion.

#### Standardising cost comparisons between countries

With the exception of the UK, all case studies have taken place in eurozone countries. Even with a common currency, however, there are differences in the purchasing power of the euro in different countries. To achieve 'purchasing power parity' (PPP), Eurostat publishes an annual set of co-efficients for each country to enable standardised cost comparisons. In our case these have been aggregated at the GDP level for 2009 to be consistent with most of the case study activity data. Applying PPP to euros gives us 'purchasing power standards' (PPS) which are 'currency units' and, where possible, these have been used in the economic modelling we have undertaken.

#### Standardising health outcomes

The survey of service users (and their carers in the dementia case study) made use of the Euroqol EQ-5D tool to provide patient-reported health outcomes. There are two scales: one comprising five questions covering a range of health status aspects; the other is a 'visual analogue' scale where respondents mark their health status on a single thermometer-like scale (1-100). The EQ-5D tool is validated for different countries and languages and thus enables comparisons of health status to be made across case studies.

It is possible to consolidate the responses to the five dimensions into a single index<sup>13</sup>. It is this consolidated index which is used in the scenarios which follow.

<sup>&</sup>lt;sup>13</sup> Dolan, P, 1997, Modelling valuations for health states. Medical Care, 35 (11), pp. 1095-1108



The potential levels of outcome that can be considered in this exercise are constrained by the demarcations that were established at the outset and the data that has been possible to collect. However the use of Futures Workshops has allowed us to consider wider options based on expert opinion - and beyond the scope of the data - than might otherwise have been the case.

## QALYs (Quality Adjusted Life Years)

This is a measure of the value of health outcomes. It is based on the number of years of life that would be added by an intervention. Each year in 'perfect health' is assigned the value of 1.0 down to a value of 0.0 for being dead although, using the EQ-5D, a QALY can also be negative (implying a situation 'worse than death').

The concept of 'cost per QALY' is used in the economic modelling section to provide a means of comparing the value of outcomes between the case studies.



#### Diabetes

#### **General Observations**

Type 2 diabetes was chosen as a topic for a case study because of its status as a long term condition (LTC), and the trend towards increasing treatment in the primary health care (PHC) sector. The services and associated clinical processes included in the case study demarcation are variously concerned to prevent progression, control symptoms, encourage self-management, maintain health and avoid complications (see the WP2 Methodological Handbook).

The evidence from the case instances supports different scenarios that are dependent on the level of development of their regional systems. All of the scenarios require service development, especially in primary health care, but their characteristics vary according to the complexity of operations management possible. In addition there may be some degree of hierarchy in the scenarios in that those which are more complex (eg 'zero complications') may only be possible following the establishment of simpler scenarios.

Our summary economic analysis shows wide variations in costs and outcomes between case instances. For example, in demand segment DS3 (patients receiving oral medication), Valencia (Spain) has the lowest costs and is amongst the lowest in terms of outcomes, but returns one of the highest health outcomes rates per standardised Euro. Keski-Suomi (Finland) and the Netherlands case instance (Nieuwe Waterweg Noord, Delfland, Westland Oostland – known as NWN&DWO) have better outcomes but spend a lot more per patient and per QALY. Figure V-1 below illustrates all case studies (excluding Bamberg, the German case instance) with respect to the lowest cost case instance (Valencia, Spain).



Figure V-1. Cost (PPS) relative to outcome (EQ-5D) for DS3

The UK and Greece also spend alot more, but in these cases measured health outcomes are lower than in Spain. For the UK this is partly attributable to the underlying morbidity of the population in the region studied, which includes a high proportion of people of South Asian origin, and for whom an active programme to avoid complications is prioritised over preventive work to slow progression. For Greece,



where there is little development in PHC, services are commonly provided in relatively expensive secondary care environments rather than primary care settings. As a consequence patients might attend as frequently as necessary for closer monitoring of their condition.

## **Proposed Scenarios**

Bringing together the detailed evidence from the case instances, user surveys and the Futures Workshops, we have formulated three scenarios that represent good value, but whose applicability will be dependent on the degree of integration of the regional system:

- Low cost: maintain patients as long as possible in early stages of condition. There is an
  important role for generalist nurses in the community to encourage lifestyle change and
  help to minimise anti-diabetic drug use. There is also a key support function for them in
  doing this from specialist diabetes services usually found in secondary care settings.
- Diabetic control: active management of patients at all stages of the condition including pre-diagnosis. The level of 'glycosylated haemoglobin' (HbA1c) - and maintaining a balanced level of it - is a key clinical outcome here.
- 'Zero complications': ensuring that those diagnosed with type 2 diabetes do not experience a 'raised risk' for stroke, AMI (acute myocardial infarction), blindness and sight problems, and peripheral vascular disease and amputations. This requires both enhanced monitoring and treatment of hypertension and cholesterol amongst diabetic patients, and also greater focus on health promotion initiatives. Good registers and information systems are required to support this scenario in order for appropriate treatment points to be recognised and acted on for a given patient.

# 'Low cost' Scenario

The low cost scenario aims to maximise value, expressed as outcome relative to cost, in health systems where overall funding levels are low. This requires:

- Opportunistic intervention within primary care, in particular by practice nurses to encourage and support lifestyle changes in patients
- An increase in the training and support roles of specialist staff so they can provide appropriate and timely assistance to the primary care team and help them to maintain stability in the patient's condition.

Treatment costs for type 2 diabetes patients are largely determined by demand segment. This is because of the high costs of drug therapies, and especially of insulin treatment. In some countries patients move rapidly to drug therapies (i.e. demand segments DS3 and DS4) as illustrated by figure V-2.

For health economies with funding levels below EU averages the best use of investment may be in services that support patients to remain in lower cost demand segments (i.e. to maintain the patient on 'diet only' regimens), or to avoid progression to insulin therapy for those patients already receiving oral antidiabetic medication. Figure V-3 illustrates clearly the considerable jump in costs of treating patients in more severe stages diabetes - particularly as insulin treatment becomes necessary. The key resource in this scenario is the generalist nurse working in primary care, most commonly based at a general practice.




Figure V-2. Percentage prevalence in catchment population



Figure V-3. Annual cost of care by demand segment

Nursing forms a relatively low cost component of diabetes care in all case instances, and significant input could be possible (see figure V-4 below).





Figure V-4. Annual Unit Costs (€) of treating a patient requiring oral medication (DS3)

The scenario does not necessarily imply working to routine monitoring at fixed time intervals: commentators at several diabetes futures workshops highlighted that to do so was neither particularly effective nor efficient. More flexible working would enable nurses, with support from specialist diabetes staff when needed, to focus support on patients having difficulty with symptom control, and help them avoid progression to more complex stages of their condition.

To keep costs down the emphasis is not on regular diagnostic tests that will encourage additional medication, but on targeted patient support to encourage self-management, especially through diet and lifestyle control.

Note that it is likely that some patients will not be diagnosed at an early stage and therefore outcomes may not be good in all cases. However the Spanish case instance does support the contention that this approach, with its emphasis on health promotion rather than drug treatment, can generate good value for money where resources are limited.

# 'Diabetic control' Scenario

This scenario is focused on diagnosing as many patients with type 2 diabetes as possible, identifying those at risk of developing diabetes, and actively monitoring and intervening in symptom control. It requires:

- Information systems to identify <u>and</u> review patients
- Regular monitoring of patients, with substantial calls on diagnostic services

• The ability to undertake timely corrective actions including medication to maintain symptom control.

The case instances in the Netherlands and Finland are the closest to this scenario, and the processes above are key features of the diabetes service within PHC. As shown in figure V-1 this is more expensive



than the 'base case' of Valencia [Spain], but the reported quality of life measures are also substantially higher.

This is also reflected in the clinical outcome measure of average HbA1c level, which is the principal clinical marker used to demonstrate control, and shows a similar pattern of variation between cases as the EQ-5D index of quality of life.

We note however that in some futures workshops there was concern to avoid changes in the clinical definition of diabetes or at risk cases, and in particular any lowering of target HbA1c levels. What was done in the interest of identifying patients could result in medicalising them, and increase rather than decrease the numbers progressing to oral medication or insulin therapies.



Figure V-5. Percentage of patients with HbA1c < 53 mmol/mol

The case instances in the Netherlands and Finland also include the extensive use of patient support elements as described in the 'low cost' scenario. The additional use of information systems to generate call and recall of patients for monitoring could allow more targeted review cycles, with priority given to patients having difficulty with compliance.

## 'Zero Complications' Scenario

This scenario aims to ensure that patients with diabetes are not at increased risk of complications such as vascular or cardiac events as a result of their diabetic condition. It requires:

- Close monitoring in primary health care of all diabetic patients for cardiac and vascular and other comorbidities
- Secondary prevention, including use of medications to lower blood pressure and cholesterol levels



• Coordination and integration of condition specific management processes across the regional system.

It reflects the treatment model used in the Tower Hamlets case instance in the UK, where the emphasis is more on managing the non-compliant patients rather than attempting to reduce HbA1c levels further.



Figure V-6. Treatment model in Tower Hamlets (Source: Tower Hamlets Primary Care Trust)

The treatment of complications was included in the case study to the extent that foot care and diabetic retinopathy is part of core review processes in a number of case instances, although dealing with problems detected is not. Other complications were left entirely outside the demarcation of the diabetes case study, being seen as an outcome indicator of the care process. However this scenario includes primary and secondary preventive actions as part of the core processes for patients with diabetes. In practice the requirement is for greater integration of services rather than disease specific services, particularly because of the importance of monitoring for hypertension and cholesterol, and timely use of related therapies.

The move towards this scenario explains in part the higher costs associated with the Tower Hamlets case study in the UK. For practical reasons greater emphasis has been put on reducing complications than managing HbA1c levels, so for the UK there is relatively early reliance on medications, and also of cholesterol lowering therapies - in particular statins. This is reflected in the graphs at figure V-7 below, which show that, although recording lower levels of HbA1c control, Tower Hamlets exceeds the other cases in control of cholesterol and blood pressure.





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Figure V-7. Care balance in case regions

The costs of this scenario will be higher again that the 'low cost' and 'symptom control' scenarios, and there will not be visible gain in terms of the outcome measures used in the economic analysis (principally EQ-5D and HbA1c).

	Stroke	Problems with heart	Problems with lower extremities	Problems with sight
Tower Hamlets (UK)	10%	25%	19%	26%
Keski-Suomi (FI)	5%	22%	14%	12%
Bamberg (DE)	11%	24%	27%	20%
Herakleion (GR)	8%	31%	13%	19%
NWN & DWO (NL)	5%	16%	6%	9%
Valencia (SP)	5%	18%	17%	29%
All	8%	22%	16%	18%

Table V-1. Complication levels in case regions



The user surveys reported contrary values: the UK case instance had amongst the worst complication levels – hence prioritisation there – and Netherlands the least with its good symptom control. It may be that this scenario should be seen as the next step beyond symptom control, rather than a quick response to high morbidity.

The possibilities for the 'zero complications' scenario were discussed in a number of futures workshops, and in the dissemination conference held in Riga (October 2012). The implication is that there is substantial scope for the extension of primary and secondary prevention activities linked both to the comorbidities directly, and to the specific issues that diabetic patients face.

Diabetes and the related long term conditions are likely to require similar responses from the regional systems in terms of population management, including the use of information systems and the central role of the PHC system in coordinating these and consequent treatment responses. The direct role of public health specialists working alongside PHC staff was proposed as another mechanism for developing these roles.



# Stroke

## **General Observations**

Stroke was chosen as a topic for case study because of the relatively recent developments in emergency acute care processes, including the time critical issue of thrombolysis, which needs to be administered within 3 to 4 hours of onset to patients who can benefit. This requires rapid ambulance response together with prioritization of possible strokes within the ED, since a CT scan is essential to diagnose and identify the type of stroke. Beyond this immediate response is the requirement to access specialist stroke services in a timely fashion, and in most countries these are being set up in stroke units in designated hospitals. This pattern of service development was set out in the 2006 WHO Helsingborg declaration<sup>14</sup>. All case instances provided evidence to suggest that they were working towards full implementation of the recommended care processes. More formally case instances demonstrated this by completion of the EQAT-22 checklist developed by the EC funded European Registers of Stroke (EROS) project<sup>15</sup>. However the case study and user survey data demonstrated that the stage of development varied widely and this provided some insights into the best value approaches for European regions to adopt.

Given that stroke provides a case study for which we know there is a direct link between process efficiency and patient outcome, the interest in the case study analysis and modelling has focused on the processes that appear to have the greatest impact on outcome. Although this is commonly supposed to be related to maximizing access to thrombolysis, there are indications from our research that early access to specialist stroke care may be more significant across the patient population. Furthermore the concentration on the hyperacute phase in operational planning may mean that in some regions any further gain in outcomes may be dependent on greater coordination and preventive work within primary healthcare. Our scenarios are based on these hypotheses.

Our summary economic analysis of costs and outcomes indicates that the Valencia case instance in Spain has the lowest 'cost per QALY', and this is associated also with the lowest unit costs and EQ5D values. Figure V-8 shows values for ischemic strokes in all case studies (except Germany for which cost data were not available) with respect to this. Notably the case instance in the Netherlands reports the best outcome, and with unit costs lower than the other three case instances.

<sup>&</sup>lt;sup>14</sup> Kjellström T, Norrving B, Shatchkute A., 2007, Helsingborg Declaration 2006 on European stroke strategies. Cerebrovasc Dis. 2007, 23(2-3):231-41. Epub 2006 Nov 30

<sup>&</sup>lt;sup>15</sup> European Registers of Stroke (EROS) Investigators, Heuschmann PU, Di Carlo A, Bejot Y, Rastenyte D, Ryglewicz D, Sarti C, Torrent M, Wolfe CD (2009) Incidence of stroke in Europe at the beginning of the 21st century. Stroke 40:1557-63.





Figure V-8. Cost (PPS) relative to outcome (EQ-5D)

The case instance in Greece has similar outcomes to the Spanish one, and this is associated with a lack of specialist stroke facilities. The Finnish and UK case instances lie in between, with better outcomes than Greece or Spain, but at greater cost than the Netherlands case instance.

# **Proposed Scenarios**

Bringing together the detailed evidence from the case instances, user surveys and the Futures Workshops, we have formulated two scenarios that represent good value, and which may represent different levels of development in achieving the objectives of the Helsingborg declaration:

- Rapid access: ensure patients can access specialist stroke services as soon as possible after the onset of symptoms is reported. Although this allows thrombolysis in cases where the patient is both suitable and diagnosed in time, this scenario prioritises the specialist access over the hyperacute phase, as it is appears that the average outcome per patient may be greater, and further investment in speeding up the hyperacute phase unproductive.
- Early identification: further increase in the speed of access to hyperacute and other specialist treatment requires quicker notification to both the hospital and ambulance services. This, in turn, implies greater awareness amongst patients, carers and the public (especially those at greatest risk of a stroke). Initiatives within primary health care can support this, and potentially lead on to greater preventive effort in maintaining vascular health.

Potentially a third scenario could be outlined related to community rehabilitation. This would complement the developments in primary health care in the early identification scenario and is already a natural extension of the specialist stroke unit service in regions where these are already developed. However the community health aspects lay outside the demarcation of the stroke case study, and we have



insufficient detail on the process elements to set out such a scenario fully.

## 'Rapid Access' Scenario

The Rapid Access scenario represents a major step in the implementation of the Helsingborg declaration. This requires:

- Ambulance procedures to ensure patients with stroke symptoms are taken to the hospital with specialist services
- Prioritisation of patients for diagnosis within the ED.
- Immediate access to stroke specialists, and admission to stroke unit.

The key resources in this scenario are the specialist physicians (often neurologists, or in the UK geriatricians) and specialist stroke nurses, supported by physiotherapists.

The pace of development of specialist services differs widely between the case instances, as summarised in figure V-9. The countries with full access to stroke units also have the best outcomes (figure V-10). The Brighton (UK) case, which was in transition to a full specialist service at that time, also shows high outcome levels, but it should be noted that the user survey only included patients treated in the stroke unit at some stage in their care.



Figure V-9. Design of services (from operational modelling)





Figure V-10. Quality of Life Indices (from User Survey)

The case instance data appear consistent with the argument that a greater improvement in outcomes is possible from specialist intervention, rather than from further investment in very fast access to enable thrombolysis. There are two arguments here: firstly that the total number of eligible patients for thrombolysis is relatively low (the actual numbers in the six case instances are shown in figure V-11). Whilst the high thrombolysis levels in the Netherlands and German cases will be contributing to the positive outcomes, the levels are rather lower in the Finnish and UK case instances, although reported outcomes are also relatively good.



Figure V-11. Thrombolysis Levels (from Case Study data)

Overall the level of 15% as reported in Germany is thought to be something of a limit hence for the majority of patients other processes will be more important for securing positive outcomes.



# 'Early Identification' Scenario

This scenario is concerned with increasing awareness amongst patients of stroke symptoms, especially those at greatest risk. This will include those who have previously had a stroke or TIA (transient ischemic attack) or who are otherwise assessed as having poor vascular health. It principally involves actions within primary health care to identify such patients, ensure they are fully informed, and that services are also aware of the risks and can respond quickly if symptoms arise. It requires:

- Information systems to identify patients, starting with those that have already had an adverse event
- Briefing of patients, and regular monitoring
- Interventions to improve vascular health
- Increased levels of thrombolysis

The last element may seem paradoxical, but relates to the underlying processes whereby patients are able to access emergency services. The situation is most clearly demonstrated by the Brighton (UK) case where, because the specialist service was still developing, a further year's data was analysed to identify the progress in ensuring that the hyperacute processes were getting faster, as summarised in figure V-12. Although the number of CT scans within an hour of admission doubled, and the number scanned within 3 hours of admission reached 76%, the actual number of thrombolyses remained unchanged at 31 in each year.



Figure V-12. Time from admission to CT scan

The detailed Brighton data provides some explanation for this, in particular the delay between the onset of the stroke and the notification to medical services, as summarised in figure V-13. Nearly half of



patients did not contact services until 2 hours or more had elapsed, and hence the chance of completing a CT scan in time for thrombolysis was small, however fast the ambulance might be. On this basis the scenario proposes that beyond a certain point improved outcomes for stroke patients from hyperacute services can only be achieved by coordinated actions within primary health care.



Figure V-13. Hours from onset to first contact

We note that the detail of this scenario overlaps with the 'zero complications' scenario for diabetes, which is concerned inter alia with improving vascular health. Both require similar responses from the regional systems in terms of population management, including the use of information systems and the central role of the PHC system in coordinating these and consequent treatment responses.



### **Hip Osteoarthritis**

### **General Observations**

Hip Osteoarthritis (HipOA) was chosen as a topic for case study as a representative of elective treatment processes, but one for which it was already known that substantial gains in patient outcomes could be observed. Various initiatives in recent years were also likely to mean that variations could be observed in both the pre-operative and operative phases of treatment.

A key finding from the user survey was that no significant difference could be found in the average EQ-5D index between the cases. This was thought to be attributable to the high success rate for the operation in restoring mobility to patients. Differences in outcomes would therefore be limited to the transient changes in quality of life, and in turn these would be dependent on when patients were called for treatment, how long they waited and whether there were complications from the operation.

Beyond this the value of different scenarios would be based on the efficiency of the processes. Here there were contrasts between closely managed processes within dedicated facilities (SW London, UK), similar flexible workflow but within a general acute hospital (eg Keski-Suomi, Finland), and services reactive to individual demand (eg Larisa, Greece). The key performance elements here relate to waiting times and length of stay, the latter also affected by the extent to which the patient pathway is directly managed by nurse practitioners.

