



Challenges for the Management of Long Term Medical Conditions

European Health Forum Gastein 2006 'Health sans frontières'

Meeting Report

Chairman: **Miroslav Mikolášik MEP** (Committee on Regional Development, Committee on the Environment, Public Health and Food Safety, Slovakia)

Speakers: **Professor László Gulácsi** (Head of Health Economics and Technology Assessment in Health Care Unit, Corvinus University of Budapest, Hungary)

Dr Josep Picas Vidal (General Manager, Barcelona City Primary Care Services at the Catalan Institute of Health, Spain)

Dr Ian Banks (Patients Forum UK, BMA Patient Liaison Group, President European Men's Health Forum, United Kingdom)

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Executive Summary

Organised by the European Men's Health Forum (EMHF) in partnership with Schering AG and Clinical Solutions, this lunch workshop gave a stimulating overview of the challenges caused by the growing prevalence of long term medical conditions in Europe. A constructive debate took place to help identify steps to measure future progress (in the management of these conditions) across EU borders. Part of the official programme of the European Health Forum Gastein 2006, the meeting was held in the Grand Park hotel with a record number of 60 participants from 16 countries representing key health policy makers, senior representatives of European health services, patient organisations, and MEPs.

"The increasing burden from long term medical conditions threatens to overwhelm European health services unless innovative management systems are put in place." said Mr Mikolašik MEP. "Member States and the European Commission need to take this particularly seriously. There are huge variations in hospital admission rates for long term conditions". Three presentations delivered by international experts prompted a debate around three perspectives. Economics and politics of macro management, the use of innovative technologies to meet new care provision challenges and the central role of the patient in the transition from health care to social care, particularly from the perspective of men's poor use of such services.

The meeting was extraordinarily interactive thanks to some excellent chairing by Mr Mikolašik MEP. Prof Ian Banks was among the audience. Armed with a roving microphone, he shared thought provoking insights and took a large number of interventions from the floor. The meeting overran. Several participants who couldn't be given a chance to speak for lack of time, were invited to send their contributions via email.

The following urgent recommendations were accepted by the meeting:

- **European governments and the Commission must prioritise the management of long term medical conditions**
- **There should be greater investment and evaluation of innovative management systems for long term medical conditions (e.g. telephone outreach systems)**
- **Health information and patient enablement programmes must recognise the needs of patients based on their social-economic group, ethnicity and gender**

The report presents a synopsis of the presentations and a summary of interventions from the participants.

The organisers are committed to further the debate with participants to the 2006 workshop, and to act on its outcomes. This report has been circulated during 2007 to a panel of European stakeholders who will be asked to highlight work being carried out in their area to address these issues.

EMHF and its partners are pleased to announce that they will report on progress made during the European Health Forum Gastein 2007.

Background

For the last few years, health managers have been pressing ministers to switch their focus to the increasing number of patients with long term medical conditions who account for about 75% of the use of hospital beds.

Large though this demand already is, the first of the baby boomers (born in the first two decades after the Second World War) are now reaching the age of 60 and an OECD study predicts that the cost for managing these conditions could nearly double over the next 20-30 years from an average 6.7 to 12.8% of GDP.

A large proportion of these costs is due to emergency admissions. It is estimated that more than a million emergency admissions a year to UK hospitals are accounted for by people being repeatedly admitted. The most common problems are heart and respiratory illness in older people. The cost of repeated admissions is estimated at £2.3bn in the UK alone.

With advances in treatments, many patients are living longer. Some diseases such as HIV/AIDS or certain forms of cancer are no longer considered short term.

Progress is needed across a number of fronts. Un-doctored areas need to get more physicians. With earlier diagnosis and appropriate care in the community, many patients would have been able to look after themselves as burgeoning expert patient programmes are demonstrating. In these schemes, patients learn self management techniques including handling pain-relief and feelings of frustration or depression, and communicating more effectively with health professionals.

