

Healthcare for healthy ageing

Post-conference report
Conclusions from Uppsala Health Summit
3-4 June 2014



#uppsalahealthsummit



Uppsala Health Summit 2014

We all know that healthcare today is faced with ever greater challenges. We are faced with both economic and ethical dilemmas, and while advances may open new possibilities for improved care, many do not reach the patient today. Continuing research and innovation open new possibilities. But as possibilities expand, so do the issues.

Uppsala Health Summit is an international arena for frank and challenging dialogue, exploring possibilities and dilemmas associated with medical advancements that can improve health and health outcome. Uppsala Health Summit stimulates dialogue from various perspectives, such as medical, economic and ethical.

Uppsala Health Summit lays the foundation for long-term relationships and insights that can help you in your work to improve health outcome in your part of the world.

Uppsala Health Summit convened decision-makers, opinion-formers and experts for two days, June 3-4 2014, to discuss how we can use research results and innovations to promote healthy and autonomous ageing, questions of utmost importance in front of the demographic development.

This report summarizes conclusions from seven different workshops, as well as the plenum discussions commenting on workshop results. Workshops were conducted according to the rule: "Let's spread what was said in the room, but not who said it."

Uppsala Health Summit is arranged in Uppsala, Sweden, by partners with long experience of healthcare development, who see the potential for improving healthcare and health outcome in a global perspective.

The effort is run as a collaboration between Uppsala University, the Swedish University for Agricultural Sciences, Uppsala County Council, the City of Uppsala, the Swedish Medical Products Agency, the National Veterinary Institute, the network World Class Uppsala and VINNOVA, Sweden's Innovation Agency.

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Preface

In early June 2014, some 180 initiated persons – experts, decision-makers and opinion-formers – gathered at Uppsala Health Summit to discuss how we can use knowledge and innovations to promote healthy ageing.

An ageing population is a great asset to society, and a sign of success for public health. But, as many presenters and delegates commented during the summit, growing old may not be a goal in itself, unless we can live a good and reasonably healthy life.

Healthy ageing is an area that includes many aspects. Uppsala Health Summit's organizers had decided to focus on two themes: *Prevention for healthy ageing*, i.e. how we can compress morbidity and reduce physical or mental impairments, and *Care for autonomous ageing*, covering how to best provide the medical and social assistance needed, when needed.

Uppsala Health Summit strives to be an arena for sharing insights between the summit delegates. Workshops and dialogue are therefore an essential part in the program. This report summarizes the conclusions from the seven workshops held during this summit *Healthcare for Healthy Ageing* and the following panel discussions commenting on the conclusions.

The overall impression from the seven workshops and the discussions in plenum was the feeling of controlled optimism. *Yes, we can change our life styles, and new technologies offer us great possibilities both to improve health, care and autonomy, but we still don't make full use of our potential.* So what prevents us from using these opportunities?

Many delegates evoked the need to *re-think healthcare systems*. How can we find ways of financing investments in prevention or care entailing costs in one part of society, but bringing savings or increased welfare in other parts? But “Healthy choices need healthy societies”, as one panellist put it, and the current financial crisis in Europe makes this challenge harder to deal with.

Empowerment and self-responsibility were keywords in many discussions, whether they evoked life style, mental health, or technologies for prevention and care. There was general agreement that much can be achieved within current budgets from better cooperation between actors in society. Mind-sets, *our perception of elderly* or other users of technologies, were also raised as a possible obstacle for applying new technologies and methods in care and healthcare.

But concerns were also raised regarding *personal integrity*, e.g the use of genomics based diagnostics, and for *how increased self-responsibility can be combined with equity*.

A number of interesting suggestions, for immediate or more long-term actions, came up in workshops and panel discussions. Every workshop had its own rapporteur who, in cooperation with the workshop leaders, has compiled the conclusions from each workshop for this report.

All workshops were conducted under the Uppsala Health Summit rule that you shall be free to say what you want and think, without being cited afterwards. Therefore, reports from the workshops cover what was said, main arguments and conclusions, but not who said what.

All plenary keynotes, inspiring presentations preparing the workshop discussions, are available on our website, www.uppsalahealthsummit.se. Finally, as chair of Uppsala Health Summit's steering committee, I want to thank all delegates, speakers and workshop leaders, for valuable and thoughtful contributions during the summit, and invite you all to continue the discussion.



Anders Malmberg
Deputy Vice-Chancellor Uppsala University
Chairman Uppsala Health Summit

Program

June 3, 9:00–17:00

8:00 Registration opens
Coffee served outside plenum hall

OPENING OF CONFERENCE in plenum

9:00 Professor Anders Malmberg, Deputy Vice-Chancellor, Uppsala University
Welcome to Uppsala Health Summit 2014.