Our summary economic analysis of costs and outcomes indicates that the Greek case instance had the lowest cost but also the lowest outcomes on most of the measures investigated. Figure V-14 shows values for the average change in impairment levels reported in the user survey. The UK (SW London) and Finnish (Keski-Suomi) cases instances both show similar outcomes on this measure, although the adjusted cost is lower in Finland (which uses similar processes to the UK, but within a general hospital environment). The Netherlands case instance (Tilburg) also has better outcomes - but at a lower level - possibly reflecting the tendency observed in the case study for patients to be operated on earlier in the progression of the condition, so that there was less observed change in impairment levels. The reported outcome for the Spanish case instance (Valencia) was similar to Greece, but the adjusted cost was much higher.





Figure V-14. Cost (PPS) relative to outcome (less impairment)

## **Proposed Scenarios**

Bringing together the detailed evidence from the case instances, user surveys, the Futures Workshops and subsequent operational and economic modelling, we have formulated two scenarios that represent good value. The first focuses on the efficient generation of value through enhanced operations management, the second develops discussions in workshops about the future thresholds at which operations should take place, and the potential to develop alternative therapies.

- Process quality: ensuring that patients are treated as quickly as possible, in terms both of the wait for treatment and the length of stay in hospital.
- Managed demand: closely tied processes arranged between primary health care and the elective hospital services to manage the thresholds at which patients are treated. This could include interventions at younger ages, but with conservative treatment as the norm.

# 'Process Quality' Scenario

The *Process* Quality scenario includes processes that speed up the patient journey whilst reducing complications such as reoperations and repositions. This requires:

- Good information systems to minimise waiting times and schedule resources
- Flexible theatre session times



- Advanced nurse practitioners to manage patients into theatre and through the recovery process
- Adequate volume of procedures to ensure expertise maintained across the different clinicians

The SW London Elective Orthopaedic Centre was the only single-specialty case instance within the case study and it handled a volume several times that of the others. In the workshops there was some discussion as to whether dedicated facilities are needed for maximum efficiency: in the SW London workshop it was noted that the workflow procedures there had been adopted in a number of other UK hospitals despite problems in the UK with inflexible theatre sessions.

Services that had the shortest lengths of stay for hip replacements also had the shortest waiting times, and the highest proportion of patients discharged directly home rather than to a step down rehabilitation facility. Figure V-15 shows the average waiting experience in each case instance, with much shorter waits for both consultation and subsequent operation in the Netherlands and UK case instances.

These regions also reported the lowest lengths of stay in hospital and the highest proportion of patients discharged directly home (figure V-16). More detailed analyses for the operational modelling indicated an inverse relation between length of stay and nurse staffing levels: although the Netherlands and UK cases had higher nurse staffing per bed day, the faster throughput meant that there were lower levels of nurses per operation, contributing to lower costs.



Figure V-15. Waiting times to specialist consultation and operation





Figure V-16. Length of Stay in Hospital and Discharge Destinations

# 'Managed Demand' Scenario

The user survey in particular highlighted that patients in the Netherlands case were operated on earlier and at younger ages than other patients. Overall operation rates per capita varied widely between the case instances, as shown in figure V-17.



Figure V-17. Variations in Access Levels (from Case Study)



Participants in Futures Workshops discussed at length the opportunities for earlier preventive interventions and the possibilities for agreed thresholds at which replacement operations should be undertaken. In the long run the best outcomes were not necessarily obtained by early operation as patients would then need one or possibly more revisions subsequently.

The Managed Demand scenario would require:

- Pathways agreed by GPs and orthopaedic surgeons across the regional system regarding operating thresholds, including a pain threshold element
- Clinical decision support systems to support and control patient referrals
- The introduction of less invasive procedures for patients below these thresholds.



### Dementia

## **General Observations**

Dementia was chosen as a topic for case study as an experiment to establish the extent to which the methodology for describing the underlying processes and their impact on outcomes, and in particular the operational modelling approach, could be extended to a domain for which the development of *integrated* care is seen as the key requirement to improve outcomes. In the event it was not possible to design an operational model, but the various case study and user survey findings indicated interesting variation of approach, and the Futures Workshops were able to provide substantial insights for the formulation of future scenarios.

Because of the complexities of modelling patient flows the case study investigated whether there was a detectable impact on acute hospital performance according to the configuration of out of hospital services. While the results were unclear, differences in the nature of services provided were indicated, and the user surveys provided further dimensions to this. Diagnosis of dementia, whether this is undertaken at milder levels of confusion, and whether either institutional or community based responses are available, appear to be key issues. The needs of carers are also central to what processes may deliver best outcomes, and the user survey also assessed these.

Differences in the average EQ-5D index between the cases are thought to be attributable to differences in the underlying processes and hence the dependency level of people with dementia living at home. Figure V-18 shows that Keski-Suomi in Finland records a much higher average EQ-5D index amongst people with dementia living in their own homes than the other case instances. Quality of Life for dementia patients can be very low, and this is therefore a surprising result. We believe, however, it is largely explained by the assessed confusion levels of people with dementia living at home reported in the survey. These demonstrated that the Finnish patients had much lower levels of confusion than elsewhere, as summarised in figure V-19.



Figure V-18. Average EQ-5D index amongst people with dementia living in their own homes





Figure V-19. Levels of Confusion in People with Dementia living at home

The key difference in the Finnish case was the existence of specialist memory clinics, leading to much earlier diagnosis of dementia than elsewhere, and which also appeared to lead to earlier permanent admission to care home. For the other countries - and this was a major topic in Futures Workshops - , memory clinics were only seen as a positive development if there was a service response available for patients once diagnosed. With limited pharmaceutical (preventive) options currently available and, given the objective in other countries to avoid or delay permanent care home admission, the introduction of memory clinic assessment and diagnosis was not seen as a priority.

The development of community based services in the future was seen in the workshops as being inextricably tied to the willingness of carers to support people with dementia and the extent of support given, in turn, to them (the carers). The user survey identified substantial differences between case instances in quality of life measures, as shown in figure V-20.





Figure V-20. Burden of care to carers

The variation was correlated to the overall hours of care provided by statutory services. In practice the viability of care processes to support a person with moderate or severe dementia at home was thought to be dependent on the total level of care available whether from statutory or informal sources. The hours of care available as reported in the survey are shown in figure V-21. The greatest burden on carers, as indicated by a low BSFC score in figure V-20, is found in the Spanish and UK cases instances, and this is associated with the low levels of community based support shown in figure V-21.





Figure V-21. Annual hours of care available

The differences in levels of support also help explain the differences in discharge outcomes from the acute hospitals identified in the case study, and shown in figure V-22. Here the Finnish practice is to discharge to a step down facility, whereas in the Greek case instance patients were nearly always discharged home. There is a close correlation between the total hours of care available to care for the patient at home and the probability that a patient will go home immediately after an acute hospital episode.





Figure V-22. Discharge Destinations following acute hospital episode



Figure V-23. Total hours of care per patient per year by percentage discharged home



### **Proposed Scenarios**

Bringing together the evidence from the case instances, user surveys, and Futures Workshops, we have formulated three scenarios that represent good value. The first aims to describe the processes that would constitute an integrated service for people with dementia, both in and out of hospital. The other two scenarios recognise that full integration across processes, services and service providers is a long term aim, and identify transitional arrangements: one focused on driving development from the hospital into the community; the other led from primary health care:

- *Full integration:* ensuring that all relevant services are available and coordinated, the condition is diagnosed at an early stage and preventive therapies are available, and that carers are fully supported. This represents the most 'ideal' scenario.
- Hospital coordination: Acute hospitals diagnose dementia where it impacts on care delivery (mainly patients with moderate to severe dementia), and ensure primary and community health services are fully informed.
- PHC coordination: patients are diagnosed by GPs with subsequent monitoring of symptoms in PHC and referral to and coordination of other services.

Note that none of the scenarios is led by specialist mental health services, and this reflects the views of Futures Workshop participants that dementia is primarily a condition of old age, and should be cared for alongside other consequences of ageing such as frailty, rather than primarily through mental health.

## 'Full Integration' Scenario

The *Full Integration* scenario includes all processes that can be identified to ensure that people with dementia can continue to live dignified lives, including remaining in their own homes for as long as possible subject to the quality of life for them and their carers. This requires:

- Good information systems to allow shared care across different agencies and services
- Close involvement and support to carers to enable them to maintain their caring role
- A full range of services to meet direct care needs and those arising from comorbidities
- Memory clinics to provide early diagnosis (assuming preventive therapies become available in the future),

This represents a full range of services that would bring about integrated care for people with dementia. It is represented in the flow chart developed by the case study, reproduced here as figure V-24. This simplified process flow illustrates the complexity of the potential pathways crossing between primary, secondary and long-term care settings.

## 'Hospital Coordination' Scenario

The Hospital Coordination scenario recognises that development of integrated care will be uneven, and it may be more productive to introduce processes in those services that may be best able to lead other services and service providers. This scenario would require:

- assessment on admission of older patients for memory and cognitive problems
- liaison and outreach nurses to link to other services and support inpatient services
- data sharing arrangements with other key services
- carer support services

This would enable a move towards an approach to dementia care in line with other Long Term Conditions, and could form part of an overall regional approach to management across all such conditions, as discussed for the cases of diabetes and stroke. Being led from the acute hospital sector it would concentrate resource on the more dependent patients, mostly those with moderate or severe dementia, and would not require the wide scale introduction of memory clinics. Equally it is not dependent on primary



health care to coordinate services, hence would allow some progress in the medium term in regions without developed PHC.

# 'PHC Coordination' Scenario

The PHC Coordination scenario aims to exploit processes being established more widely in PHC, and thus would provide a way to progress in regions where PHC is being prioritised. This requires:

- Opportunistic or routine assessment of older people by GPs to identify dementia
- Use of information systems to ensure services are notified of need and can track care histories
- Community liaison staff (nurses or social care) to coordinate and support care delivery, and provide in-reach to acute hospitals

The PHC Coordination scenario is similar to the Hospital Coordination scenario in its focus on opportunistic diagnosis and the use of liaison roles and information sharing. Again it does not require substantial input from memory clinics. In the long run it is likely to provide a more comprehensive range of services with better patient coverage, and would fit better with a regionally based approach to other health services, as discussed in the next section.



#### FP7-241741 - MANAGED OUTCOMES:





# 5.2. Concluding Remarks

These fall into two groups concerning methodological approaches and scenarios respectively.

# Methodological

- Here the conclusions relate to the use of the Futures Literacy approach to ascertaining comment and opinion from expert groups. One reason this method was chosen was the potential for capturing this type of information quickly and in a highly focused manner. With suitable adaptation for the nature of the groups involved – and in particular for limited time availability – the methodology proved effective and engaging for both workshop facilitators and participants alike and useful material were obtained in all instances where a workshop was conducted. The materials developed were straightforward to adapt, replicate and translate for use in different local languages.
- There were some immediately positive effects noted by those taking part from the act of participation itself, and there was helpful comment and direction which supported the development of the scenarios, particularly in the dementia case study which has been otherwise the more difficult of the case studies for which to obtain detailed and reliable routine data.
- As an alternative to using a more standard 'Delphi' approach it was also successful given the limited resources available and time scales on which we had to operate. Being able to focus on working with particular stakeholders and brief them beforehand with initial case study analyses was efficient and effective.
- In terms of further development of the Futures Literacy methodology in this field an important finding in the application was of understanding the target audience. The majority of participants at all workshops were mainly working at 'operational' rather than 'strategic' levels within their organisations or domain of interest and this had an impact on how some of them perceived 'what was possible'. This finding is an area for further development beyond the MANAGED OUTCOMES project.

## Scenarios

Some common themes across scenarios developed for the different cases emerged in the deliberations of the Futures Literacy workshops. Central to all of them was the importance of the *regional system* in providing the focus for the operations management interventions. The scenarios support the view of the region as the community of service providers that can meet patient needs at all stages of the care pathway, and hence the appropriate level to analyse process and outcome relationships, to model them, and to create change. Whilst the four case studies led to the formulation of very specific scenarios, there were common features that are likely to apply across the health care system. These include:

It is possible to design low cost processes that can give the maximum outcome per unit of expenditure (ie QALYs per €). The economic analyses demonstrate these relationships, and have led to some scenarios that may be most appropriate in regions with low current expenditure levels, such as those in new member states. However the opposite does not apply, that is a health region which is already currently 'low spending' will not automatically maximise outcome per unit of expenditure. Indeed, such a region will typically have a weak supporting management infrastructure and spending may be misdirected; resulting in those poorer regions spending a higher amount for each QALY than more prosperous regions. This is particularly the case if processes involving expensive hospital or pharmaceutical services are not mediated by timely intervention in primary care. All four case studies demonstrated elements of this.



- Beyond this the scenarios highlight ways in which increasing expenditure on specific processes can further *increase outcomes* for patients. However, as might be expected, there are diminishing returns to scale ie the cost per QALY starts to increase. The degree to which this occurs can be reduced by careful design of operational processes.
- The relevance of taking a 'whole system' perspective. In all of the case studies we found that important insights were gained from modelling and analysing the combined effects of care processes rather than the isolated effects of individual services or processes. In the workshops this perspective was taken further than the 'demarcation' that was necessary to define the case study boundaries. In particular several scenarios have implications for what might be undertaken both 'upstream' (ie earlier interventions) and 'downstream' (post-intervention) which could have impacts on both process efficiency and outcomes for the patient. For example, maintaining people with dementia at home by supporting their carers in particular and thus helping to prevent unnecessary admissions to or accelerating their discharge from acute hospital settings. Or, with respect to acute stroke care, earlier identification of stroke symptoms by the public may lead to thrombolysis having a greater impact in stroke care than it currently has because more people access it within the procedure's time constraints.
- The key role of the primary health care (PHC) system to ensure the coordination of services at the operational level across the region. PHC is the focus for much future service development to support care closer to home, patient self-management, and support for carers. It is also important to note that this implies the 'primary health care team' not only general practitioners as nursing staff especially have an important role to play in the ongoing monitoring, education and close contact with patients in need of chronic care management (such as in the diabetes case).
- Promotion of patient self-management (and support for carers to help them manage patients at home). As well as education this extends to use of telehealth and telecare to support living at home - both in task of daily living as well as monitoring of medical conditions. Note that these are elements in a wider redesign of the care system, and other processes also need to be in place to ensure good outcomes.
- Health care information systems designed to enable different care professionals and organisations integrate their operations so they can be more responsive and targeted in providing services for patients and carers. It is also vital for these systems to be linked with patient monitoring systems in the community in order that appropriate and timely interventions might be made.

The extent to which 'cultural' dimensions impact on the demand for and supply of services is more tricky to elicit directly from the case studies. In part the culture may be an influence on what resources are allocated to particular processes, rather than a defining factor in the operations management task. For example, while in the Greek case instance, informal carers are a crucial component in providing care for people with dementia, that is also influenced by the fact that there are no long-term care home facilities available in the region in the same way as there are in the Finnish case instance. Here, though, other cultural effects may be coming into play as there is a tendency for early admissions to long-term care homes for patients with lower levels of confusion than in other case instances. Cultural dimensions, therefore, may be as much or more bound up with regional supply of services and may not of themselves influence the relationships between processes and outcomes.



# VI. APPENDICES

i.Summary findings of workshops (by case study).ii.Reports from completed Futures Workshops (by country).iii.Futures Workshop Invitation Letter and Agenda: Stroke Workshop, UK.iv.Detailed cost and outcome analysis for each case study.





# *i.Summary findings of workshops (by case study)*

## FUTURES WORKSHOPS CASE STUDY SUMMARY – TYPE 2 DIABETES

The workshops were designed to derive views and definitions on:

- what constitutes 'health' in a general sense as well as with more specific respect to people who have type 2 diabetes
- the current and potential future direction of service provision for diabetes services, with a time horizon extending 30 years ahead.

Workshop findings reported here:

• Greece, Spain and the Netherlands. No workshop was held in Finland. A smaller-scale 'expert meeting' was held in the UK.

## Definition of health and being healthy

Across all case studies a broad view of what should be regarded as 'being healthy' was common, ie extending beyond the minimum requirements for staying alive and extending into both physical and mental health and well-being; following the WHO ethos. The case for the importance of being in control of one's own life - and recognising and accepting a degree of personal responsibility for doing so - as much as possible and being supported to do so was clear from all sites. This could be enhanced with greater personalisation of medical and social care, more easily tailored towards a specific individual's needs. Physicians should not manage disease, but health (Spain).

Demography (increasing numbers of older people) and issues of unhealthy lifestyle and obesity – especially in younger age groups. Socio-economic factors are also important and were raised in both Greece (with the additional issues of the effects of the severe economic crisis), and in the Netherlands. People in higher socio-economic groups are more likely to respond to lifestyle advice and changes than those in lower groups. The trend in these factors leads to some pessimism that health status as it impacts on type 2 diabetes will improve over the next 30 years. Discussion in the Netherlands suggests that government regulation affecting factors such as diet and smoking will have an impact, but so will cutbacks on healthy living promotions (eg on physical exercise). 'Active citizenship' with informed patients (Spain).

Cure for type 1 diabetes likely in next 30 years, but not for type 2.

Issue of constantly redrawing the threshold of diagnosis – not always to the good. In the Netherlands this is already down from 7.5 to 7.0 HbA1C and could go lower, but why? Very early diagnosis is not necessarily beneficial for the patient; the effect is just to define more people as 'ill'.

## **Diabetes** services

Definite focus of all case study sites is on more community and primary care-based management of type 2 diabetes in the future. In the Netherlands this means a further extension from GPs to doctor assistants/ lifestyle coaches and greater use of IT to individualise programmes for patients. Greece would follow a similar trend to PHC-based care but probably remain more clinician focused. Patient education and responsibility seen as key aspects to enable this trend to be successful; also a role for patient associations (and informal carers).



Screening and protocols to monitor and intervene for more complex patients at the earliest possible stage. Continuity of care needs improving and especially the linkages between primary and secondary care.

Use of technology to improve community-based team work and to provide trusted sources of information for patients and carers (Spain).

## FUTURES WORKSHOPS CASE STUDY SUMMARY – STROKE

The workshops were designed to derive views and definitions on:

- what constitutes 'health' in a general sense as well as with more specific respect to people who have had a stroke
- the current and potential future direction of service provision for stroke services, with a time horizon extending 30 years ahead.

Workshop findings reported here:

• Finland, Greece, UK, Spain, Netherlands.

### Definition of health and being healthy

Across all case studies a broad view of what should be regarded as 'being healthy' was common, ie extending beyond the minimum requirements for staying alive and extending into both physical and mental health and well-being; following the WHO ethos. The case for the importance of being in control of one's own life - and recognising and accepting a degree of personal responsibility for doing so - as much as possible and being supported to do so was clear from all sites. This could be enhanced with greater personalisation of medical and social care, more easily tailored towards a specific individual's needs.

However, whether this would actually happen over the next 30 years was more open to debate. In Greece, for example, the severe economic situation was seen as having a serious impact and long-term impact on health status in coming years; in the UK disparities among socio-economic groups exacerbated by the economic situation were also recognised, but childhood obesity and diet were also seen to be important drivers of poorer health in the future. The demography of European countries will also have an implication with an increasing proportion of the population being elderly and with more likelihood of associated chromic conditions which may contribute to strokes.