There is no shortage of schemes. What is needed now is sustained medical and ministerial commitment.

The presentations

Professor László Gulácsi (Head of Health Economics and Technology Assessment in Health Care Unit, Corvinus University of Budapest, Hungary)

The overall health care costs of Long Term Medical Conditions (LTMC) in relation to societal cost is rapidly growing. In fact, total societal costs of LTMC, and their distribution among diagnoses and different groups of society, are unknown to us. This is so even though in many cases (e.g. rheumatoid arthritis, brain disorders) relevant indirect costs exceed direct costs by a ratio of 3 or 5 to 1.

Accordingly, it is difficult to make appropriate policy decisions in terms of LTMC, and priorities are hard to set without knowing real societal costs. Although we know little about LTMC-related health policy priorities, published appraisals are primarily made up of LTMC-related HTAs, e.g. National Institute for Health and Clinical Excellence (NICE) which can be considered pre-decision prioritisation tools.

HTA priority setting is closely related to policy decisions, and emphasises LTMC burden. Data from different European countries have revealed considerable inequalities with respect to the efficacy of LTMC therapies. For instance, survival rates for various cancers in Hungary are considerably worse than in more developed

countries, and than in neighbouring countries. Health economic studies have shown that the cost of gained life and life-year, as well as cost per QALY, are not so much less in EU states of the east than in those of the west.

Improving health status and reducing inequalities probably do not cost less in eastern EU states than in the higher GDP EU15. Much cost cutting is taking place in the new EU Member States based on the false assumption of cheaper local cost per QALY. Therefore, it is imperative to increase cost-effectiveness rather than contain health care budgets.

Conclusions

The presentation highlighted the importance of primary prevention and screening, and framed the choice by policy makers to prioritise care for infectious disease or accidents against long term conditions. Some governments underestimate cost effectiveness by only considering healthcare costs. They tend to exclude the vast indirect costs of these conditions to society from the equation and cross-border variations in reported cost effectiveness for similar interventions may be strongly influenced by political culture. Cost effectiveness must be improved rather than healthcare budgets being cut. If true costs were taken into account, more resources would be dedicated to the management of LTMCs.

Dr Josep Picas Vidal (General Manager, Barcelona City Primary Care Services at the Catalan Institute of Health, Spain)

During the last decades, several factors have begun to shape the management of healthcare services. Better environmental conditions and improved healthcare services have generated an increase in life expectancy albeit with more people suffering chronic conditions. Patients, now, are better informed about their illness and more aware of their rights. They ask for more quality yet they act as a “consumer of ordinary services” demanding “fast medicine”.

The answer from healthcare providers is beginning to show. Medicine is beginning to be industrialized. Tools normally used in others industries and services are being introduced to allow better management of the business process. For example, IT solutions, process definition and evaluation, marketing tools aimed at influencing patients' behaviours are among several paths that could contribute to a more cost-effective delivery of health services.

The case presented is situated in Barcelona City, which counts 1.4 M habitants, 4 teaching hospitals, and 68 primary care centres. Their conceptual model is based on the development of several strategies to find the most effective way of providing healthcare services, i.e. reducing the face to face encounters while assuring and improving the quality of the services. Tools used have included computerization and decisions support systems (computerized guidelines), new roles for healthcare professionals (specially nurses), a call centre to follow up patients with chronic conditions, and the development of group sessions for some conditions (i.e. some programs of experts patients and other group activities linked with a program of physical activity improvement).

Preliminary data on these activities is on patients with cardiac health failure, as a full program, and some group activities with patients with anxiety, depression and

osteoarthritis focused on patients with high use of medical services. Results showed a significant involvement of healthcare professionals, a good level patient satisfaction. They revealed the beginning of a change in the patterns of patients' demand and professionals' behaviour.