9:10 Minister introductory speech: Ulf Kristersson, Swedish Minister for Social Security
Is ageing an opportunity or a problem?
Why do we need to keep people healthy?

Theme: Investing in prevention for healthy ageing

This first day, we will focus our attention on implementation of different prevention measures. What changes are needed on a system level? What changes can we implement here and now?

The discussions will cover prevention of physical and mental health, the role and limits of life style changes as well as of diagnostics and screening. In the discussions, we will touch upon the personal versus society's responsibility for prevention.

PLENUM SESSION

9:30 John Beard, Director, Department of Ageing and Life Course, WHO
Prevention needs for healthy ageing.
An international policy perspective.

10:10 Professor Lars Lind, Linnaeus Chair of Medicine, Uppsala University
Patient registers and primary prevention
– A vision for how epigenetic studies can help us design personalised prevention programmes.

10:45 Coffee served outside plenum hall

11:15 Mitch Higashi, Chief Economist, GE Healthcare
Challenges healthcare providers face investing in prevention and early detection – How industry is demonstrating the value of technology.

11:45 Mary Durham, Vice President Research, Kaiser Permanente
Integrating prevention measures in a healthcare system. Why and how?

12:15 Lunch for healthy ageing



13:15 – 15:15 BREAK OUT SESSIONS

Parallel Workshops on Prevention

Workshop A:

Life-style changes
– How to reach
concordance?

Workshop B:

Diagnostics and
screening for
disease prevention.

Workshop C:

Maximizing public
mental health
– Empowering
strategies and
determinants of
mental health in
elderly populations.

15:15 Coffee served outside plenum hall

PLENUM SESSION

15:45 Professor Hans Rosling, Gap Minder

Myths about ageing populations, health and money.

16:15 Panel discussion

Summing up discussions from workshops.
Dialogue with panel and round tables.

**18:30 Dinner at Norrlands Nation,
Västra Ågatan 14, Uppsala**

June 4, 8:30–16:45

Theme: Care for autonomous ageing

Our focus this second day is on how we can provide care and healthcare for our old and frail in the near future to ensure a good life, often interpreted as a high degree of autonomy as possible.

We will discuss how our care and healthcare systems can adopt a more person centred approach, including the use of technologies in the care and healthcare situation as well as specific dietary needs to meet risks of sarcopenia and cognitive decline. We will also discuss how current systems for evaluation of new treatments for the old and frail influence future development of treatments for this group.

**8:15 Information and registration desks open
Coffee served outside plenum hall**

PLENUM SESSION

8:45 What did we learn yesterday?

9:00 Introductory speech by H.M. Queen Silvia

**9:20 Professor Claus Wendt, Soziologie der
Gesundheit und des Gesundheitssystems,
University of Siegen**
Comparative health policy and healthy ageing.

**9:50 Anders Ekholm, Deputy Director, Institute for
Futures Studies**
Technologies for autonomous ageing – gains, risks,
needs and obstacles.

**10:15 Professor Ben van Hout, Health Economics
and Decision Science, University of Sheffield**

Costs and benefits in new treatments for elderly
– How can we estimate the value?

10:45 Coffee served in workshop areas

11:00 – 13:00 BREAK OUT SESSIONS

Parallel Workshops on Care for autonomous ageing

Workshop D:

Food for age-
ing – Individual
and societal
perspectives.

Workshop E:

Care for the
person, not for
the system
– A person-
centred
perspective on
the coopera-
tion between
care and
healthcare.

Workshop F:

Technologies
for healthy
ageing
– Implemen-
tation of tech-
nical aids in
home care
and nursing
homes.

Workshop G:

Respecting the
elderly's need
in medical-
and economic
evaluations
of drugs.

13:00 Lunch for healthy ageing

PLENUM SESSION

**14:00 Nicklas Lundblad, PhD, Director of Public
Policy and Government Relations, Google**

Data-driven innovation. The view from Google,
the challenges and the opportunities.

Coffee served in plenum hall

14:45 Panel Discussion

Summing up discussions from workshops.
Dialogue with panel and round tables.

15:45 What will you bring back home?

**16:15 Closing remarks from Erik Weiman, Chairman,
Uppsala County Council Executive Committee
and member of Uppsala Health Summit
steering committee**



Investing in prevention for healthy ageing

Reports from Workshops
June 3

Workshop A Life-style and prevention – how to reach concordance?

Workshop B Diagnostics and screening for disease prevention

Workshop C Maximizing public mental health in ageing

Panel discussion

Life-style and prevention

– how to reach concordance?