There was also the recognition that the definition of health was driven by societal values – a UK hope was the idea of 'normalising' attitudes by the public towards people who have had a stroke. In Greece it was noted that the healthcare industry also has an impact by 'medicalising' conditions that were previously not seen as such. This is likely to increasingly be the case with developments in genetics-based research.

#### Stroke services: general

Interestingly, there was a noticeable focus across all case studies on the development of services both 'upstream' and 'downstream' of acute stroke care services. 'Upstream' services shift attention to prevention and community services provision, while 'downstream' is about enabling people to live in society and the community so the importance of clinical rehabilitation of the individual followed by their 'societal' rehabilitation.

Some general concern expressed (GR) about overall funding of services and whether moved towards an insurance-based system, for example, or a greater reliance on private services (eg for



rehabilitation) in the future would lead to potential problems of a 'two-tier' service for those who can pay and those who cannot.

### Hospital-base services

Technology and operational changes will continue to speed up the hospital care – including more efficient and rapid diagnosis and treatment within the hospital system through reorganising pathways, introducing stroke management protocols and reducing lengths of stay as well as the development of more portability of equipments such as scanners. The concept of a 'one stop shop' for professionals and for specialist rehabilitation to start as soon as possible. Also the possibility of organising some more mobile services linked to smaller satellite units. However, as noted in Greece, technology will still only be there to assist medical staff rather than replace them.

### 'Upstream' services

This is very important in the eyes of participants from all countries. Education for the public to recognise and act on having or seeing someone have a stroke is crucial (but this also extends to ensuring community health and social care professionals). Wider than this is education about life-style choices (eg diet) and providing trusted and accessible information and messages. There is a balance to be struck between providing the right amount of information that people will understand and react positively to, and providing the wrong sort - which is perceived as too complicated or intrusive or starts to unnecessarily alarm people and make them more anxious when they do not need to be. Better targeting and tailoring of messages and advice – supported by appropriate telehealth perhaps – is the way to progress this.

In the UK there was also discussion on the role of the State in actively intervening with, for example, legislation governing salt levels in food. There are also issues of 'trust' which may need to be regulated in some way at a national (or regional) level.

Development of the upstream care delivery system requires organisational/ professional barriers to be addressed (UK) to enable early detection and targeting of at-risk patients (and their management in the community post-stroke).

There were some more radical ideas from the Dutch workshop with respect to the development and use of implants that would check vital functions and help a person to maintain the 'right lifestyle'. If a stroke occurs, the system will determine what treatment is required, but follow-up care would have to be dealt with at home. The implant would be based on your DNA profile and risk profile and support you accordingly. You will have more control over your health but also have more responsibility.

#### 'Downstream services'

Need to support and enable the carers of stroke patients to be more actively involved in patient support and management – and especially where family networks are not necessarily local. Dependence on others can be a 'fear factor' so needs to be addressed. Linkages between professional groups in the community and to voluntary/ informal and private sectors are crucial. Issue that increasing the privatisation of rehabilitation services could lead to inequity in service provision and potential outcomes.

In the Netherlands there was a view that there would be stricter criteria and protocols involved so that although patients will receive necessary intensive treatment program, there may be more individual responsibility for longer-term support in their home environment.

More attention on end of life care and 'better dying' to be part of 'better living' (UK).



# FUTURES WORKSHOPS CASE STUDY SUMMARY – HIP OA

The workshops were designed to derive views and definitions on:

- what constitutes 'health' in a general sense as well as with more specific respect to people who have had a hip replacement
- the current and potential future direction of service provision for hip OA services, with a time horizon extending 30 years ahead.

Workshop findings reported here:

• Finland, Greece, UK, Netherlands, Spain

## Definition of health and being healthy

Across all case studies a broad view of what should be regarded as 'being healthy' was common, ie extending beyond the minimum requirements for staying alive and extending into both physical and mental health and well-being; following the WHO ethos. The case for the importance of being in control of one's own life - and recognising and accepting a degree of personal responsibility for doing so - as much as possible and being supported to do so was clear from all sites. This could be enhanced with greater personalisation of medical and social care, more easily tailored towards a specific individual's needs.

However, whether this would actually happen over the next 30 years was more open to debate. In Greece, for example, the severe economic situation was seen as having a serious impact and long-term impact on health status in coming years; in the UK disparities among socio-economic groups exacerbated by the economic situation were also recognised, but childhood obesity and diet were also seen to be important drivers of poorer health in the future. The demography of European countries will also have an implication with an increasing proportion of the population being elderly, but also that younger people will require/ demand hip replacements at an earlier age – increasing expectations which were noted across all case study sites.

In NL the hope was expressed that hip replacements will not be necessary in 30 years time. Hip problems might be treated with medicine and tablets, or even in the pre-birth phase by preventive care for those who are genetically prone to bone problems at later ages. Potential for genetic advances also noted in Spain.

Lack of supply of hip replacements on NHS will directly affect demand (Greece) – exacerbate equality of access to healthcare as others opt to go privately.

NL: There will be fast access for all, to services that are patient focused. As information is widely available, the patient has more influence in the decision making process. The patient will be less dependent on individual health professionals.

## Hip OA services

Hip OA care will involve more technology and less people and there will be a counterbalance to technology by increased attention to life style and, for instance, herbal medicine. More individualized care with clinical collaboration only when necessary (NL).

Interestingly, there was a noticeable focus across all case studies on the development of services both 'upstream' - shifting attention to prevention and community services provision - while 'downstream'



is about enabling people to live in society and the community so the importance of clinical rehabilitation of the individual followed by their 'societal' rehabilitation.

Some general concern expressed (GR) about overall funding of services and whether moved towards an insurance-based system, for example, or a greater reliance on private services (eg for rehabilitation) in the future would lead to potential problems of a 'two-tier' service for those who can pay and those who cannot.

There was also a view that conservative management of hips will increase and alter the perception of need for an operation. Where operations are needed there may be smaller implants and less invasive surgery. This must be balanced against the potential need for second operations if people are operated on at an earlier age and have more than one replacement in their lifetime.

The role of genetics (eg stem cell technology, artificial blood, genetically-engineered replacement cartilage) in the future was also mentioned across case studies, and the ability this gives for more personalised and tailored care.

Advice will be provided by an alternative intelligence, your avatar, that you can consult anywhere. All knowledge is available for everybody; high levels of transparency in information on healthcare performance (Spain).

## Hospital-base services

Technology and operational changes will continue to speed up the hospital care – including more efficient treatment within the hospital system through reorganising pathways and the use of robotics. The UK case study site was a leading example of a single-specialty facility which has honed its operations in this way. Other places operating within a multi-specialty facility have further to go (eg in Greece).

NL: Hips will be operated in day care, and move from large centres to smaller community based centres. There will be no complications. In the very long term hip OA care will be organized in small communities and no in hospitals. Will rely on 'community responsibility' to enable this to happen.

## Community services

A shift towards prevention and as much work to be done in the community as possible including more 'directed' post-op support through family and informal carers. Telecare and telehealth will increase. With more internet-based information for the public there may be trends towards competition between hip replacement facilities and for clinicians' role as arbiters of information. More collaboration between specialists and other care professionals if care is to move out of hospital settings – 'franchising' of expert hip OA organisations could be a result.



# FUTURES WORKSHOPS CASE STUDY SUMMARY – DEMENTIA

The workshops were designed to derive views and definitions on:

- what constitutes 'health' in a general sense as well as with more specific respect to people who have dementia
- the current and potential future direction of service provision for dementia services, with a time horizon extending 30 years ahead.

Workshop findings reported here:

• Greece, UK, Finland, Spain (no workshop was held in the Netherlands)

### Definition of health and being healthy

Across all case studies a broad view of what should be regarded as 'being healthy' was common, ie extending beyond the minimum requirements for staying alive and extending into both physical and mental health and well-being; following the WHO ethos. The case for the importance of being in control of one's own life - and recognising and accepting a degree of personal responsibility for doing so - as much as possible and being supported to do so was clear from all sites. This could be enhanced with greater personalisation of medical and social care, more easily tailored towards a specific individual's needs.

With dementia there is also the recognition of the health of the carer being crucial and the need to maintain and support their ability to continue caring. Concept of a 'supporting community' seen as very important in all case studies, together with an increased role for telehealth and telecare focused on specific needs of people with dementia and - crucially – supporting their informal carers (Spain). However, it was noted that telecare cannot replace human care and support, especially for people with dementia.

There was also the recognition that the definition of health was driven by societal values – a hope expressed both in England and Finland in particular - was the idea of 'normalising' attitudes by the public towards people who have dementia in the same that has been achieved over the past 20 years for cancer.

Earlier diagnosis may be possible, but to what effect for the patient if there is no treatment? Knowing genetic disposition to dementia may be useful in developing personalised health care plans, but may also adversely affect insurance and other lifestyle aspects.

Wider definitions of health should incorporate end of life care issues.

Dementia is here to stay, but there will be a relative increase in vascular dementia as a result of the current younger generation.

#### Dementia services: general

The concept of keeping people at home as long as possible was seen as important in all partner countries and this will increase importance of the role of the voluntary sector as well as community health and social care services (such as day care).

Increasing role of memory clinics could be one focus for this, although there are issues about identifying dementia too early when there may not be any effective therapies to offer.



A recognition that improved inter-professional communication is required to provide an integrated approach to dementia management. The idea of personalised advice and care management plans with a large amount of input from the patient and carers backed up with nurse-led - rather than predominantly doctor-led - care services.

More specialism in fewer hospitals with regard to dementia services (although this will not prevent people with dementia turning up in acute hospitals for other medical conditions).

Services are moving towards earlier diagnosis in the community and, with the economic pressures, will be relying more on informal care and the voluntary sector to provide support for people with dementia and their carers – as well as private sources of funding for many of these. Demographic and economic changes will drive service developments as well – fewer children, often more dispersed in location – will be able to provide informal care; in Finland there will be additional financial sustainability pressures given the current pattern of care home placements for relatively young people with dementia. Questions were raised about where an additional workforce to provide care will come from (Finland).

The further development of drug therapies and when they are applied will be an important element in care provision and may offset some of the increased burden from the condition. Still some unknowns about possible long-term effects of these drugs or of some of the contributory factors to dementia (Finland). Prevention issues for the current younger generation.




# *ii.Reports from Futures Workshops (by country)*

# **UK: STROKE FUTURES WORKSHOP**

Workshop Title:	Managed Outcomes Stroke Futures Workshop
Workshop date and time:	23 March 2012, 12.30 – 17.00
Location:	Crawley, Surrey

# Names of invitees attending:

- Cora Duncan (Service Improvement Manager, NHS Sussex, Sussex Managed Clinical Networks - Heart/Stroke)
- Alec Fraser (research Associate, King's College, London).
- Nicky Gainsborough (consultant stroke physician, Brighton and Sussex University Hospitals NHS Trust)
- Mark Holmes (stroke and rehabilitation ward manager, Brighton and Sussex University Hospitals NHS Trust)
- Ingrid Kane (consultant stroke physician, Brighton and Sussex University Hospitals NHS Trust)
- Michelle Long (Occupational Therapist, Brighton and Sussex University Hospitals NHS Trust)
- Kimberley Smith (Occupational Therapist, Brighton and Sussex University Hospitals NHS Trust)
- Sally Wood (Occupational Therapist, Brighton and Sussex University Hospitals NHS Trust)

# Workshop organisers

- Riel Miller (lead facilitator)
- Paul Forte
- Tom Bowen

# Other MO partners attending

- Tomi Malmstrom (Finland)
- Ama Auvenin (Finland)
- Elpida Pavi (Greece)
- Sylvia Elkhuizen (Netherlands)
- Teresa Meneu (Spain)
- Raquel Faubel (Spain)

Summary record of the workshop: group and plenary discussions and conclusions

There were 2 separate groups plus plenary feedback looking at expectations and aspirations around level 1 issues:

- the definition of being healthy changing over the horizon to 2030 and implications for stroke?
- potential changes to the health care system changing over to 2030 and implications for stroke services?



Discussion around the topic of health and well-being included some interesting concepts - 'staying alive' is not enough, 'being healthy' is better' – and - 'will people have to be healthy in order to work longer, or will be healthy because they have to work longer?

Growing inequality of socio-economic circumstances will continue and as there is a strong relationship between economic situation and food (poverty leads to poor diet and greater processed food intake). Obesity will be a major factor leading to poorer future health for many. Demography also a factor - ageing an stroke prevalence (although stroke is multi-factorial; lower smoking rates? Decreased salt in foods?) Also a disparity between genders using health services – especially primary prevention.

Can the same be done for food (salt in particular) as had been done for smoking and drinking? More regulation of food, especially for children?

Access to healthcare issues include: decreasing community nurse visits and increased specialisation of different professionals. There is also an issue of increasing regulatory barriers between health and social care which is a problem for multidisciplinary working.

Increasing responsibility for one's own health status (in part driven by reduced health and social care funding) allied with earlier checks by GPs, and self-administered tests/ information from internet. Embedding of health check procedures in everyday life; bringing health services closer to people.

Question of 'trust' in information and information providers. 'Shipman problem' (GP who murdered patients) has led to greater risk aversion in community services, just when more emphasis on community services is necessary.

Positive predictions

- 'One-stop shop' for healthcare professionals; more multi-disciplinary teams and working.
- Develop positive impact of peers and peer networks and increase voluntary efforts to break social isolation
- People taking more personal responsibility for their health with more focus on efforts to decrease blood pressure
- Telecare and telehealth appear promising in terms of delivering new forms of healthcare.

For level 2 there were two separate groups plus plenary feedback looking at:

- what does it mean to be "healthy" in 2030?
- how the organization of the many different systems for assuring wellness, including the role of stroke services, has changed?

Belonging to a community and greater personal capacity/ responsibility. This is aided by greater intergenerational support and different generations living together or, even if further apart physically, greater opportunities for networking through the internet. Changes in societal values with work increasingly a 'variety of self-expression'.

Sources and bases of knowledge have changed. There are now different forms of learning and the ability to have a highly connected society with the potential for greater personalisation of healthcare. People can be a member of a community on one hand, but with 'personal space' on the other. Question of technology being potentially both potentially 'connecting' or 'isolating'.

Level 3 was a short plenary-only session.



- Is tomorrow's zero stroke happening today? Stroke always likely to be present; can be minimised but not eliminated.
- Need for 'better dying' to be part of 'better living' and more public education about stroke and its aftermath. 'Normalising' stroke for the general public so that old-age disability arising from it has greater acceptance. Death and dying agenda is very important: normalising death at home; not being regarded as being 'pushed' back in the community but arising because it is a better location.
- Need to do more now to empower patients to choose what to do about their own care.
- Recognise that unhealthy lifestyles are actually 'supported' by healthcare system.

#### Workshop organiser comments and conclusions

This was the first (pilot) workshop for the series of workshops across all partner countries; hence the attendance of colleagues from partner countries to observe and learn through experiencing the day of presentations and discussions.

The workshop was quite well-attended by stakeholders from the local case study site and there was good involvement throughout the day from all participants. Additional experts with whom the UK partners have had previous contact, were invited from Guy's Hospital but were unable to be present although one of their research team did attend and participate. This highlighted one of the difficulties of running this type of workshop – obtaining a sufficiently broad and large range of stakeholders requires a long lead-time (especially for senior clinicians).

The FL concepts were quite well understood and there was, in general, good discussion in both of the two groups with occasional intervention by facilitators to keep discussion moving. Partner colleagues observing the sessions noted that the overall structure appeared well-balanced between presentations, group-sessions and plenary discussions.

There were some difficulties in keeping focused on the time scales involved – especially when looking trying to look 20-30 years ahead; one observer noted that sometimes the discussion seemed to dwell more on the current situation compared with 20-30 years ago.

• A comment from one of the consultant stroke physicians was on how useful the day had been as it was 'good to take a breather from the front-line'.



# **UK: HIP OA FUTURES WORKSHOP**

Workshop Title:	Managed Outcomes Hip OA Futures Workshop	
Workshop date, time and location:	2 May 2012, 09.30 – 16.00	
Location:	Epsom, Surrey	

# Names of invitees attending:

- Jane Andoe, General Manager, Scheduling Team
- Zoe Beer, Research Asst, Research Team
- Paula Cox, Dep Clinical Lead, Theatres, Clinical Team
- Charlotte Dibble, Asst Service Manager, Scheduling Team
- Caren Dove, Projects lead, Clinical Team
- Gaye Hadfield, Research Business Manager, Research Team
- Jane Harrison, Lead physiotherapist, Clinical Team
- Sue King, Director of Nursing, Clinical Team
- Sarah Langfield Clinical Lead, pre-assessment OPD & Outreach, Clinical Team
- Margaret Seppings, Senior Sister, Clinical Team
- Giles Stafford, Consultant Surgeon
- Steve Thomas, EOC Director
- Suzanne Tyne, Lead PACU, Clinical Team
- Mark Van Vlokhoven, Lead Radiographer, Clinical Team
- Jo Wilkinson, Service Manager, Scheduling Team
- All from Epsom Orthopaedic Centre (EOC)

# MO partners running the workshop

- Riel Miller (lead facilitator)
- Tom Bowen
- Paul Forte

# Summary record of the workshop: group and plenary discussions and conclusions

Discussion on future trends and hopes was particularly good in the first two sessions. Common threads were that:

• the NHS would become more fragmented



- Managed Outcomes
  - there would be more emphasis on prevention and screening of illness.

There were contrasting opinions of the implication for hip replacements arising from future lifestyles: obesity and poor lifestyle being contrasted with greater importance on healthy lifestyle trends – in fact this may reflect greater polarisation in society between those with and without wealth. However, there would be an increase in the number of joint replacements also driven by the demographics of an increasing number of older people.

The future role of the family in supporting patients post-operatively was raised – this could potentially include some training for them to help the patient's recovery.

A greater role for medical and biotechnology (stem cells, etc) was also forecast and, overall, a more process-driven response to hip replacements. Smaller implants; less invasive surgery.

In 2040 there was much more emphasis on personalised and tailored health care – eg personal stem cell banks; more direct access to specialists rather than referral by GP; greater time spent on personal research of the condition.

The question of trust was raised – the role of clinicians as arbiters of information will be even more significant. Much greater amounts of information via the internet and the idea that there could be patient scoring of treatments and facilities 'facebook'. In turn, this would force health care providers to be more 'customer-focused' and consider ways of extending the range and responsiveness of their services. This could include vertical integration of services or franchising arrangements.

Workshop organiser comments and conclusions

The workshop was well-attended and there was good involvement throughout the day from all participants. The concepts were well understood and group sessions were animated through their own discussion – no additional intervention was required by facilitators.

While the first two group sessions worked well, the final plenary session was less engaging. This may reflect the make-up of the participants who were all from the same organisation and very much focused on delivering a specific health care service, rather than being in control of policy levers at a higher level which might have an impact on some of the bigger themes discussed around equality and access in society.

It was judged a success by those participating and the inclusion of the comparative data from partner case studies generated interesting discussion and an interest in further follow-up:

'We are all looking forward to meeting in a few months to review the final figures (never seen my team so animated with facts and figures!)' Steve Thomas, EOC Director.

A further meeting has already taken place with a subgroup from the workshop to explore in greater detail the performance data highlighted as significant in the workshop, and to discuss the strategic consequences for the provider service. Another review is scheduled to discuss the emerging scenarios once further modelling is completed. The EOC sees its participation in the workshop and follow-up activities as a major opportunity for strategic review.