Conclusions

Barriers to closer collaboration between general practitioners, nurses and social workers are more historical than political. Computers and IT technology provide essential tools to enable the complete and effective follow up of patients. Such systems can enable them to live in the community while primary care remains the gate keeper of healthcare provision. The Barcelona system was designed for acute conditions but could be adapted to long term conditions. A more balanced political focus between acute and long term care should be encouraged.

Dr Ian Banks (Patients Forum UK, BMA Patient Liaison Group, President European Men's Health Forum, United Kingdom)

Across Europe, men have on average greater levels of morbidity and mortality compared to women. They also make more inappropriate use of primary care services. The result is a higher rate of hospital admission over the age of 50 years. There are a number of causes for these differences, one of which is a lower level of health literacy than women. This is exacerbated by services poorly targeted and with little gender sensitivity. In effect, men are a 'hard to reach group'. Addressing men's health needs through better information on which they can act, combined with focused delivery of primary care services, will impact on emergency hospital admission rates.

Self care and self management along with early diagnosis are key factors especially for long term medical conditions. In the UK for instance, it is optometrists/opticians who most frequently diagnose diabetes in the male population. Such long standing undiagnosed and untreated diabetes significantly increases co-morbidity. Similarly, melanoma has a higher incidence in men but lower mortality, in all European countries. Late presentation appears to be a major factor for poor clinical outcomes.

In the UK there have been a number of projects addressing these issues and the impact on women's health as well as the men themselves. These will be discussed giving evidence-based reasons for optimism when it comes to male health education and health literacy.

Conclusions

Use of health services across Europe is not uniform, and there are large variations depending on socio-economic group, ethnicity, and gender. Men can be considered a hard to reach group concerning health literacy. Men's poor use of primary care services is a significant factor in hospital admission rates and mortality. Men will be admitted as a hospital emergency almost twice as often as women over the age of 50 years.

Summary of interventions from the participants

Hepatitis C to be addressed as an emergent long term condition

ND: "what was missing a little bit I think, and I am asking also, are the communicable diseases, and in particular the great epidemic of Hepatitis C. I would say that indeed AIDS has been limited within Europe in the 0.5, or less prevalence, but I think Hepatitis C should also be addressed as an emergent problem."

Service commissioning, a key opportunity to bridge with community care

EN "... we have done some work looking at evidence about the contribution that pharmacists can make to improving the care of people with a wide range of long term conditions, and it has highlighted the need for service commissioners to be aware of what different professions and different types of services can bring to long term condition services. We certainly have concerns about the devolution of service commissioning in England down to the general practice level, and what sort of changes that will bring. Will it mean that GPs effectively commission their own services or will they be looking more broadly to commission the whole range of services, including medicine management, that people with long term conditions need?"

Independence of living for patients requires investment in social services

NT "I am slightly conscious of the danger of compartmentalisation. If you just look at medical costs and healthcare costs, and I think particularly with long term conditions, what people want is to live independently, and so I would like to make a plea for investment in community-based services which very often don't appear in the healthcare statistics and the cost statistics. So I understand that you want to say please invest more money in the healthcare. But you know I think we shouldn't forget that there is also another side of care that people need and maybe want even more, because it enables them to live independently.

Patients are also experts

IB "We are trying to encourage people to be able to look after themselves and manage their condition using their own common sense and their own ability rather than allowing the medical profession to say we are the only people, and I am speaking as a doctor, we are the only people who can look after them. So it is positive suggestions about how we can improve people's ability to be able to look after themselves and manage their own condition. That's what we are looking for."

Expertise about empowering patients to self-manage should be disseminated

IV "following on from that we had recently a presentation from Canada about their care managers ... we found it very attractive but I was wondering whether it was operating already in other EU countries. Community based persons who are not doctors, who are in charge of co-ordinating the care required by a person with any chronic condition in the community, so I suppose, making sure the appointments are taken and the follow up is alright, and the schedules are what they should be. So we all found that very attractive, but Canada is far away and I was wondering whether there were such experiments going on in the EU countries."