# **UK: DEMENTIA FUTURES WORKSHOP**

Workshop Title:	Managed Outcomes Dementia Futures Workshop	
Workshop date, time:	21 June 2012, 12.30 - 17.00	
Location:	Woodhall Spa, Lincolnshire, UK	

Names of invitees attending:

- Ellen Armistead, Chief Executive, Lincolnshire Community Health Services
- Kay Darby, Interim Manager, Lincolnshire Community Health Services
- Dr Chris Foote, former consulatant geriatrician and Balance of Care Group
- Dr Dee Gallop, GP and Lincolnshire Partnership Foundation Trust
- Dr Gill Garden, Consultant in Psychological Medicine, United Lincolnshire Hospitals NHS Trust
- Ian Howarth, Regional Manager, Alzheimer's Society
- June Walker, Business Manager, Lincolnshire Partnership Foundation Trust
- Colin Warren, Head of Mental Health Commissioning, Lincolnshire Primary Care Trust

All, except Dr Chris Foote, were from various Lincolnshire organisations involved in dementia care services.

#### MO partners running the workshop

- Paul Forte (lead facilitator)
- Tom Bowen

#### Summary record of the workshop: group and plenary discussions and conclusions

The first group session discussed definitions of 'being healthy' and hopes/ vision for health in 2040 for the health service generally and dementia services in particular. While similar broad definitions of health such as 'living to maximum potential' and 'being comfortable with physical/ mental condition' were common, there was doubt as to its achievability.

It was noted that people are living longer with morbidity being 'compressed' into fewer years at a later age. This older generation at least, is regarded as being relatively wealthy although there was a sense of greater gaps and inequalities in health within the same age groups and differences in the perception of dementia between younger and older age groups. The health of younger people was also thought to have declined in recent years. This has potential implications for managing future 'health time bombs' such as obesity.

With respect to dementia in particular in the future; it was noted that people know more about dementia as a condition now, but that acceptance and knowledge of it is 'where society was at 20 years ago with regard to cancer'.

The idea of a supporting society/ community is very important with important consequences for quality of life and community-based service provision, and increased use of telecare and ICT solutions to support not only greater autonomy in patients but also with carers. An increased role for voluntary sector organisations is expected, while there will be more specialism in fewer hospitals and those going



to into hospital will be more unwell generally. However, more specialised - and less holistic - care may be detrimental to people with dementia. There is likely to be better preventative measures for Alzheimers (but not other dementias).

# Hopes for 2040

- Hope for more choice and control including the right to die in a dignified way, more talking about it.
- Increased plurality and more personal funding
- People will want to look after those with dementia more readily more support for carers
- Communities/ networks to support people with dementia
- Greater inclusion/ less exclusion or stigmatism
- More openness with greater sharing of knowledge and information across care professionals/ patients and carers.
- Better preparation for decision making.

Discussions for levels 2 and 3 took place as a single group. In 2040 we see more acceptance of mortality: medicine no longer expected to extend life in all circumstances. Economic austerity over the past 20 years has had an effect on extended family support – leading to a greater need for nuclear family ties and staying together to provide support for each other from childcare to old age. There are larger gaps in available services which now have to be picked up by the community and widespread use of telecare. More resources have gone into carer support as the only way of plugging the gap.

Voluntary sector providers are important but have now become 'super-providers' in their own right operating on a large scale.

- Dementia is here to stay, but there is less Alzheimer's and more vascular dementia due to the poor health of the younger generation in the early 21st century
- There is better holistic assessment of the patient and carer importance of 'heterarchy over hierarchy'.

Workshop organiser co	omments and conclusions	

What this particular case study lacked in terms of number of attendees, it more than made up for with the quality and range of those attending. All were senior managers or clinicians and they were ready to engage in extensive discussion (which went on for half-an-hour after the scheduled finishing time of 17.00).

Some attendees were particularly struck by the FL material presented in terms of reconsidering how to view 'futures' in the field and there was lively debate about issues ranging from operational to philosophical in the field of dementia. No additional intervention was required by facilitators in either of the groups for the Level 1 session, nor in the level 2/3 session (which was held as a single group).

There were some issues of concern raised about the 'Learning Intensive Society' concept as it cannot apply to individuals with dementia. What is important is not 'Who am I?' but 'What matters for you?' Need to respect who they were; the networks around them are key. This merits further consideration in reviewing and tailoring FL materials in future work with particular patient groups.



# **GREECE: TYPE 2 DIABETES FUTURES WORKSHOP**

Workshop Title:	Managed Outcomes: Diabetes Futures Workshop, Greece
Workshop date, time and location:	22 May 2012, 15.30 – 20.00. Athens, Greece

Names of invitees attending:

- Konstantinos Athanasakis, PhD, Health Economist, Teaching and Research Fellow, Department of Health Economics, National School of Public Health, Athens, Greece,
- Stella Argyriadou, MD, General Practioner, Health Centre of Chrysoupolis
- Apostolos Dolgeras, Research Fellow, Department of Health Economics, National School of Public Health, Athens, Greece, ex Chairman of OPAD (National Insurance Fund for civil servants)
- Gregory Kaltsas, MD, PhD, Endocrinologist, Associate Professor, Medical School, University of Athens, Greece
- Eleftheria Karambli, Health Economist MSc, Research Fellow, Department of Health Economics, National School of Public Health, Athens, Greece
- Athanasia Karounou, Chairperson of Panhellenic Association of Diabetic Patients
- Zesoula Manika, MD, diabetic patient
- Andreas Melidonis, MD, Diabetologist, Consultant/Head of Diabetes Centre, General Hospital Tzanneio, Pireaus
- Elpida Pavi, Senior Lecturer, Department of Health Economics, National School of Public Health, Athens, Greece
- Georgios Piaditis, MD, Consultant/Head of Endocrinology Department, General Hospital G. Gennimatas, Athens

Names of MO partners organising/ attending:

- Elpida Pavi (lead facilitator)
- Apostolos Dolgeras
- Eleftheria Karabli
- Konstntinos Dolgeras
- Maria Liatsou

Summary record of the workshop: group and plenary discussions and conclusions

Discussion on the future of diabetes in Greece was based on the questions for each of the two levels according to the methodology used. For Level 1, the questions concerned A. definition of health



and health determinants, B. predictions for 2040, and C. hopes for the future. For Level 2, the discussion focussed on the question D. the 2040 imaginary society.

Findings are as follows:

**A.** Most participants endorsed WHO's definition of health. Subjective perception of health according to the dimensions chosen by each individual was also mentioned, as well as the differentiation of the definition of health according to age group (in older age, more importance is assigned to the dimensions of mental well-being and ability for self-care).

As health determinants, most social determinants as defined by WHO were mentioned, as well as the genetic background (distinction between exogenous and endogenous determinants).

**B.** For 2040, most participants foresee that the population will be less healthy due to aging (increase of life expectancy, age as the main risk factor for degenerative diseases) and economic downturn, although medicine will have progressed. Some improvement of the health may be seen at the young and middle age groups. Of the health determinants, economic situation, education, technology, and information technology will also play a significant role in maintaining health, thus increasing the inequalities.

In relation to primary health care (PHC), it is foreseen that PHC will be stronger than today. The health care system cannot but be reformed so that more rationalization is achieved, and it will be a major factor for social cohesion.

In relation to diabetes type 2, the following are foreseen:

- Better understanding of the etiology of diabetes type 2.
- Information technology progress which will facilitate patients to find the information they need, and overall, a more informed/aware society. The question is to what extent this information availability will be centrally organized by the health care system or not.
- Patients' associations will have a greater role, and the patients will be more empowered, and patients' education will play an important role in compliance. Overall, there will be more support to the diabetic patient. Still, there may be some problems in the doctor-patient relationship concerning trust.
- Although due the economic crisis in Greece there was some fear about Greece staying out of the European community, eventually, most participants believed that Greece will continue its European path, thus, the developments about diabetes in Europe will also take place in Greece but perhaps at a slower pace.
- The progress of the diabetic care is directly related to the developments in PHC in Greece.
- Inequities in access to care will continue to exist.

**C.** Participants hope (would like) to see continuity of care and thus improvement in patient compliance, improvement of the processes of the NHS, improvements in PHC, and improvements in access to care (including, through information technology and telemedicine). Still, there may be some negative developments.



For the diabetes care services, participants hope for the following:

- A national programme for the prevention and control of diabetes based on scientific evidence and social criteria (as to the level of coverage by social vulnerability group) with a balanced, specialized, multidisciplinary and multisectoral approach.
- Organised screening programme (based on guidelines) which will give the opportunity for more effective interventions to patients at the pre-diabetic stage and to the newly diagnosed.
- So, there will be more patients, but with the progress and developments of research and medical practice there will be better treatments and even cure.
- Specially trained team (not just doctors) for the management of diabetes will achieve higher efficiency and will increase the trust relationship and the communication between patients and the care team, with more empowered patients.
- Diabetic care will increasingly move to PHC, which will contain costs.
- Still, for the patients with complications, there will have to be specialized centres at tertiary care level.
- For continuity of care, good links there must be between PHC/secondary HC and these specialised centres.
- Better management of resources and adoption of protocols (control of number and type of lab tests according to protocols) will increase efficiency, and will allow for better (rationalised) insurance coverage for diabetes)

**D.** In 2040, in the imaginary society, the definition of health will not change. Digital literacy is part of the knowledge/education, and not an autonomous dimension of health. Scientific and technological developments (particularly through genetic testing) will give the opportunity to know more about the future of our health (this may impact negatively on mental health), so that prevention can be better achieved (interventions to delay onset of disease), which will result in lower costs.

Participants see that a change may take place as to what defines a disease (e.g. obesity is a disease or a risk factor?).

Vaccines will be developed (even for diabetes, or Alzheimer).

Access to quality care will be improved. All stakeholders will participate in decision-making, more emphasis will be placed on the trust relationship between doctor and patient, as well as better and easier access.

There will be continuity of care with more emphasis on PHC. Technology will facilitate the doctor-patient contact which will continue to be indispensable, even though the doctor will use better the technology.

Trust systems for the creation of knowledge in relation to diabetes type 2 will have the following characteristics:

- Advanced knowledge/awareness given to the patient and managed for accuracy and trust by the state (approved/accredited sites, supervisory role) and by the medical profession (reliability of information, updating, continuous professional development).
- Patient access to information through technology, so patient more informed and knowledgeable when contacting the doctor. Thus, more empowered patient means more responsibility of patient for managing his/her disease.
- Confirmation of soundness of patient's information/knowledge by doctor.



- Doctor (necessarily) very knowledgeable on current developments in diabetic care.
- Better knowledge will not per se lead to better care. This will be achieved through health system's reform.
- Control of the quality on new health technology and of its diffusion through:
  - o medical research based on bioethics
  - o approval procedures e.g. HTA organisations, FDA etc.
  - o Post-authorisation studies on medicines: publish results to public and patients
  - Doctors to inform patients about new health technologies
  - o Incorporation of new information into guidelines
  - $\circ\,$  The state and the medical scientific societies to be responsible for the dissemination of the new knowledge.

#### MO organiser comments and conclusions

The workshop was well-attended and there was good involvement throughout its duration from all participants, apart from the last plenary (level 2 plenary) when some of them had to leave, so the reporting back from the two groups was shortened in order to allow for more time for discussion. The concepts were well understood and group sessions were animated through their own discussion – no additional intervention was required by facilitators.

While the current economic crisis was mentioned by some participants as an inhibiting factor for optimism in their expectations, it did not prevent participants from being engaged and actively participate in the procedure.

Indeed, all participants found the futures studies concepts as something new and very interesting to them, and asked for feedback.

The development of genetics together with information technology are seen as major determinants of the future developments in diabetes care, which needs some reinforcement and reforms in Greece.

It is noted that in all futures workshops, sections C. and D. have overlaps and similarities, because for the level 2 imaginary future society (D.), most participants project what they hope to see in the future, as they state it in C.



# **GREECE STROKE FUTURES WORKSHOP**

Workshop Title:	Managed Outcomes: Stroke Futures Workshop, Greece		
Workshop date, time and location:	19 May 2012, 15.00 – 19.00. Athens, Greece		

Names of invitees attending:

- Konstantinos Vemmos, Internist, Stroke Specialist, ex-Consultant/Head of Stroke Unit of Athens University General Hospital "Alexandra"
- Apostolos Dolgeras, Research Fellow, Department of Health Economics, National School of Public Health, Athens, Greece, ex Chairman of OPAD (National Insurance Fund for civil servants)
- Fotios Iliadis, Internist, Lecturer, AHEPA Hospital, Medical School, Aristotle University of Thessaloniki, Greece
- Eleftherios Thiraios, General Parctitioner, Senior Registrar, Health Centre of Vari, Advisor to Hellenic Ministry of Health
- Eleftheria Karabli, Health Economist MSc, Research Fellow, Department of Health Economics, National School of Public Health, Athens, Greece
- Eleni Koroboki, Internist
- Konstantinos Makaritsis, MD, PhD, Assistant Professor of Medicine, University Hospital of Larisa, Medical School, University of Thessaly
- Charalambos Milionis, Assistant Professor of Internal Medicine, Medical School, University of Ioannina
- Georgios Daios, Internist, University of Thessaly
- Elpida Pavi, Senior Lecturer, Department of Health Economics, National School of Public Health, Athens, Greece
- Androniki Plomarotoglou, Neurologist, YGEIA Hospital (private sector)

Names of MO partners organising/ attending:

- Elpida Pavi (lead facilitator)
- Apostolos Dolgeras
- Eleftheria Karabli
- Konstntinos Dolgeras
- Maria Liatsou

Summary record of the workshop: group and plenary discussions and conclusions



Discussion on the future of stroke in Greece was based on the questions for each of the two levels according to the methodology used. For Level 1, the questions concerned A. definition of health and health determinants, B. predictions for 2040, and C. hopes for the future. For Level 2, the discussion focussed on the question D. the 2040 imaginary society.

Findings are as follows:

**A.** Participants agreed to the WHO's definition of health. Additionally, the following definition was given: healthy I sth eperson who has the ability to respond to problems an attacks by the environment and to remain functional, but this response to reinforce the body to deal with similar problems/attacks in the future.

Subjective perception of health according to the dimensions chosen by each individual was also mentioned, this being influenced by age. Furthermore, good communication with the overall environment and response to problems was mentioned as a criterion of health.

Health determinants are distinguished in not modifiable (gender, age, genetic background, etc) and modifiable (social, economic, etc).

**B.** For 2040 participants foresee that life expectancy will increase while the overall health of the population will deteriorate due to demographic and economic changes, but also due to iatrogenic changes (due to the medicalisation of the society more persons will be characterized as non-healthy through the detection of risk factors either already known today or discovered in the future). The burden of chronic diseases will increase.

Current economic crisis will impact negatively on health due to the deterioration of the social determinants of health and of the cohesion.

Research (particularly genetics) will put more people on the non-healthy category. Physical health may improve, but mental/behavioural health will deteriorate. However, a positive factor will be the research on prevention.

In relation to the health system, participants foresee an expansion of the private sector, with well informed patients who will seek quality care and have high expectations. The public sector (NHS) will not be more effective neither efficient due to management problems and its decrease of capacity may lead to exclusions (population groups not covered, inequalities). State health insurance will also deteriorate (less coverage, selection of people to cover according to genetic profile and their risk factors, ethical dilemma who to treat, difficulty to cover expensive new medical technology) and more emphasis will be placed on private insurance (as in the Netherlands).

There will be reduced public health expenditure and social welfare provisions, and increased private health expenditure



Health professionals (particularly nurses) are not foreseen to be better trained in relation to the needs and the level of the knowledge development.

As for the strokes, the prevalence will increase due to demographic reasons. Care will probably improve through the operation of specialized stroke units.

**C.** Participants hope (would like) to see the development of networks of units (both of the public and the private sector) which provide care for the management of chronic diseases in a complementary way.

They stress the powerful role or the state through the adoption of a basic package of care (including prevention) covered by insurance and equity in access to this package of care services. In parallel, by complementary/supplementary private insurance this package may expand.

Participants hope that large well-organised and highly specialized Stroke Units will be developed in each geographic region of the country. For such centres to be efficient (as part of the overall system) emphasis was given on:

- Well structure primary health care (PHC) (prevention, early detection, screening, modification of risk factors, treatment).
- Improvement of health behaviours through incentives (by NHS and insurance), interventions to social determinants of health (health in all policies) and school-based prevention.
- Information/education of general public and the vulnerable groups on importance of early diagnosis and treatment important role of empowered and well informed patient and patient organisations)
- Correct guidance to patients facilitating patient journey for fast access to diagnosis and treatment.
- Timely treatment of acute phase of stroke for the entire country, without geographic inequalities.
- High quality networks (as described above): stroke units and satellite hospitals, together with rehabilitation units
- For all the satellite hospitals, "mobile" team of experts on stroke who work within the hospital, and improvement of "reception" (A&E) for fast access of patient to specialised doctor, in order to ensure timely and high quality care of the acute phase of stroke.
- Adoption of protocols for the entire management of stroke patients.
- Better linkage with other specialists / reinforcement of teamwork (including speech therapists, physiotherapists, psychological support, etc).
- Appropriate rehabilitation to start within the hospital (appropriate human resources required), with the aim to discharge the patient quickly either to a rehab centre or at home.
- Support system to family carers.

In relation to research and technology, the following were mentioned:

- The treatment of ischemic stroke (infarct) will be very different, with better thrombolysis and thus less disability.
- Genetic treatments for risk factors
- Availability of polypill will improve patient compliance.
- More health infrastructure.
- Treatment protocols for managements of technology (better/efficient use of resources if doctors are aware/educated)



**D.** As far as the imaginary society in 2040, during the discussion two trends emerged: one was more conservative, that is, changes are not going to be that great in the forthcoming 30 years because the rate of developments will decrease (compared to the previous 30 years) (even research will have an upper limit, after which there will only be marginal improvement).

The other was more optimistic for greater developments, and that there will be an overall improvement of the health of the population. The developments in medicine will decrease the health differences among the various age groups, and the health of the elderly will improve (the 80-year-old person of the future will be able to do the things that the 60-year-old person of today does).

Still, in the knowledge/learning intensive society, the person may turn into a phobic one, and thus feel less healthy. The mere knowledge (knowing the blood pressure) does not translate into managed/controlled blood pressure per se. Knowing a negative genetic predisposition the person may develop mental health problems (mental health will be a major issue).

Regarding technology, significant changes are expected in the field of stem cells and cloning. This will impact on health care and may actually decrease costs. Diagnostic technology will expand greatly and will allow detection of diseases (even those which will manifest in the future). Still, diagnostic technology will not substitute the doctor.

There will be a decrease of the average length of stay in the hospital, even for stroke patients (thrombolysis pill for treatment at home "the hospital of the future will be the home of the patient"), and it will be possible to regenerate neural tissue with the use of stem cells.

The person/patient will be appropriately informed and educated, so that early symptoms of stroke will be recognized and through telematics it will be possible to have direct contact with specialists for getting information and treatment even at home. So, the hospitals will eventually treat only the most severe cases.

There will be improvement in the treatment and rehabilitation so we will achieve almost complete cure and functionality.

The patient will have access to safe and reliable information through technology, so the role of the doctor changes into a co-ordinating/advisory one (the patient is guided in the chaos of information, gets personalised care). However, this increased feeling of security, may lead the patient not to change behaviour into a healthier one.

Scientific control systems will ensure the soundness and reliability of the available information.



Resources should be appropriately directed (funding research with direct effect on clinical practice). Expensive technology may lead to exclusions and thus inequities.

#### MO organiser comments and conclusions

The workshop was well-attended and there was good involvement throughout its duration from all participants who are very motivated with their own work on stroke. The concepts were well understood and group sessions were animated through their own discussion – no additional intervention was required by facilitators.

Both group sessions worked well. Both groups were enthusiastic about the methodology and enjoyed for rigorous imagining. While the current economic crisis was mentioned by some participants as an inhibiting factor for optimism in their expectations, it did not prevent participants from being engaged and actively participate in the procedure.

Indeed, all participants found the futures studies concepts as something new and very interesting to them, and asked for feedback.

Even though one scenario was not so optimistic, overall it is anticipated that medical technology and information technology will have an impact. The patient will be more empowered and able to recognise early symptoms, and the whole organisation of care will provide quicker access to care (either at home or at hospital) so that disabilities are minimised. Networks of specialised stroke units and hospitals with a "mobile" stroke team will provide quality care. Great emphasis was given on health promotion and disease prevention.



# **GREECE HIP-OA FUTURES WORKSHOP**

Workshop Title:	Managed Outcomes: Hip Osteoarthritis/replacement (Hip-OA) Futures Workshop, Greece
Workshop date, time and location:	16 May 2012, 15.30 – 20.00. Athens, Greece

Names of invitees attending:

- Sokratis Varytimidis, Orthopedic Surgeon, Assistant Professor, University Hospital of Larisa, University of Thessaly
- Apostolos Dolgeras, Research Fellow, Department of Health Economics, National School of Public Health, Athens, Greece, ex Chairman of OPAD (National Insurance Fund for civil servants)
- Eleftheria Karambli, Health Economist MSc, Research Fellow, Department of Health Economics, National School of Public Health, Athens, Greece
- Maria Kitta, PhD student, Orthopedic Clinic, University Hospital of Larisa, University of Thessaly
- Konstantina Kotsifi, MD, Physical Rehabilitation Specialist, Rehabilitation Centre ANAPLASIS (private sector)
- Konstantinos Malizos, Professor of Orthopedics and Head of Orthopedic Clinic, University Hospital of Larisa, University of Thessaly
- Georgios Babis, Associate Professor of Orthopedics, Attiko University Hospital, Medical School, University of Athens
- Konstantinos Bargiotas, Orthopedic Surgeon, Senior Registrar, Orthopedic Clinic, University Hospital of Larisa
- Zoe Dailiana, Assistant Professor, Orthopedic Clinic, University Hospital of Larisa, University of Thessaly
- Elpida Pavi, Senior Lecturer, Department of Health Economics, National School of Public Health, Athens, Greece
- Panagiotis Spyropoulos, Professor of Physiotherapy, Technical University of Athens
- Efstathios Chronopoulos, Assistant Professor of Orthopedics, Ag. Olga Hospital, Medical School, University of Athens

Names of MO partners organising/ attending:

- Elpida Pavi (lead facilitator)
- Apostolos Dolgeras
- Eleftheria Karabli



- Konstantinos Dolgeras
- Maria Liatsou

#### Summary record of the workshop: group and plenary discussions and conclusions

Discussion on the future of dementia in Greece was based on the questions for each of the two levels according to the methodology used. For Level 1, the questions concerned A. definition of health and health determinants, B. predictions for 2040, and C. hopes for the future. For Level 2, the discussion focussed on the question D. the 2040 imaginary society.

Findings are as follows:

**A.** Participants defined health in line with WHO's definition of health.

It was noted that the definition of health as perceived by the individual and as judged by the health professional may differ, and this may lead to different health priorities. For the patient, a subjective definition of health may include the dimension that he/she can have activities without any external assistance.

As for health determinants, genetic profile and environmental socio-economic determinants of health (as defined by WHO) were mentioned.

**B.** For 2040, participants foresee that the population will be less healthy due to aging (increase of life expectancy, increase of burden of various diseases related to age). The deterioration of the economic situation and the climate/environment will also have a similar negative impact on the level of health.

However, through prevention and physical exercise, it will be possible to improve health to an extent, so that even older adults (even elderly) are in a better physical health. Prevention will be facilitated through better education and information which in turn will be facilitated by information technology. Citizens will be more health literate. However, this means patients with higher expectations (which the system may not afford to meet).

I relation to the health services, in the medium term a deterioration is anticipated, due to the economic downturn and the lack of resources (mainly financial). Still, the number of doctors in Greece will remain high. Lack of resources puts a strain on the NHS particularly in view of the anticipated increased demand for public sector health care due to the decreasing available income of citizens.

So, the demand will not be able to be met which will lead to a selection of patients and inequalities. Medical technology will improve, but due to its high cost may result in inequalities in access to (high technology) care.



In relation to hip replacement due to hip osteoarthritis, the following are expected:

- Increase of prevalence of hip osteoarthritis due to demographic reasons.
- Treatment will be related to patient's ability to pay, thus accessibility will decrease (socioeconomic inequalities).
- Possible scientific developments in genetics may lead to the opposite direction (improvement of health) and technology may improve prevention.
- Research will continue to be expensive to run, and there will be limitations in access to its conclusion.
- The first hip replacement will be done at an earlier age on average (index operation).
- During the first forthcoming 15 years there will be increased demand for total hip replacement and for revisions, but the NHS will not meet the demand (problematic accessibility) so we will have a decreased number of hip replacements (issues for consideration are the quality of prostheses/cost).
- Thus, there will be a need for less costly interventions/material or development of medicines or methods which lowers the need for hip replacement.

In general, regarding the future of the treatment of the hip osteoarthritis:

- Around 2040 there may be new medicinal products for pharmaceutical treatment or other alternative treatment to the surgical.
- The need for cost containment will lead to investment in prevention and innovation (still, globally, there is a tendency for decreasing investments in innovation).
- Specialised centres for "mass production" of hip replacements are not expected in Greece.
- There may be cuts in the insurance coverage for hip osteoarthritis, and stricter criteria for proceeding with the replacement.
- Rehabilitation will almost fully be provided by the private sector.

**C.** Participants hope (would like) to see better functionality for the older adults with greater autonomy (physical) and thus improvement of their well-being.

For health services, they would like to see:

- Gold standard for access to a care service (ie. hospital, orthopaedic clinic, etc) to be its effectiveness, efficiency, quality control, evaluation and assessment. Cost-effective treatments (adopting guidelines and protocols) to be approved and reimbursed.
- Prevention of complications (patient registry for monitoring) means cost-containment.
- Better management of the hospitals of the NHS, even if this means to adopt private sector features. Rational management, without any political involvement. Change of the reimbursement system (global budgets, DRGs)
- Faster diffusion of research results into clinical practice, and no inequities in access.
- Development of specialized centres providing integrated care (including rehabilitation. This may result in less costs.
- Equity in accessibility to specialist care irrespective of geographic location of patient's residence, improvement in waiting lists.



**D.** In 2040, in the imaginary society, the definition of health will not change. Patients' expectations may change because their perception of health and quality of life may change. Patients will be more knowledgeable because they are computer literate and have improved access to information. Still, this may result in a more phobic society about health and increased 'medicalisation' of health.

Thus, the doctor-patient relationship will change from a hierarchical one into a more interactive.

In relation to information and knowledge creation:

- The increased access to information will also lead to personalised information.
- Possibly, special software systems may substitute to a certain extent the role of doctor in diagnosis and symptoms identification, if patients can put the results of some tests or their somatometric characteristics and the system returns suggestions (patients already have access to questionnaires about health on the internet).
- There may be internet communities of patients with mutual information-giving and self-help.
- While today the information on the internet may be found in a haphazard way, in the future, more and more specific, accurate and reliable information will be found, through a very strict information quality control system which cannot but be adopted. Most probably, a major problem due to the open access and perhaps misuse of all this information which will take place abroad, will trigger changes in Greece, so that trust systems (as political response) will be the responsible bodies which will have to take over (state, ministry of health), with scientific medical organizations taking the lead (perhaps an independent body from the state). The system will also ensure privacy of personal data.
- Companies or other bodies may sell "filtered" and reliable information, particularly to health professionals.

In relation to technological developments:

- a genetic test will give us much more information that we know today.
- implanted chips will send information about the health of the patient which will enable the doctor to plan a personalized pharmaceutical treatment based on the genetic profile of the patient.
- pharmaceutical treatment will be so effective that it will substitute to a great extent the need for surgical treatment of the hip osteoarthritis.
- there will be substitution of current surgical treatment by robotic surgery and use of new biogenetic material (current research may solve the problem of the cartilage deterioration)
- there may be the artificial blood
- rehabilitation will be done fully through new technologies (computerised waves, etc).

In relation to the provision of health services:

- there will be a shift towards prevention, because the technological developments will make prevention more cost-effective.
- technology will change how health care is provided.
- there will be a trend for technology (like telemedicine applications, tele-diagnosis, etc) to substitute medical knowledge/diagnosis.
- the doctor will have to work in collaboration with other health professionals, or even scientists (biochemists, chemists, etc.) who will complement the doctor.
- all these will lead to a change in the role of the doctor but mainly on diagnosis. The doctor cannot be substituted, particularly in treatment planning and implementation.



- major parts of care will move into primary health care (PHC) or at home, so that the hospitals will
  provide very specialised treatments.
- resources will be distinguished into those for elective and those for non-elective treatments.
- if Greece remains in the European union, the same trends will take place in Greece, perhaps with some delay.

MO organiser	comments and	conclusions
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The workshop was well-attended and there was good involvement throughout its duration from all participants. The concepts were well understood and group sessions were animated through their own discussion – no additional intervention was required by facilitators.

Both group sessions worked well. While the current economic crisis was mentioned by some participants as an inhibiting factor for optimism in their expectations, it did not prevent participants from being engaged and actively participate in the procedure.

Indeed, all participants found the futures studies concepts as something new and very interesting to them, and asked for feedback.

The development of genetics, new era pharmaceuticals, biomedical technology together with information technology are seen as major determinants of the future developments in hip osteoarthritis care.



# **GREECE: DEMENTIA FUTURES WORKSHOP**

Workshop Title:	Managed Outcomes: Dementia Futures Workshop, Greece		
Workshop date, time and location:	15 May 2012, 09.00 – 13.00. Athens, Greece		

Names of invitees attending:

- Aggeliki Andrianaki, Family Caregiver
- Apostolos Dolgeras, Research Fellow, Department of Health Economics, National School of Public Health, Athens, Greece, ex Chairman of OPAD (National Insurance Fund for civil servants)
- Areti Efthymiou, Psychologist, Head of Day Care Centre, Athens Association of Alzheimer's Disease and Related Disorders
- Apostolos Efkarpides, Director of Nursing Services, General Hospital "Vardakio & Proio", Ermoupoli, Syros
- Eleftheria Karabli, Health Economist MSc, Research Fellow, Department of Health Economics, National School of Public Health, Athens, Greece
- Konstantinos Moschovakis, Psychologist, Head of the Department of Outpatient Protection, Department of Mental Health, Ministry of Health and Social Solidarity
- Maria Bozi, Neurologist
- Elpida Pavi, Senior Lecturer, Department of Health Economics, National School of Public Health, Athens, Greece
- Antonis Politis, Assistant Professor, 1<sup>st</sup> University Psychiatric Clinic, University of Athens, Eginitio Hospital
- Konstantinos Prouskas, Psychologist-Gerontologist, Head of Aged Care Unit
- Paraskevi Sakka, Dr Neurologist-Psychiatrist, President of Athens Association of Alzheimer's Disease and Related Disorders

#### Names of MO partners organising/ attending:

- Elpida Pavi (lead facilitator)
- Apostolos Dolgeras
- Eleftheria Karabli
- Konstantinos Dolgeras
- Maria Liatsou

Summary record of the workshop: group and plenary discussions and conclusions



Discussion on the future of dementia in Greece was based on the questions for each of the two levels according to the methodology used. For Level 1, the questions concerned A. definition of health and health determinants, B. predictions for 2040, and C. hopes for the future. For Level 2, the discussion focussed on the question D. the 2040 imaginary society.

Findings are as follows:

A. Most participants endorsed WHOs definition of health, and emphasized quality of life, social functionality and holistic approach for somebody to be defined as healthy. Mental health was also stressed as an important dimension.

Social environment emerged as a determinant of health, with mention of interpersonal relations in family, workplace, etc. All social determinants (as defined by WHO) were also mentioned. Equitable accessibility of health services and integration/continuity of care also emerged as determinants.

Specially trained personnel with increased skills also will play a determining role.

Particularly for dementia, early diagnosis and disease management were stressed as determining the effect of care.

B. For 2040 most participants foresee that the population will be less healthy due to aging (increase of prevalence of dementia and increase of burden of mental disease).

Early diagnosis/identification of dementia will change the view of who is considered healthy. Developments in genetic determinants and risk factors for dementia will make some of those thought to be healthy, to be termed as potential patients (this will have health insurance and legal impacts).

Technology will play a greater role, and the "right to health" will be facilitated by technology (better accessibility, more synergistic model between doctor and patient).

Concerning dementia, in the future, social support and social networks will deteriorate, so family relations will be reinforced to account for this. The welfare state will decrease (N.B.: effect of Greek crisis was evident in this workshop).

The increase of the burden of dementia will be offset by new medicinal products, and information technology.

However, the voluntary sector and solidarity will increase due to improvement of the knowledge and awareness about the disease. Patients will be more empowered.

Dementia care services will be expanded in order to meet increased demand, because eventually the family will not be able to meet all dementia needs. The state will act as facilitator/supervisor of the care, but co-payments will have to be covered by patients (services partly funded by state partly by patients).

As an alternative scenario to the increase of dementia prevalence, it was proposed that there may be a spectacular progress in some technology (new medicines of new genetic/biologic interventions) which will control the disease, and thus the burden will not be that big. This will impact on the way dementia care is delivered.



C. Participants hope (would like) to see the development of more memory clinics and dementia day centres of the public sector (and out of the hospitals)

Also, they would welcome the expansion of community care and home support with more local support network.

They would like to see differential approaches for different groups of patients, a change in the attitude of the health professionals, interventions at early stages, structures/services for the support of the carers, and terminal stage services.

They would also welcome a model of life for the demented person within the community, and the family life (either in their own homes or in host homes for a few days) (for relieving the family).

Finally, they would like to see a National Strategic Plan for dementia care in Greece, where the state will have a central planning role. Both public and private structures will be able to offer care to the patient and support to the carer. Differential care covered by the insurance system according to stage of disease with co-payments would also be welcome.

D. In 2040, in the imaginary society, the definition of health will change: there will be the addition of the concept of "digital literacy". In order to be healthy you will have to be digitally literate, because most of the care (from prevention to disease management and cure) will be delivered with the assistance of information technology (through a portal). The digitally literate citizen/patient will eventually have better health, greater autonomy and will receive services from networks.

There will be medicine without doctors and without patients. Doctors will be mainly researchers who will produce knowledge accessible to patients. Together with feedback from patients, a corpus of knowledge will be developed which will substitute to a significant extent current procedures. Information will be available and usable by citizens, so that deviations from health will be identified early, and appropriate (early) interventions will prevent the development of disease.

Progress on genetics for the early detection of who is going to be diseased will pose bioethics issues, as well as insurance issues.

There will be progress in biomarkers, so every citizen will have a personalised healthcare programme to follow, from birth for his/her entire life. This will be due to the immensely increased early diagnosis potential. Still, an alternative scenario is that there will be uniformity of care protocols, so all will be treated the same way. This difference eventually may not be that contradicting as it seems.

Patient access to such information/data/programme would create a fully empowered and knowledgeable patient who will be capable of a continuous self-assessment of his health.

The researchers will be those who will play the role of the trust system (they produce the knowledge) while the nurses will act as the manager of the knowledge/information available to patients/citizens, so the nurse will be closer to the patients as an advisor/consultant.

Of course, there will be some citizens who will opt out of this information/healthcare programme network (available through a portal/cloud/ etc).

Also there may be some economic limitations, which will lead to social inequalities in the access to dementia care.



This information system will be neither public nor private, but social, according to the model of social networks.

Finally, new criteria for memory problems, dementia and autonomy will be developed, and will be more precise in defining the stages and the conditions of the disease.

#### MO organiser comments and conclusions

The workshop was well-attended and there was good involvement throughout its duration from all participants. The concepts were well understood and group sessions were animated through their own discussion – no additional intervention was required by facilitators.

Both group sessions worked well. Group A was more enthusiastic about the methodology and more able for rigorous imagining. While the current economic crisis was mentioned by some participants as an inhibiting factor for optimism in their expectations, it did not prevent participants from being engaged and actively participate in the procedure.

Indeed, all participants found the futures studies concepts as something new and very interesting to them, and asked for feedback.

The development of genetics and biomarkers together with information technology are seen as major determinants of the future developments in dementia care, which will fall, not only on the public sector, but on the private as well (this may have inequitable impacts).



# THE NETHERLANDS: TYPE 2 DIABETES FUTURES WORKSHOP

Workshop title:	Managed Outcomes Diabetes Futures Workshop NL	
Workshop date, time	and: 28 September 2012, 12.00 – 16.30.	
Workshop location:	Rotterdam The Netherlands	
Names of invitees att	ending:	
<ul> <li>Mattees van Dijk,</li> </ul>	<ul> <li>Mattees van Dijk, GP with special interest in Diabetes type II, medical coordinator for the diabetes program for Care Group ZEL for Family Medicine. Participant i the working group for the Dutch Diabetes case instance.</li> </ul>	

• Ymte Groeneveld GP, 34 years of experience as GP, involved in education of GP's, performed a PhD research on the introduction of specialized Diabetic Services for GP's in Leiden.

Names of MO partners organising/ attending:

- Jan Vissers
- Sylvia Elkhuizen
- Mahdi Mahdavi
- Paul Forte

Summary record of the workshop: group and plenary discussions and conclusions

Discussion step one: expectations, values & hopes, 5-7 years ahead.

There is a difference between experienced illness (complaints) and physical illness (objective abnormalities).

Believe in the malleability of health will decrease. There will be a difference between people with low and high social economic status (SES). Tendency to increasing unhealthy lifestyle, with obesity and higher risk of DM II will continue in lower SES population. In the higher SES population the awareness of responsibility for one's own health will increase.

Regulations by government and the economic crisis will have an impact. If driving a car is less affordable, and cars are banned from city centres, people will cycle more often which stimulates a healthy life style. However, most regulations are more economy-driven with life style improvements as emergent side-effects. Insurance companies become more risk-bearing and stop preventive programs that do not pay-back in a short term. Due to the crisis, some life style incentives are stopped, such as programs to help people quitting from smoking. Also, people are more responsive for their own health by increasing the amount of health care costs that have to be paid by themselves.

Discussion steps two and three: rigorous imagining – Diabetes care in 2040, and rediscovering the present

Do you need people for health care in 2040? We see a tendency to move from health care curers to health care coaches who support wellness. The differences in importance of different functions will change. Doctor-assistants are as important as the doctor. IT and computers will substitute much of the current diabetes care.

DM type I can be prevented or cured. DM type II will stay, but medication will cost less and can be purchased in the drugstore. Diagnostic information is available for everyone, so a doctor visit is less



needed. The last 25 years, the DM II health management improved a lot. Protocols are introduced, and more attention is paid to early diagnoses. However, the current way of diabetes care with regular check-ups is not very effective and efficient. Next step will be to introduce more patient-tailored care that takes into account the patient specific needs for diabetes care instead of prescribing the same protocols for everyone.