The technology exists and is ready to be deployed

JW "We have been working very actively in the last sort of year to eighteen months to take on board exactly what you are suggesting, which is working with general practitioners in the UK, particularly to look at managing patients in the capacity where you can actually encourage them and empower them to take care of their own conditions so

that they can remain within the community and that their condition is not escalated from a chronic or long term condition into an acute condition.

It is predominantly going to be outbound telephone calls to patients to find out where their issues lie, anything from medications, to exercise, to diet, to psychosocial elements to empower the patient to improve their quality of life living with a long term medical condition.”

OECD study documents interface issues between acute and long term care

“I am excited to learn about this project in Barcelona. We are in a way privileged to have information from Spain in this regard and I would like to share with you that the OECD is currently conducting a study which looks at co-ordination of care across care sections. We use co-ordination of care as a generic term to encompass the movement of patients through the system, to understand what our countries, what the OECD countries and by the way we have also included countries which are EU members but not OECD members, we also included Romania and Bulgaria which are due to exit the Union. We wanted to understand what countries have been doing in terms of policy responses to challenges which arise from the increased need to co-ordinate care for an increasing share of population in order to maintain or lift the level of efficiency in the healthcare system. To understand what countries did or what countries are planning to do, we conducted a questionnaire and asked government countries to respond to an array, to a series of statements in a qualitative manner ticking a scale from 1-5 and to give us a feeling what kind of policies, what kind of problems and what kind of debates countries are doing currently regarding the issue of co-ordination of care. I would like to share with you one interesting result. Looking at 25 questionnaires we have been getting back so far, countries indicate firstly that quality of care is the most important concern when co-ordination of care issues are debated. Secondly, the most important problems countries indicate are problems occurring at the interface between acute care and long term care. This is consistently across all countries regardless of which financing or delivery type they have. We have some other very preliminary results but we can maybe talk about this bilaterally if you wish to.”

Limits to the negotiating power of patients?

ND: “I wanted to ask you what was the participation of patient groups in the development of this programme and in the implementation. There were some things that you presented like the contract for example, that you developed, and there is a question of what is the negotiating power of the patient who does not want to walk 30 minutes or stop smoking or other risk, you know, factors. So I would like you to address those issues.”

Better health literacy for patients is increasingly important

AvZ: “Nowadays we see that most of the people are people with long term medical conditions but our systems are still managed and organised in the way we learned it in the past. So what I want to suggest, and that was one of your questions, is that we invest much more in the preparation of the people. Now we see that for most people a long term medical condition is a part of their lives, that we must invest much more before they come a sufferer of that condition, to prepare them to play the right role at the moment and at the same time we should change the healthcare system.”

Presence of co-morbidities require door to specialist referrals remains open

JW: “I just wanted to emphasise first of all the integration of care with the other parts of community care and social care, but also there are now a number of pressures either in terms of cost pressures or to remove boundaries between professions which are all totally laudable but there are some risks and I would just urge that progress is monitored and evaluated because I am aware of some research being carried out in Massachusetts at the moment where they are looking at the referral rates by nurses, specialist nurses to

other professions and we have to bear in mind that chronic conditions have a lot of co-morbidities and we need to make sure that we don't shut off the door to referrals to other specialist areas."

Integrated care just as important as prevention and cost effectiveness

GD: "having done the research study on care for the aged at risk of marginalisation it turned out that actually the most important problem we saw was the split or the gap between the social care and the healthcare and when we come back to the first speaker, ... one of the important things was prevention on the one hand and cost effectiveness on the other hand, but the main point actually is to see to it that we have more integrated care, so that's the point from us."

EU funded programme to share expert patient practice

NB "I know that patients' experts, the notion of patient experts, is quite familiar in a number of Member States, but I still think there is a job of work to get the idea of that concept really recognised in a number of countries and I believe, and it would be one of my recommendations, would be to try and push for some sort of European project, perhaps through the next Public Health Programme, specifically on patient experts, the notion of patient experts, good practice, bad practice, in that area."