Environmental factors will play an important role in developing a healthy life style.

#### <u>Scenarios</u>

The current way of diagnosis is aimed at diagnosing the patient at the earliest moment. The Netherlands do not have a regular screening program. Question is whether a very early diagnosis is always beneficial for patients. Knowing about an illness doesn't improve the experienced quality of life.

There is a tendency to lower the threshold of 'healthy' HbA1C. Currently in The Netherlands, the accepted level is 7.0. This will move towards 6.5 and even lower. This adds to the effect that more people will be seen as 'ill'.

Especially the targeted use of specialist services and the allocation of resources to the different demand segments is a very interesting scenario.

#### MO organiser comments and conclusions

Six participants accepted the invitation. Unfortunately, three cancelled shortly before the meeting, and one didn't show up. Therefore, the group was very small. However, the two GP-participants were very interested in the project and the ideas and there was a vivid discussion with them and between them about future scenarios concerning diabetes. The format for the Futures Workshops with group discussion followed by reporting back was not followed, but we did follow the three steps.

The concepts were well understood, both by the GP who participated in the project before, as by the GP for who all material and concepts were new.



# THE NETHERLANDS: STROKE AND HIP OA FUTURES WORKSHOPS

Workshop title: Workshop NL	Managed Outcomes Hip Osteoarthritis and Stroke Futures
Workshop date, time:	20 September 2012, 12.00 – 17.00
Workshop location:	St. Elisabeth Hospital, Tilburg, The Netherlands

Names of invitees attending:

- Ireen van der Voort, nurse coordinator, orthopaedics, St. Elisabeth hospital
- Annette van Wezel, outpatient nurse, orthopedics, Tweesteden hospital
- Saskia Bosten, quality assurance staff member orthopaedics, St. Elisabeth hospital
- Wendy van Limpt, team manager orthopaedics ward, St. Elisabeth hospital
- Maartje Wijnen, education staff/nurse orthopaedics, St. Elisabeth hospital
- Marcel Boonen, manager orthopaedics, St. Elisabeth hospital
- Jocova Vervoort, nurse practitioner CVA, St. Elisabeth hospital
- Anita Tinga, rehabilitation physician, Rehabilitation Centre Leijpark
- Paul de Kort, medical consultant neurology, St Elisabeth hospital
- Mirjam Aaftink, ergotherapist, Plan Practice for Ergotherapy
- Marjo van Gils, ergotherapist, De Wever, organisation for elderly care
- Ivonne Jacobs-van Rooij, team manager paramedical team, Schakelring, organisation for living & care services for elderly
- Susan van Limpt, team manager stroke unit, St. Elisabeth hospital

Names of MO partners organising/ attending:

- Paul Forte, lead facilitator
- Jan Vissers
- Sylvia Elkhuizen

Summary record of the workshop: group and plenary discussions and conclusions

#### Discussion step one: expectations, values & hopes (Hip OA)

We expect that health for Hips OA\_in the future will be dominantly malleable, and that patients do not suffer from pain anymore.

We expect that there will be more choice for patients, but that this will also lead to a split in private and public services, and that those who can pay will have more choice.



Hip OA care will involve more technology and less people. We expect also a counterbalance to technology by increased attention for life style and for instance herbal medicine.

Hips will be operated in day care, and move from large centres to smaller community based centres.

Will there still be (a need for a) health insurance organization?

We hope that hip replacements will not be necessary in 30 years time. Hip problems can be treated with medicine and tablets, and even be treated in the pre-birth phase by preventive care for those who are genetically prone to bone problems at later ages.

There will be no complications.

There will be fast access for all, to services that are patient focused. As information is widely available, the patient has more influence in the decision making process. The patient will be less dependent on individual health professionals.

At the moment being healthy is considered as very important, and patients have high demand to be healthy. In 30 years time being healthy will not be an issue anymore.

Patients will be in control of personal decisions on life and death issues.

#### Discussion step one: expectations, values & hopes (stroke)

Being healthy implies a balance in body and mind, living without illness and disabilities, with own responsibility for a healthy life style.

Though the trend of lifestyle and obesity is still downward, we expect that the increased awareness will be able to counterbalance this problem.

We expect that there will be more incentives to do the right things.

We expect that the health care system will use stricter criteria and protocols, and will offer for each category of patients an intensive treatment program, but after that everybody is responsible for organising support in the own environment

We expect more emphasis on prevention and education, more insight into the function of the brains and its recovery, more treatment possibilities at home.

We hope that there will be less stroke patients due to the increased attention for prevention.

Healthy is now interpreted as equal to young, but in the future also people at older age can be healthy; so being healthy needs to be defined for different ages.

The diagnosis of stroke can be faster due to CT facilities in the ambulance.

#### Discussion step two: rigorous imagining – Hip OA care in 2040

Hip OA care in the far future will not be delivered by hospitals, because there will be no hospitals anymore. Health care will be organized in small communities. People feel responsible to care for each other within these communities.

Advice will be provided by an alternative intelligence, your avatar, that you can consult anywhere. All knowledge is available for everybody.

Mental and physical disabilities will be handled by technical intelligence, and everything will be organized from the home.



There will be fluidity in systems (like the murmuration). There will be more individualized care, and systems will be gone. Collaboration will only be there when necessary.

The privacy will be gone, as all information is available in information systems (facebook world) and big brother is watching your health.

# Discussion step two: rigorous imagining – Stroke care in 2040

Stroke will not exist anymore in the future due to prevention and chips implanted that checks your vital functions and helps you to maintain the right lifestyle. The chip will provide you with all information based on the most recent protocols and information available in the health system but will also perform some control on your life style and health.

If you get a stroke, the system will determine in what treatment category you fall, you will receive a very intensive treatment, and after that you have to deal with it yourself with support of 'domotica' (home automation).

Everything is organized from the home.

Knowledge and support you can get from the 'supermarket'. Your chip will – based on your DNA profile and risk profile - guide you to buy the things that you need.

You will have more control over your health but also have more responsibility.

MO	organiser	comments	and	conclusions
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We had a combined workshop for Hip OA and stroke, but that worked out quite well. After 45 minutes of introduction and preliminary findings for both patient groups, we started the Futures Workshop introduced by Paul. For the discussions we split up into two groups to discuss the expectations, values & hopes (round one, Hip OA and stroke) and imagining the future (round two, mixed groups).

We had 13 participants, 6 for Hip OA and 7 for Stroke. For Hip OA the participants came from the St. Elisabeth hospital. Though we tried to involve one or two orthopaedic surgeons in the meeting, they did not turn up. The main argument was the pressure of patient care activities and the fact that it is difficult to allocate so much time to this sort of brainstorming,

For Stroke the participants came from the two hospitals involved in the stroke service, with also a medical consultant that stayed for most of the meeting, but also from partner organisations in the stroke services, e.g. a rehabilitation physician from a rehabilitation centre, and ergo therapists from elderly care services outside the hospital.

The role of Paul as a guest speaker and lead facilitator did work out very well. This was at the same time very instructive and entertaining.

The discussions were quite vivid, with good involvement of the participants. It was helpful to hold the discussions in Dutch. That made it easier to participate for everybody. Presenting a summary in English for the plenary discussion did work well.

The participants expressed that they had an interesting discussion and brainstorm on a future health care for hip OA and stroke that was very relevant for the work they are involved in at the moment.



#### SPAIN: FUTURES WORKSHOPS SUMMARY

Workshop Title:	Managed Outcomes Futures Workshop
Workshop date, time and location:	1 Jun 2012, 12.00 — 17.00. Valencia, Spain

# Names of invitees attending:

Experts have been selected in order to balance different professional profiles, institutions and age and sex distribution. Specific profiles have been included in specific table (i.e. diabetologist in diabetes, hospital clinicians in stroke/hipOA). Cross-sectional profiles (primary care physicians, ICT experts, health 2.0 professionals...) have been distributed in order to have one in each table. Experts who have been already involved in the case-study development has not included in the workshop trying to avoid an excessive focus on specific case data.

Briefly, 36 experts participated in the workshop. Regarding socio-demographic information, 55% were men, 45% women, and the age distribution was 2% (20-30 years), 42% (30-40 years), 25% (40-50 years), 25% (50-60 years), 6% (60-70%). Half of the participants came from public healthcare system, 30% research and 20% from others institutions (private healthcare, companies, patients, and medical mass media). Participants' profiles include physicians, nurses, middle and senior level managers, ICT experts, journalists, statisticians, patients, pharmacists, and sociologists.



	Table	Participant	Profile	Especiality	sex	age	institucion
ia	Dement	Amparo Bahamontes	nurse	care system	women	50-60	public healthcare
ia	Dement	Silvia Paz	researcher	healthcare system/health economics	women	30-40	pharma company
ia	Dement	Irene Monsonis	researcher	ICT	women	30-40	research centre
ia	Dement	Ana Navarro	researcher	ICT	women	30-40	research centre
ia	Dement	Fran Rodenas	clinician	primary care	men	40-50	private healthcare
ia	Dement	Sandra Huertas	researcher	social services	women	20-30	research centre
ia	Dement	Juan Carlos Navarro	researcher	social services	men	40-50	research centre
ia	Dement	Jaume Alapont	health 2.0		men	40-50	public healthcare
ia	Dement	Sergio Garcia	macro manage	ement	men	40-50	private healthcare
ia	Dement	Maria Jose Lloria	macro manage	ement	women	40-50	public healthcare
	Dement	Bernardo	macro manage	ement	men	50-60	public



ia		Valdivieso					healthcare
ia	Dement	Juan Bautista Gomez	macro managemer	nt	men	60-70	public healthcare
s	Diabete	Toni Martinez	researcher	diabetes	men	30-40	research centre
s	Diabete	Cecilia Vera	researcher	ICT	women	30-40	research centre
s	Diabete	Maria Martinez	researcher	ICT	women	30-40	research centre
s	Diabete	Nacho Basagoiti	clinician	primary care	men	50-60	public healthcare
s	Diabete	Blanca Gómez	clinician	public health	women	30-40	public healthcare
s	Diabete	JoseMi Carrasco	researcher	public health	men	30-40	research centre
s	Diabete	Juan Bru	health 2.0		men	40-50	public healthcare
s	Diabete	Ángel Escudero	health 2.0		men	50-60	public healthcare
s	Diabete	Alain Ochoa	health 2.0		men	40-50	scientific journal
	Diabete	Sergio Guillen	ICT companies		men	50-60	technology



S						company
Diabete s	Carmen Pastor	macro manage	ement	women	50-60	public healthcare
Diabete						
s	Carmen Temina	patient associa	ation	women	60-70	patient
Stroke/ Hip	Pilar Argente	clinician	ambulatory surgery	women	40-50	public healthcare
Stroke/ Hip	Juan Viñoles	clinician	ambulatory surgery	men	50-60	public healthcare
Stroke/ Hip	Maria Jose Nodal	researcher	evaluation	women	30-40	research centre
Stroke/ Hip	Pilar Soriano	researcher	evaluation	women	30-40	research centre
Stroke/ Hip	Raquel Faubel	researcher	healthcare system/health economics	women	30-40	public healthcare
Stroke/ Hip	Julian Librero	researcher	healthcare system/health economics	men	30-40	public healthcare
Stroke/ Hip	Elisa Soriano	mesomanage ment	hospitalization at home	women	50-60	public healthcare
Stroke/ Hip	Vicente Traver	researcher	ICT	men	30-40	research centre
Stroke/	Carlos	researcher	ICT	men	30-40	research



Нір	Fernandez					centre
Stroke/ Hip	Javier Chirivella	researcher	social services	men	40-50	research centre
Stroke/ Hip	Emilio Baixauli	clinician	traumatology	men	50-60	public healthcare
Stroke/ Hip	Pablo Sendra	health 2.0		men	30-40	public healthcare


## Names of MO partners organising/ attending:

- Teresa Meneu (lead facilitator)
- Raquel Faubel
- Maria Jose Nodal
- Bernardo Valdivieso
- In addition, one member of our research group has been included in each table. They were trained about workshop methodology and key data for the corresponding case study.

#### Summary record of the workshop: group and plenary discussions and conclusions

In all the discussions, patient empowerment and co-responsibility are a common issue. Experts consider very relevant to define the role of the patient and care-givers in the new paradigm of the healthcare system.

Other recurrent issue was the use of teleresources. Technological advances should go more focused in real needs of the healthcare system avoiding super-specialization or medicalisation. Organizational changes will be happened in order to get patient-centred and personalized healthcare.

Health literacy, health promotion, prevention and primary care aim for the health management instead of a healthcare system focused in diseases treatment. The new paradigm also includes a big effort on chronic diseases management during the stable health stage and home as a services provision point.

Trustworthy information for the healthcare performance and health/economic outcomes would be relevant for the assessment, evaluation, benchmarking, improvement...

#### MO organiser comments and conclusions

All the workshop has been developed in the same day but working in parallel sessions for each case study. A total of three different discussion tables have been performed: one for diabetes, one for dementia and one for stroke/hip. Stroke and hip were joined together in order to have more members in the discussion but the chairman tried to focus each item both in stroke and hip specific issues.

Each session (1, 2, 3) has been introduced by the lead facilitator with a common general presentation, followed by parallel discussion in three different tables. After each session, all the conclusions were put together. To end up, a plenary session were developed in order to close the workshop and to collect feed-back from the experts attending.

All the participants were very involved in the workshop. Discussions arose spontaneously at the tables and discussions were very animated. In each table, all the participants have good participation and all try to explain their feelings and ideas about the future. Discussion was well balanced and distributed among the participants. Nevertheless, in the session 2, two different trends emerged from several tables: one of them more pessimists, the other more focused in learning society. Facilitator re-conducted in several occasions the discussion in other to go deeply to the questions proposed in the methodology.



Some of the feed-back feelings from the participants are included below:

- "Really strange (but good) to discuss openly and at length about healthcare with several different profiles" *Hospital Clinician*
- "Different background in the participants but very similar feelings". Manager
- "Sometimes it's difficult to make you understand due to the technical language. Today we had the opportunity to bring our points closer". *ICT expert*
- "Very funny to meet other people working on the same field but with different approach. Maybe we could keep in touch with others participants for futures collaborative tasks". *Researcher*





## SPAIN: TYPE 2 DIABETES DETAILED NOTES

## Session 1 ('level 1')

 What does it mean to be "healthy" now? And what determines if someone is healthy or not?

- Make your best prediction about people's health in 2040:
- Do you expect people will be more or less "healthy"?
- Will the definition of being healthy have changed?
- Will the determinants of health have changed?
- What will the health care system look like?
- What do you expect will have happened to diabetes services?

### • What are your hopes for health in 2040:

- What improvements would you like to see in the way health is defined? In the way it is determined?
- What do you hope for diabetes services?

We must not view diabetes from the point of view of a disease, but from the point of view of a condition of life. According to Valentin Fuster: We have been involved in prevention, has lengthened life .... but it has cost too high and can lead to collapse. We want people to be more and more healthy. In the future, we should not focus on disease, but in health, by:- Prevention-Promotion- Education. Fuster's idea for a future: Physicians should not manage disease, but HEALTH.

How can we achieve this?- Active citizenship / sociological change Health should be the responsibility of each, which raises the question of co-responsibility. The practitioner must give a little more responsibility and let the patient take small decisions on their health. The patient must have an active role, backed by professional support.- Is not to inform, but train. Health should be "Steeped in everything", ie no use, for example, the day without snuff or the day of the fruit in a school. Learning in health should be more continuous.- Increase primary care services: to increase the technical means for the first responses to questions not centralized. For example, to call the doctor by phone (already done, but currently takes little practice because the primary physician has no time.) -> Relocation partially, by telephone, telemedicine.- Promotion, involving the user, and getting feedback from the patient.- Organization of workshops in clinics, focused on providing tips for healthy living.- Steps to achieve it: 1 health education 2nd Health Promotion in society

We should avoid an exclusive focus on healthcare professional and medicalization of life. Health is not the health problem but a problem of society, made up of estates: education, industry, ... Health care is one more, and it is the responsibility of all actors involved.



## Session 2 ('level 2')

- Describe the nature of wellness and well-being changed in the Learning Intensive Society of 2040. What does it mean to be 'healthy' now, in 2040?
- Describe in detail the organization of different systems for assuring wellness especially those for diabetes?
- Think about systems of trust, knowledge creation and responsibility describe how these systems work in the LIS of 2040 and how do they relate to diabetes services?

First, there was a discussion about the possibility that society evolve to small businesses rather than large. This idea came from the future idea of people leaving the crowded cities and returning to smaller cities, where coexistence and relations between its inhabitants back to prominence. Later, the idea was suggested that certain large projects can only be carried out by large and powerful. This would be solved with small group's partnership, forming large companies able to meet those challenges. With an effort of imagination to see her future: residential complex in orbit, Mars visits, visits to the moon.

It is difficult to imagine the future, but it seems that in recent years have been broken fundamental human values such as family, contact with friends.... In the future social relations will change again, and face to face communication will increase. The future will bring advances in ecology and sustainability of the ecosystem, due to the oil problem. There will be a balance between consumption and environmental sustainability.

What we want for 2100?- No health problems. No plans to improve health, but promotion of Happiness.- We eat well, have no fat and no cholesterol.- We seek a world with less stress, with less pressure at work and with a less competitive environment and greater cooperation. We are now in a world which requires 'being the best in everything' When this disappears, the people will decrease stress and increase people's welfare.- With regard to hospitals -> service delivery, decentralization. Increased telemedicine, including remote operations.- More harmony with nature.- Live surrounded by coconut trees in the Bahamas .....

## Session 3 ('level 3')

- Think about current changes taking place around you.
- Recall the three different kinds of change discussed at the outset: substitution, complementarity and emergence.
- Consider the way you described the future of health and health care in Session 1 and compare it with the future you described in Session 2.
- If you alter your assumptions about the future does it change what you see about the changes taking place around you now? Can you see the difference between substitution



and emergent changes? Consider two or three examples of emergent and/or systemic change.

- Feeding changes when society changes
- Social networks relevance for patients: promoted from healthcare system
- Internet information: discussion about reliability
- Participatory model for decision-making (patient-physician)
- Primary care and prevention reinforcement
- Health literacy
- Prescription not just for drugs: physical exercise, workshop...
- Avoid medical language for the patient
- Patient motivation: socialization, coaching, forming part of a group...



## SPAIN: STROKE AND HIP OA DETAILED NOTES

## Session 1 ('level 1')

• What does it mean to be "healthy" now? And what determines if someone is healthy or not?

- Make your best prediction about people's health in 2040:
- Do you expect people will be more or less "healthy"?
- Will the definition of being healthy have changed?
- Will the determinants of health have changed?
- What will the health care system look like?
- What do you expect will have happened to stroke and hip services?

### • What are your hopes for health in 2040:

- What improvements would you like to see in the way health is defined? In the way it is determined?
- What do you hope for stroke and hip OA services?

## Guess what is "probable", what you expect will happen:

- How do you see the definition of being healthy changing over the horizon to 2040 and what does it mean for stroke?
- How do you see the health care system changing over to 2040 and what are the implications for stroke services?

Specify aspirations, the values underlying hopes: What would you like to see happen to the wellness and the health care system? Describe a desirable outcome – a **positive** vision that reflects things you think are important. Please be explicit about your values and hopes.