All partners must be included in the coordination process

DG: "from a previous session today, Dr Kickbusch talked about the importance of building relationships and so in the process of co-ordinating and integrating care, to challenge yourself with the question who is missing? Who else within this plan of care do we need to include and for some people that is a revelation that it is not just a doctor and a nurse, but a social worker, and in some places it is also who are the organisations within the community? So to ask the question: *Who is missing?*"

Patient expert is key to successful bridging with community setting

DG: "A second comment has to do with if we have a separate care manager in the end why is that care manager not the patient, because if you look at co-ordination of care it has to happen around the patient and as one's needs differ from acute care to the community and to a form of wellness with a long term medical condition, how does that process stay consistent. So my recommendation would be some kind of tool that would enable patients or their near ones to facilitate that process of co-ordination and to ensure that in the end when you step out of the acute care system, that your care is still managed and to have a flag for when it is time to get back into the system. Yes. And to say that in fact the patient is the expert and we need to challenge our thinking to look that way."

Workplace doctors, a key role in improving men health

M: "I was wondering whether any other country had found an intelligent way of using doctors who are in the workplace to promote men's health because you mention that men don't go to see their doctors on so on, and there are doctors who are in the pay of employers who sit in the workplace, in factories or wherever. In France we make no intelligent use of them at all because they are in pay of the employer and they are not by status, the physician of the employees. But I thought maybe this could change and, because there are all these doctors sitting around in places where people work, they really could probably help promote our men's health."

Aged population groups must not be forgotten

F: "in the view of the comments made about expert patients which is completely laudable and also, from our Canadian colleague, completely laudable but we must not forget that

there will always be in society a group of patients that need to be looked after. Let's not forget the frail elderly without relatives because they cannot do things for themselves."

Doctors have to learn from patients too

IB: "I can't agree more in terms of the expert patient. I think this is what we have to do. It is a terrible thing for me to say this because I am a member of the British Medical Association Council, but I am going to say it. The medical profession traditionally in history has robbed people of their common sense, of their ability to look after themselves because we are the clever people with our white coats and our stethoscopes and you must come to us. And I think we are now reaping a whirlwind. I think we have now expected people that they can only get the information from doctors, that they don't seek information elsewhere. What we have got to do is reverse that tide and have people seek information from other places. "

Workplace could be better used to reach men

IB: "The workplace. Men, we have found, we have done a major study on this that the best place to get to men on health issues is in the workplace. We have done study after study on this on huge organisations, not least Royal Mail, which is the biggest single employer of men in the whole of Europe, and we have done studies on them and have found that that is the best place to actually get men to talk about health issues. We did one major study to look at the insight into the prostate for instance. Don't underestimate the lack of insight men have into the prostate.We hugely improved the insight of men into the knowledge of the prostate and we have got lots and lots of examples if you would like to use them of how you can work in the workplace to produce you know men's better use of health services. Not least incidentally about absenteeism from work by actually improving their self-care, so I accept everything you have said"

Costs attached to patient centred approach

LG: "If I may, the expert patient, what cost more and what is the risk of the patient making a bad decision once or a good decision 90% of the time? How big is the impact? Okay. So I am not against the expert patient concept as a health economist, but just show me what the benefit is, how much does it cost, who is better off, who is worse off. "

Technical innovation is key

Innovation JPV: "We should be imaginative and we should innovate. I think that we should learn from services, learn from industry, and the healthcare system should change, should change with the roles of doctors or nurses or other professionals, should change taking care of processes, we should be more on the industrial insight. We are still as artist and I don't want the care of an artist, I want the care of someone who knows what he is doing when I am ill. So we should innovate and we should share information. I think that this is a good opportunity but we have to have more opportunities to share what we are innovating and taking care."