- What is being healthy? It depends on the actor (patient, physician, policy makers..)
- Healthcare system is right now very paternalistic. Patient empowerment and coresponsibility should be boosted.
- Technical and technological advances won't be enough for a organizational change
- Medicalization. Two different trends about this: some people think that there will be more medicalization in everyday life. Other people believe that current medicalization would be reverted.



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- Most advances will be done in third world, mental health, intensive medicine or preventable diseases
- Healthcare predictions: healthcare system will be more competitive, more tele-resources will be used. System will have also a paradox because it will focus in super-specialization but also with a holistic approach. Hierarchy will be continued.
- Healthcare hopes: less medicalization, patient empowerment and co-responsibility, teleresources, incentives for effectiveness, evidence based medicine. Health-centred instead of diseases centred

## Session 2 ('level 2')

- Describe the nature of wellness and well-being changed in the Learning Intensive Society of 2040. What does it mean to be 'healthy' now, in 2040?
- Describe in detail the organization of different systems for assuring wellness especially those for hip OA and replacements and stroke?
- Think about systems of trust, knowledge creation and responsibility describe how these systems work in the LIS of 2040 and how do they relate to hip OA and replacement services and stroke services?
- How has the nature or definition of wellness/well-being changed in the Learning Intensive Society of 2040? What does it mean to be "healthy" in 2040?
- How has the organization of the many different systems for assuring wellness, including the role of hip and stroke services, changed?
- Not just knowledge value: experience and wisdom value
- Personal responsibility
- Basic values and needs are/will be universal and durable
- Work for living not life for working
- Two different trends: 1. knowledge as a value, kept in small privileged population, solitude, anguished population. 2. accessible and immediate knowledge for everybody, interpretation will be personalized
- Technology: disruptive innovation in genetics, instantaneous personal communication, robots will be life form with infinitive capabilities.
- Cellular sensors to detect physiologic variations, tele-resources,

Session 3 ('level 3')



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- Think about current changes taking place around you.
- Recall the three different kinds of change discussed at the outset: substitution, complementarity and emergence.
- Consider the way you described the future of health and health care in Session 1 and compare it with the future you described in Session 2.
- If you alter your assumptions about the future does it change what you see about the changes taking place around you now? Can you see the difference between substitution and emergent changes? Consider two or three examples of emergent and/or systemic change.
- Policy strategies needed to implement changes (macro management)
- Benchmarking to evaluate and compare performance
- Transparency in the information about healthcare performance
- Clinical guidelines needed but in a useful format (a book it's not useful)
- Better information collection and exploitation resources



## SPAIN: DEMENTIA DETAILED NOTES

## Session 1 ('level 1')

 What does it mean to be "healthy" now? And what determines if someone is healthy or not?

- Make your best prediction about people's health in 2040:
- Do you expect people will be more or less "healthy"?
- Will the definition of being healthy have changed?
- Will the determinants of health have changed?
- What will the health care system look like?
- What do you expect will have happened to diabetes services?
- What are your hopes for health in 2040:
  - What improvements would you like to see in the way health is defined? In the way it is determined?
- What do you hope for stroke and hip OA services?
- Not all changes are improvement
- Patient co-responsibility relevance
- Health system should form instead of inform
- We should avoid medicalization
- More primary care vs hospital care
- Use of tele resources
- Education, promotion and prevention relevance
- Health is not a healthcare problem. Health is a society problem.

## Session 2 ('level 2')

• Describe the nature of wellness and well-being changed in the Learning Intensive Society of 2040. What does it mean to be 'healthy' now, in 2040?



- Describe in detail the organization of different systems for assuring wellness especially those for dementia?
- Think about systems of trust, knowledge creation and responsibility describe how these systems work in the LIS of 2040 and how do they relate to dementia services?
- Physicians and hospitals still will be in charge of the healthcare
- Incorporate improvements but without losing human values
- Relevant changes in social relationships: coming back to face to face
- Ecology and environmental sustainability will be needed
- Not just health promotion, happiness promotion
- Less stress, less competitiveness, more cooperation
- Health services decentralization
- Use of telemedicine resources (even tele-surgery)

## Session 3 ('level 3')

- Think about current changes taking place around you.
- Recall the three different kinds of change discussed at the outset: substitution, complementarity and emergence.
- Consider the way you described the future of health and health care in Session 1 and compare it with the future you described in Session 2.
- If you alter your assumptions about the future does it change what you see about the changes taking place around you now? Can you see the difference between substitution and emergent changes? Consider two or three examples of emergent and/or systemic change.

This is the unique group following the expected structure of the session 3. Nevertheless, the conclusions were very similar to the other tables' discussions according to the plenary final session.

- Substitution:
  - Relevant part of healthcare system to focus on chronicity (organizational changes).
  - Social care instead of drug prescription for dementia.
  - High resolution for acute process.
- Complementary:



- Technological resources for elderly and chronic patients (tele-monitoring and information systems).
- Social services for these patients.
- Emerging:

•

- ICT for homecare and tele-monitoring.
- Support to the caregiver: education, motivation, breaks.
- Home as a care provision centre aiming to the integration of the patient (not isolation)



## 31.7.2012

# FINLAND: STROKE FUTURES WORKSHOP

Workshop Title:	Managed Outcomes Stroke Futures Workshop
Workshop date, time and location:	12 June 2012, 12.30 – 15.30. Jyväskylä, Finland

Names of invitees attending: All from Keski-Suomi Hospital District (KSSHP) unless otherwise noted.

- Mikko Lintu, Chief doctor, Emergency services
- Satu Auvinen, Chief doctor, Rehabilitation
- Sari Avikainen, Head of department, Neurology
- Jouni Ranua, Head of section, Neurology
- Marjaana Aapakari, Head nurse, Neurology
- Heikki Janhunen, Head of emergency department
- Minna Hälinen, Specialist, Neurology

### Names of MO partners organising/ attending:

- Ari-Matti Auvinen (lead facilitator)
- Tomi Malmström
- Paulus Torkki
- Antero Vanhala

Summary record of the workshop: group and plenary discussions and conclusions

The following topics were raised in the discussions:

- health as a relative or absolute condition?
  - quality of life as a factor
  - "mental health" and psychological health
  - own responsibility vs. system responsibility
  - governance of one's own life
- dependence as a fear factor
  - cultural concept also of dependence (see hip discussion)
  - dependence on others is the ultimate fear
- the effectiveness of stroke treatment and centralization
  - response time as a key factor in effective treatment
  - sufficient population basis
- stroke and lifestyle
  - own involvement



- division-of-labour between public and private healthcare
  - the definitive role of public sector in emergency treatment
  - the potential role of private sector in rehabilitation
- technological changes
  - CT technology and portability
  - ambulances and "hospital building independence"
  - monitoring (video consultations) in rehabilitation etc.
- public campaigning for early detection
  - customers/citizens/patients but also healthcare personnel
- technological / medical developments
  - complicated diagnosis can be becoming easier
  - CT scanners and their development (portability)
  - however, regional structure (long distances) hamper deployment for quick treatment for many potential patients (demographic structure in remote areas)

#### MO organiser comments and conclusions

The workshop was carried out with seven practitioners and all the sessions were done as a single group. The discussions were a bit dominated by one of the practitioners but also other people got involved.

The presentation of stroke results was quite straightforward and only few comments were mentioned after the presentation. Moreover, the results were not raised again in the following sessions.

There was a strong emphasis of hospital district's region in all of the sessions' discussions and not all of the participants were able to put themselves in the future environment. However, there were some interesting points raised especially in the first two sessions.

Overall, quite successful workshop with some interesting comments but the discussion was not running smoothly all the time.



## FINLAND: HIP OA FUTURES WORKSHOP

Workshop Title:	Managed Outcomes Hip OA Futures Workshop
Workshop date, time and location:	12 June 2012, 09.00 — 12.00. Jyväskylä, Finland

Names of invitees attending: All from Keski-Suomi Hospital District (KSSHP) unless otherwise noted.

- Maija Pesola, Chief doctor, Department of surgery, Orthopedics
- Päivi Salonen, Head nurse, Orthopedics
- Marja Pehkonen, Head nurse, Orthopedics
- Konsta Pamilo, Specialist, Orthopedics

### Names of MO partners organising/ attending:

- Ari-Matti Auvinen (lead facilitator)
- Tomi Malmström
- Paulus Torkki
- Antero Vanhala

Summary record of the workshop: group and plenary discussions and conclusions

All the participants were actively participating into discussion. The participants allowed themselves open-minded imagination and the following topics were raised.

- structure of demand
  - demographic factors (the amount of 85 year old citizens is increasing)
  - the amount of younger people in hip operations (revisions?)
  - level of expectations by the patients
- pain and the concept of pain
  - generations and the concept of pain
  - loneliness and pain (pain is hardest at nights)
  - tolerance of pain and need for "quick fixes"
- structure of community
  - understanding of personal abilities and social structure
- emphasis in treatment
  - no revolutionary developments in materials etc. since 70s
  - potential of conservative treatments
- conservative treatment vs. operations
  - expectations for operations



- "happiness" and ideals-of-life
  - image of perfect life and acceptance of decreasing health
- private companies and their role
  - insurance-based treatments
  - choices (also the choice of hospitals)
- level of incidents and genetic factors

#### MO organiser comments and conclusions

Some of the invited persons were not able to attend the workshop and after all there were four practitioners. However, the workshop was carried out as one single group and discussion was very lively throughout all the sessions. All the practitioners participated to the discussion. The participants understood well all the concepts and allowed themselves to imagine the future.

The group was really excited by the comparative results presented in the beginning of the workshop. Same themes were raised up into the discussion also in the following sessions. The participants thought that it would be important to carry on the research as there have been some structural changes at the hospital district after the initial data collection.

In the first and second stage sessions understood well the tasks and many interesting topics can be picked up from the discussions. In the third level session the participants felt it a bit difficult to connect anticipations to the future imaginations and the discussion was more focused to the describe themes of the first two sessions in more detail.



# FINLAND: DEMENTIA FUTURES WORKSHOP

Workshop Title:	Managed Outcomes Dementia Futures Workshop
Workshop date, time and location:	1 October 2012, 09.00 – 12.00. Jyväskylä, Finland

Names of invitees attending:

- Katariina Kalliopohja, Specialised Nurse, Central Finland Health Care District
- Sirkka Keikkala, Unit Director, Senior Physician, Jyväskylä area Health Care Centre Hospital
- Virpi Rasinaho, Development Manager, Central Finland District Association of Alzheimer Society of Finland
- Pirkko Soidinmäki, Manager of Service Unit, OIVA Center of Jyväskylä
- Ritva Tikkamäki, Senior Physician of Neurology, Central Finland Health Care District

### Names of MO partners organising/ attending:

- Ari-Matti Auvinen, Aalto University, HEMA Institute (lead facilitator)
- Tomi Malmström, Aalto University, HEMA Institute
- Antero Vanhala, Aalto University, HEMA Institute (invitations, recording, minutes)

Summary record of the workshop: group and plenary discussions and conclusions

In this futures workshop, the essential themes of the discussion were the following: the altering definition and perception of health, dementia as a part of ageing, demographic changes, technological devices and the future of dementia care by 2030.

According to the definition and perception of health, it was noted that prevention will find new forms and methods. Preventive medication is likely to grow and early intervention is possible in e.g. the health checks already in the age of mid 50s, and thus new possibilities for effective intervention are provided. However, there is still limited knowledge about the potential harmful side effects of preventive medication of dementia. The information regarding the health of the brain will be directed to younger generations with the emphasis of regular exercising and healthy diet. A new risk factor in the near future is the growing stress level in daily work, which may lead to a growing risk of dementia.

An essential element in the prevention is the utilization of various communities. However, in our individualised societies, this requires also structural changes and the actual provision of venues and places where ageing people can meet and socialize (e.g. day centres and community centres).

There took place also an interesting speculative discussion regarding the new unidentified potential causes of dementia. There is not much scientific evidence yet of the impact of hazardous (chemical) materials in our living environment or the impact of the food additives as causes for



dementia. However, within the experts there was no unified opinion of the potential impact of environmental chemical factors and their relation to dementia, but it is an interesting area to follow.

Previously it was understood that dementia is an elementary part of ageing – however, this picture is one-sided as a large number of ageing people are really active and also fully capable. It is obvious that as the population is getting older, also the number of dementia patients will be growing. In our contemporary environment in Finland it seems that the children of dementia patients cannot easily accept that their parents require care – new type of dependencies does not suit the daily life of the children.

The attitudes in the society have been getting more neutral towards dementia. The third sector (foundations, associations, voluntary work) is likely to take a larger role in the care of dementia through its various services.

According to the demographic changes, it was noted that the number of senior citizens in the area of Keski-Suomi will double by 2030. The structural change within the region is pushing people towards cities and remote rural areas will not anymore be suitable for the elderly, as the various (health and social) services will be increasing centralized to regional centres. The smaller municipalities are thoroughly challenged by the decreasing population (and the amount of net tax payers) and the growing proportion of the elderly citizens in the population of a municipality.

An interesting – although short – discussion tackled the issues of growing ethnic populations in the area of Keski-Suomi. In short term, this brings up issues of various cultures in elderly care, in long term it can also cause genetic diversity, which is according to the health of population in a region a positive factor.

In the discussion regarding the possible use of technologies, it was noted that technologies cannot replace the "human touch". For instance, monitoring the inhabitants of in service apartments can be effective, but it has also its limitations. Appropriate technological devices are by their nature "non-intrusive", such as door alarms in the apartments of the dementia patients. Also there is interesting potential in intelligent clothing, intelligent medical dispensers etc. However, the participants paid also attention to the fact that for dementia patients too much technology can be harmful and, for instance, the use of robots can cause hallucinations for the patients.

For the future of dementia care by 2030, the essential factor in the development of our society is whether we are still ready to take care of the weaker and the invisible or whether the atmosphere in the society gets even more selfish. It is also likely that the customers / patients grow to be more demanding: in the near future they are belonging to a generation, which has been used to services (contrary to the elderly of today in Finland). The critical challenge is also the recruitment of the personnel for the care activities. This can be an important constraint in the development of dementia care in Keski-Suomi and in Finland.

## MO organiser comments and conclusions

The workshop was attended by five people, which worked and discussed well jointly. As the number of participants was small, no breakout groups were used and instead the discussion was undertaken in one room only.

The participants of the futures workshop discussed fluently various challenges of the future and were ready to share also ideas and assumptions – such as the potential impact of the environmentally hazardous chemicals and their possible relation to dementia.



The relatively seamless cooperation and collaboration between the primary health care, the specialized health care and the third sector in Keski-Suomi was a pleasant surprise for the facilitators. There was an atmosphere of facing the various challenges jointly and assisting another instead of building up barriers and borderlines between the various actors.



# iii.Futures Workshop Invitation Letter and Agenda: Stroke Workshop, UK

Brighton and Sussex NHS University Hospitals

Dear Colleague

# EU MANAGED OUTCOMES PROJECT: STROKE FUTURES WORKSHOP

We would like to invite you to join us for this Stroke Futures Workshop. The location will be at an offsite venue in the Gatwick area, and the date will either be:

- Thursday 15<sup>th</sup> March 12.30 17.00, or
- Friday 23<sup>rd</sup> March 12.30 17.00

The confirmed date will depend on the responses we receive to the invitations, so please let us know which dates suit you so we can finalise one of them as soon as possible.

The main purpose of the workshop is to explore the assumptions we make about the future of stroke care services. Participants will clarify and expand their anticipatory assumptions, a critical component of decision making in the here and now.

The workshop forms a key part of the Managed Outcomes stroke case study. This is a 3-year EU-funded project exploring the use of resources - their associated impact on health outcomes - in six different EU countries. Stroke is one of four selected case studies, with a particular focus on that part of the care pathway from time of onset to immediate post-acute care.

The Balance of Care Group has been working closely with us on the BSUH stroke unit on the UK case study and has some interesting headline findings from our European colleagues' case studies to share with you at this event, as well as working with you on stroke futures.

The workshop will be led by Riel Miller, a leading world figure in futures methodologies, and is guaranteed to be a stimulating and thought-provoking event. A draft agenda is attached; a final version and venue details will follow in due course.

The event is free of charge and includes a buffet lunch and refreshments. We do hope you will be able to attend for the full workshop and would be grateful if you would confirm your attendance in advance as soon as possible with:

Russell Leney: <u>Russell.Leney@bsuh.nhs.uk</u> Tel 01273 523104

Yours sincerely,

Dr Ingrid Kane

Consultant Stroke Physician





# DRAFT AGENDA

# STROKE FUTURES WORKSHOP

- 12:30 13:15 Lunch, Introduction, Results from EU partner stroke case studies
- 13.15 13:30 Overview of Strategic Foresight and Futures Literacy
- 13.30 14.15 Level 1 Group Exercise: Values, Expectations and the Subject
- 14:15 15:00 Level 1 Reporting Back
- 15:00 15:30 Introduction to "rigorous imagining"
- 15:30 16:15 Level 2 Group Exercise: Stroke Care Unlimited
- 16:15 16:45 Level 2 Reporting Back on Group Exercise
- 16:45 17:00 Wrap-up: Reconsidering Anticipatory Assumptions





# *iv.* Detailed cost and outcome analysis for each case study

After extensive study and examination of the available data from the WP3 case studies and the questionnaire survey, the following cost and outcomes analysis was carried out for each partner country/case study, which was used for the economic modelling which complemented the operational modelling and final scenario building of WP4.

### 1. Diabetes case study

For <u>costs</u>, the following indicators from the case study operational models were used:

- cost of care per patient per year (all DSs)
- cost per DS2 patient per year (patients under dietary management)
- cost per DS3 patient per year (patients under dietary management + oral medication)
- cost per DS4 patient per year (patients under dietary management + oral medication + insulin)

Note that for the Tower Hamlets-UK case instance patients could not be categorised in the DSs as in the other case instances, so for Tower Hamlets-UK the costs represent an estimate, based on the average length of stay in each demand segment of all the other case instances as reported in the case studies' data.

For <u>outcomes</u>, the following indicators from the case study questionnaire survey were used:

- mean EQ-5D (all patients)
- mean EQ-5D of DS2 patients
- mean EQ-5D of DS3 patients
- mean EQ-5D of DS4 patients
- Note that, under the assumption that the quality of life (that is, EQ-5D score) is stable during the year, the EQ-5D score equals the QALYs.

#### 1. a Cost per QALY of diabetes

Table VI-1 shows the cost (in PPS) per patient and Table VI-2 shows the mean standardised EQ-5D score for all diabetic patients and for each DS for each of the study areas. It is evident that for each case instance, as disease progresses from DS2 to DS3, the cost increases and the quality of life decreases.



Patient group	Keski-Suomi, Fl	Herakleion, GR	NWN, DWO, NL	Tower Hamlets, UK	Valencia, ES
All DSs	628	876	764	1145	647
DS2	76	84	113	150	29
DS3	425	603	375	561	188
DS4	1329	1165	1349	1924	1050

Table VI-1. Cost (in PPS) per diabetic patient

Table VI-2. Standardised mean EQ-5D score of diabetic patients

Patient group	Keski-Suomi, Fl	Herakleion, GR	NWN, DWO, NL	Tower Hamlets, UK	Valencia, ES
All DSs	0,76	0,68	0,78	0,64	0,71
DS2	0,81	0,73	0,83	0,69	0,76
DS3	0,77	0,68	0,79	0,64	0,72
DS4	0,71	0,62	0,73	0,58	0,66

Figure VI-1 presents the mean cost (in euros and in PPS) per QALY for all patient groups, while Figure VI-2 the relevant figures in PPS only, for all patents and for each DS separately.

These findings suggest that while when all patients are considered together the lowest cost per QALY is found in Keski-Suomi-FI, when the DSs are considered separately the lowest cost is found in Valencia-ES. Furthermore it is evident that as the patients progress from DS2 to DS3 and DS4, the costs per QALY is increasing. That is, with increasing progression of the disease, similarl increases in cost in relation to patients' status occurs.

Note that the figure for Tower Hamlets-UK is an estimate.





Figure VI-1. Cost per QALY for all diabetes patients (all DSs)



Figure VI-2. Cost per QALY for all diabetes patients (all DSs) and by DS

Figure VI-3 shows the same findings as figure VI-2, but, additionally, the angle of the line shows the rate at which the cost per QALY increases when moving from each DS to the other. While all case instances seem to start with quite similar cost per QALY for their DS2 patients, Herakleion-GR increases its cost per QALY for its DS3 patients at a higher rate than Keski-Suomi-FI and NWN&DWO-NL which seem to have a similar rate, and which, in turn, is higher than the relevant rate for Valencia-ES which remains as the most cost-efficient for each of the DSs. Keski-Suomi-FI and NWN&DWO-NL appear to be very similar.





Figure VI-3. Cost per QALY for all diabetes patients – rate of progression

#### 1.b Comparative analysis among the case instances in relation to cost per QALY of diabetes

Figure VI-4 presents the position of each case instance by graphing cost (in PPS) against EQ-5D score for each case instance when all diabetic patients are considered together. Compared to Keski-Suomi-FI, NWN&DWO-NL seem to achieve higher QALY but at a higher cost. This additional cost per additional QALY amounts to 6,506 PPS (Table VI-3). Valencia-ES, at only a little higher cost achieves somewhat lower QALY, while Herakleion-GR and Tower Hamlets-UK, at a higher cost, achieve lower QALYs.



Figure VI-4. Cost (PPS) by EQ-5D(QALY) for all diabetes patients (all DSs)

Deliverable 5: Report on scenarios of health systems



Patient	Herakleion,	NWN, DWO, NL	Tower	Valencia,
group	GR		Hamlets, UK	ES
All DSs	-3026	6506	-4242	-414

Table VI-3. Comparative difference in cost (PPS) per difference in QALY, when compared to Keski-Suomi-FI

Table VI-4 shows the relevant figures for each separate DS when compared to Valencia-ES, because for the separate DSs this case instance was found to be least costly. Both Keski-Suomi-FI and NWN&DWO-NL achieve higher quality of life but at a higher cost than Valencia-ES. However, Keski-Suomi-FI (1,031 PPS) appears to be more efficient than NWN&DWO-NL for DS2, while NWN&DWO-NL is more efficient than Keski-Suomi-FI for DS3 (2,798 PPS) and DS4 (4,465 PPS). Herakleion-GR appears most inefficient for DS3.

These findings are presented graphically in Figures VI-5 to VI-7.

Table VI-4. Comparative difference in cost (PPS) per difference in QALY for each DS, when compared to Valencia-ES

Patient group	Keski-Suomi, Fl	Herakleion, GR	NWN, DWO, NL	Tower Hamlets, UK
DS2	1031	-1540	1257	-1592
D\$3	5159	-11522	2798	-4905
D\$4	6053	-3172	4465	-11498



Figure VI-5. Cost (PPS) by EQ-5D(QALY) for DS2 patients





Figure VI-6. Cost (PPS) by EQ-5D(QALY) for DS3 patients



Figure VI-7. Cost (PPS) by EQ-5D(QALY) for DS4 patients



# 2. Stroke case study

For the stroke case study and operational model from which the cost data are drawn, ischemic strokes treated in both the stroke unit and in a normal ward are included.

For <u>costs</u>, the following indicators from the case study operational models were used:

- cost per (stroke) patient
- cost per (stroke) patient for diagnosis (S1)
- cost per (stroke) patient for treatment (S3)
- cost per (stroke) patient for rehabilitation (S4)

For <u>outcomes</u>, the following indicators from the case study questionnaire survey were used:

- mean EQ-5D
- percentage (%) of patients with Rankin score of 1 or 2

It is noted, that under the assumption that the quality of life (that is, EQ-5D score) is stable during the year, the EQ-5D score can be considered equal to the QALY.

## 2. a Cost per QALY of stroke

Table VI-5 shows the cost (in PPS) per stroke patient for the total cost, and cost by service (diagnosis, treatment and rehabilitation). The lowest cost per stroke patient is found in Valencia-ES, while the lowest cost for diagnosis (S1) is recorded in Athens-GR, for treatment (S3) in Valencia-ES and for rehabilitation (S4) in Athens-GR. These differences to a significant extent represent the differentiation in the organisation of care found in each case instance.

Service	Keski- Suomi, Fl	1 st Athens Health Region, GR	Tilburg, NL	Valencia, ES	Brighton, UK	
Stroke (total)	7080	8736	5725	4453	7197	
Diagnosis (S1)	( <b>\$1</b> ) 1155 357		960	873	898	
Treatment (S3)	5277	8319	4493	3381	6082	
Rehabilitation (S4)	649	59	272	199	217	

Table VI-5. Cost (in PPS) per stroke patient (total and by service)



Table VI-6 shows the mean standardised values of the outcome indicators. For both quality and % of patients with Rankin score 1 or 2, the highest values are recorded for Tilburg-NL.

Table VI-6. Standardised means of outcome indicators for stroke patients

Outcome indicator	Keski- Suomi, Fl	1 st Athens Health Region, GR	Tilburg, NL	Valencia, ES	Brighton, UK
EQ-5D	0.673	0.609	0.700	0.576	0.665
% patients with Rankin score 1 or 2	61.4	47.7	63.5	40.8	57.3

Figure VI-8 presents the cost (in euros and in PPS) per QALY per stroke patient, while Figure VI-9 presents the relevant figures in PPS only, for each separate service.

These findings suggest that while Valencia-ES achieves the lowest quality of life outcome, due to the fact that the cost per patient is low, it exhibits the lowest cost per QALY. This is also the case when the relevant figure is considered for the treatment (S3).



Figure VI-8. Cost (in PPS) per QALY for stroke patients





Figure VI-9. Cost (in PPS) per QALY for stroke patients (total stroke and by service)

## 2.b Comparative analysis among the case instances in relation to cost per QALY of stroke

Figure VI-10 presents the position of each stroke case instance by graphing cost (in PPS) against EQ-5D score for each case instance. Compared to Valencia-ES, all other case instances appear to achieve better quality of life, but they do so at a higher cost. Tilburg-NL appears more efficient than the others, as it is closer to Valencia-ES, while Athens-GR appears the most inefficient compared to the others (and all of them compared to Valencia-ES). This is presented in figures in Table VI-7. The additional cost per additional QALY amounts to 10,258 PPS for Tilburg-NL, while for Athens-GR it amounts to 129,778 PPS.

Keski-Suomi-FI, and Brighton-UK seem to perform similarly.





Figure VI-10. Cost (PPS) by EQ-5D(QALY) per stroke patient

	Keski- Suomi, Fl	1 st Athens Health Region, GR	Tilburg, NL	Brighton, UK
Stroke (total)	27084	129778	10258	30826
Diagnosis (S1)	2909	-15635	699	276
Treatment (S3)	19537	149633	8963	30347
Rehabilitation (S4)	4639	-4220	595	202

Table VI-7. Comparative difference in cost (PPS) per difference in QALY when compared to Valencia-ES for stroke patients

The relevant findings for each service are presented graphically in Figures VI-11 to VI-13.





Figure VI-11. Stroke patient cost (PPS) by EQ-5D(QALY) for diagnosis (S1)



Figure VI-12. Stroke patient cost (PPS) by EQ-5D(QALY) for treatment (S3)





Figure VI-13. Stroke patient cost (PPS) by EQ-5D(QALY) for rehabilitation (S4)

From the above findings it is suggested that Athens-GR appears not to perform well overall, due to the fact that it does not do so for the treatment (which requires most of the resources) although it does perform well for diagnosis and rehabilitation. For diagnosis this could be attributed to the fact that very little resources are invested in this service.

While the other three case instances appear to perform more or less similarly when it comes to treatment, Keski-Suomi-FI does not do so in relation to rehabilitation.

## 2.c Cost per unit % of patients with Rankin score of 1 or 2 and comparative analysis

Tilburg-NL appears to have the lowest cost per unit % of stroke patients with Rankin score of 1 or 2 (Figure VI-14). Indeed, while Valencia-ES is the least costly in relation to this outcome measure, when compared to Valencia-ES, on the basis of additional cost (in PPS) per additional unit % of patients with Rankin score of 1 or 2, it was found that the relevant values were 56 PPS for Tilburg-NL, 128 PPS for Keski-FI, 166 PPS for Brighton-UK and 621 POS for Athens-GR. These finding are presented graphically in Figure VI-15.





Figure VI-14. Cost (in PPS) per unit % stroke patients with Rankin score 1 or 2



Figure VI-15. Additional cost (in PPS) per additional unit % stroke patients with Rankin score 1 or 2, compared to Valencia-ES

## 3. Hip Osteoarthritis case study

For <u>costs</u>, the following indicators from the case study operational models of hip osteoarthritis were used:

- cost per hip arthroplasty



For <u>outcomes</u>, the following indicators from the case study as well as from the questionnaire survey were used:

- mean EQ-5D
- % free of reoperations
- less pain severity
- less impairment

It is noted, that apart from the % reoperations-free, the other findings for South West London-UK are only indicative. This is the case because the UK self-reported outcome measures are not directly comparable to the other case instances, due to the different methodology in recording and collecting these data in the UK.

### 3. a Cost per QALY of hip-OA and comparative analysis

Table VI-8 shows the cost (in PPS) per hip arthroplasty. The total cost is broken down into implant cost and all the other costs. The lowest cost per hip arthroplasty is found in Larisa-GR, although the cost of the implant is the highest.

	Keski- Suomi, Fl	Larisa, GR	Tilburg, NL	SW London, UK	Valencia, ES
Total cost	5971	5842	6740	7028	7072
- Other costs	4847	3469	5486	5676	5479
- Implant costs	1124	2373	1255	1353	1593

Table	VI-8.	Cost	(in	PPS)	per hip	arthroplastv
IGNIC	VI-0.	0031	<b>```</b>	,	per mp	anniopiasiy

Table VI-9 shows the mean standardised values of the self-reported outcome indicators. For each hospital which took part in the case study, the performance was recorded in terms of no need for re-operations (% reoperations-free). Thus, this is not a self-reported outcome measure, so it rather represents the hospital's performance. The highest percentage reoperations-free was recorded for Brighton-UK and Valencia-ES. Highest EQ-5D was found in Keski-Suomi-FI and



Tilburg-NL very close to this. Tilburg-NL patients were those with the least pain (highest score in 'less pain severity'), and patients of Valencia-ES followed closely by patients of Keski-Suomi-FI who reported the least impairment.

#### Table VI-9. Standardised means of outcome indicators for hip-OA patients

Outcome indicator	Keski- Suomi, Fl	1 st Athens Health Region, GR	Tilburg, NL	Valencia, ES	Brighton, UK
EQ-5D	0.802	0.740	0.800	0.780	0.825
% reoperations- free *	95.9	97.1	98.0	99.1	99.2
less pain severity	3.49	3.36	3.54	3.17	3.30
less impairment	3.35	3.08	3.19	3.36	3.04

\* data for this indicator were collected during the case study (it is not a self-reported measure like the other indicators)

As shown in Figure VI-16, compared to Larisa-GR which has the lowest cost of hip arthroplasty, all other case instances achieve higher quality of life for their patients but at a higher cost.



Figure VI-16. Hip-OA patient cost (PPS) by EQ-5D(QALY) compared to Larisa, GR



Keski-Suomi-Fl is close to Larisa-GR and, compared with it, achieves better performance at an additional cost of 2,082 PPS per additional QALY. The relevant figures for Valencia-ES and Tilburg-NL are 14,473 PPS and 14,975 PPS respectively, thus they perform rather similarly.

## 3. b Cost per % reoperations-free of hip-OA and comparative analysis

As shown in Figure VI-17, compared to Larisa-GR which has the lowest cost of hip arthroplasty, all other case instances achieve higher quality of life for their patients but at a higher cost.



Figure VI-17. Hip-OA patient cost (PPS) by % reoperations-free compared to Larisa, GR

Compared to Larisa-GR, Keski-Suomi-FI exhibits somewhat higher cost and lower percentage reoperation-free. The other case instances exhibited better performance compared to Larisa-GR but at a considerable higher cost (additional cost of 998 PPS per additional unit percentage reoperations-free for Tilburg-NL, and 586 PPS for Valencia-ES.

## 3. c Cost per unit less pain severity score of hip-OA and comparative analysis

As shown in Figure VI-18, compared to Larisa-GR which has the lowest cost of hip arthroplasty, all other case instances achieve higher quality of life for their patients but at a higher cost.




Figure VI-18. Hip-OA patient cost (PPS) by less pain severity score, compared to Larisa, GR

Compared to Larisa-GR, Keski-Suomi-FI exhibits somewhat higher cost and higher score on less pain severity (better performance) at an additional cost of 986 PPS per additional unit less pain severity. The relevant figure for Tilburg-NL was 5105 PPS. Finally, compared to Valencia-ES Brighton-UK performs worse.

## 3. d Cost per unit less impairment score of hip-OA and comparative analysis

As shown in Figure VI-19, compared to Larisa-GR which has the lowest cost of hip arthroplasty, all other case instances achieve higher quality of life for their patients but at a higher cost.





Figure VI-19. Hip-OA patient cost (PPS) by less impairment score, compared to Larisa, GR

Apart from Valencia-ES which performs worse than Larisa-GR (higher cost and more impairment), the other case instances achieve less impairment but at a higher cost. However, it appears that Keski-Suomi-FI achieves this at an additional cost of 469 PPS per additional unit less impairment, while the relevant figure for Tilburg-NL was 8022 PPS.

Overall, compared to Larisa-GR, Keski-Suomi-FI performs better than the other case instances with the exceptions of the % reoperations-free.



## 4. Dementia case study

The dementia case study has several particularities compared with the other three cases. One of these relates to the cost of care which turned out to be difficult to express in monetary terms. Another relates to the outcome measures, some of which are derived from the case studies' operational models while others are outcomes reported by the carers in the survey, and not the patients themselves. Furthermore, it should be noted, that the patients' EQ-5D score reflects a health status and quality of life measure influenced by the disease, and thus it measures need. It cannot be considered a 'pure' outcome measure, given that the natural history and progression of the disease cannot be significantly influenced by the health care system.

Given that the dementia case study assumes that it is an important objective for patients to be staying at their own home (rather than at a nursing house), the resources for the support of the care of the dementia patient who stays at home is important.

Finally, due to the very small sample of the questionnaire survey in Havenziekenhuis – NL, analysis is not reported for this case instance.

Instead of <u>costs</u>, the following indicators of resources consumed in the care of the demented patient were recorded:

- standardised mean hours of care by carer per year per patient
- standardised mean hours of care by health and social care professionals per year per patient
- standardised mean of total hours of care (by carer + by professionals) per year per patient

For the <u>outcomes</u>, the following indicators from the case study as well as form the questionnaire survey were used:

- percentage discharged at their own home (data from hospital)
- mean EQ-5D index per patient (reported by carer)
- mean score of Burden Scale for Family Caregivers (BSFC) (reported by carer)
  (standardised with 0 for highest burden and 100 for lowest burden)



 expectation to move (the patient) to care home (reported by carer) (standardised with 0 where it is most likely for the patient to move to care home and 100 for move to care home is least likely.

## 4. a Hours of care per year per dementia patient and outcome indicators

Table VI-10 shows the hours of care per year which were dedicated (spent) per dementia patient, as reported by proxies. It is noted that the hours spent for the care relate to the severity stage of the disease of the patients, as well as to structural factors like the availability or not home care institutions and community support services. The most number of hours of care per year per patient was recorded for Syros-GR followed by Lincolnshire-UK.

	Keski- Suomi - Fl	Syros - GR	Lincolnshire - UK	Valencia – ES	Nuremburg - DE
Total	2286	7372	5602	4340	4620
Hours by carer	1802	3766	5040	4128	3405
Hours by health professionals	484	3605	562	213	1215

## Table VI-10. Hours of care per year per dementia patient

The breakdown of hours of care by the carer or by professionals is graphically shown in Figure VI-20. It is evident that in Syros-GR the carers cover a greater part of the care when compared to the other case instances.



Figure VI-20. Hours of care per year per dementia patient by provider



31.7.2012

Table VI-11 shows the scores and values of the outcome indicators. Syros-GR is the area where the highest percentage of patients are discharged at home, and this relates to the lack of availability of care homes or others institutions, as well as (possibly) cultural issues. The lowest relevant figure is recorded for Keski-Suomi-FI where also the highest quality of life of patients staying at home is reported. This is further consistent with the finding that in Keski-Suomi-FI the carers have the highest BSFC, that is they are in a better condition. These two findings are interrelated and consistent due to the fact that in Keski-Suomi-FI the patients staying at home do not have severe dementia. Finally, in Valencia-ES and Syros-GR, it is most likely that the patient will not move to a care home permanently in the following year.

	Keski-				Nuremburg
	Suomi - Fl	Syros - GR	Lincolnshire - UK	Valencia – ES	- DE
% discharged at					
their own home	11.0	96.0	63.0	43.0	-
mean EQ-5D index					
per patient	0.62	0.38	0.39	0.28	0.42
mean score of					
Burden Scale for					
Family Caregivers					
(BSFC)	52.39	41.2	33.13	34.19	50.73
expectation to					
move (the patient)					
to care home	58.33	85.66	58.42	85.97	68.96

#### Table VI-11. Outcome indicators of dementia case study

## 4. b Hours of care and 5 discharged at home

As shown in Figure VI-21, there is an almost linear association of the total hours of care per year per patient and the percentage discharged home. The higher the percentage of patients discharged at home, the more the hours spent for patient's care.





Figure VI-21. Hours of total care per year per dementia patient by % discharged at home

# 4. c Hours of care and dementia patient's EQ-5D

As shown in Figure VI-22, compared with Keski-Suomi-FI where the least amount of hours of total care are spent for the patients who stay at home (not severely demented so they additionally have higher EQ-5D score). all the other case instances spent more hours for patients who have lower quality of life.





Figure VI-22. Hours of total care per year per patient by dementia patient's EQ-5D

# 4. d Hours of care by carer and mean score of Burden Scale for Family Caregivers (BSFC)

As shown in Figure VI-23, compared with Keski-Suomi-FI where the least amount of hours of care by carers are spent for the patients who stay at home (not severely demented thus the carers additionally are at a better condition – high BSFC score), in all the other case instances carers spend more hours and this results in a greater burden for them.



Figure VI-23. Hours of care by carer per year per dementia patient by mean score of Burden Scale for Family Caregivers (BSFC)



### 4. e Hours of total care and expectation to move (the patient) to care home

As shown in Figure VI-24, compared to Keski-Suomi-FI where the least amount of hours of care by carers are spent for the patients who stay at home (not severely demented, and the availability of care homes allows the carers to consider it likely that the patient may move to a care home within the following year), in all the other case instances carers spend more hours and consider it less likely for the patient to move to a care home.



Figure VI-24. Hours of total care by expectation to move (the dementia patient) to care home

All the above suggest that in order to keep patients at home more resources and community support has to be invested and offered to the carers.