Workshop responsible
Dr Pernilla Åsenlöf, Associate
Professor in Physiotherapy,
Department of Neuroscience,
Uppsala University.

The prevalence of non-communicable diseases is growing. The same pattern is seen across the world and is not related to income level. The main change over the past couple of years has been seen in low-income countries where the consequences of non-communicable diseases have grown rapidly.

Today we know that diet is the major underlying cause for disease (cancer, cardiovascular disease). Eating fruit, vegetables and fish can reduce the risk for myocardial infarctions (MI) with up to 92 per cent.¹

Despite substantial evidence there is a lack of knowledge today among healthcare physicians regarding health behaviours and effects. There is too little education and discussion regarding these issues in medical schools. It is also important to note that *asking* is not the same thing as making people change. Studies have shown that a majority of patients want to discuss life-style issues.

Main possibilities

Today many health behaviour change interventions are designed randomly and the question is: how do we make progress? It is important to specify the target behaviour, understand the context, and consider the full function, i.e. what influences behaviour. It is also important to be

systematic in the choice of intervention and to find a good combination of empowering people and societal interventions. The aim is to enlighten individuals – the logic is that if you are informed, you can make informed choices. This, however, does not mean that information is enough to make people change their behaviour.

We know that it is important with instant rewards: it is needed on all levels. People want to be fit for skiing, meet friends at the gym. Another solution or way of looking at how we become more active is by small initiatives: we know that people, in general, sit too much. Taking short breaks or standing when working by the computer are small initiatives that pay off. We also know that it is important to start with prevention early in life, when people are young.

E-health strategies and innovations for patient participation are useful in online screening and good for consultations in primary care. They can also be important and efficient instruments in the continuous feedback that is crucial to maintain change over time. Another successful strategy that has been tested is the use of *diaries* where the person formulates short-term goals and registers proximal and behavioural outcomes.

Other important issues to remember are that we are born with our genes but also with the habits of our parents. Healthy choices need a healthy society. The importance of role models should not be underestimated. Likewise, society should be built to promote healthy life-styles, for example by developing bike roads.

Critical issues and obstacles

Values and attitudes of the individual matter a lot when it comes to health behaviours, for example what do people associate with *being rich*. For some smoking, eating hamburgers, taking the car instead of the bike is perceived as desirable. It is also important to remember that it takes time to

WHO's director for Ageing and Life Course, Mr John Beard, discussed the needs for prevention for healthy ageing in an international context.



¹ Åkesson, A., Weismayer, C., Newby, P. K. and Wolk, A., *Combined Effect of Low-Risk Dietary and Lifestyle Behaviors in Primary Prevention of Myocardial Infarction in Women*, Arch Intern Med. 2007;167 (19):2122-2127



change values and attitudes. It is the culture that has to change. Something that is perceived as luxury may not be good for you.

The individual has a responsibility for his or her own behaviour – *self-responsibility*. But it is also important to discuss how choices are made – are they deliberate or automatic? We cannot ignore that there is automatic behaviour and then we have to think about how the context is arranged. It is also crucial with continuous feedback over a long period as it is easier to start a change than to maintain it. It is also important to view what kind of means we have to work with: self-determination, legislation and/or prohibition? Although, there is always an ethical warning signal when one does something that is good for the patient, but is something that may steer the individual too much.

Physician's asking about life-style may be perceived as very private and many doctors might feel that they are not supposed to ask too much about food, obesity, and alcohol. Doctors need training in talking to patients about life-style factors and for the patient it is not primarily about information, patients need motivation and skills in self-regulation, often they need to acquire life-long habits. It is important to learn good habits from the start. It is also difficult for patients to break bad habits and to stay motivated over time, which is an important fact to bear in mind and that should be respected. To stop smoking may for example be easier than changing eating habits.

Health professionals and providers of healthcare are being paid for delivering healthcare, not prevention.

It is often a case of *nudging*, i.e. helping people at the right time to make the right choices. This works when the interventions are well designed.

We have to think cross-societal and long-term
The main conclusion from the workshop was that we have to address the issues of life-style and prevention as cross-societal and long-term. All arenas should be involved in promotion of health behaviours. It should, for instance, be integrated in the work of physicians to discuss life-style issues. There is a need for interventions on many levels and, some argue, that a mental shift is needed, this is not just a medical problem. Another concern that was highlighted during the workshop was the question of: Are we concerned about budgets or about individuals' health?

Healthcare professionals should always think about the patient as a person with self-responsibility. They should make suggestions that are personalized and society should promote and support constructive alternatives, such as taxes on unhealthy food, prescriptions on physical activity.

What is good for the climate and the planet is also good for people's health. The right energy, type of food, behaviours all go together and are all integral parts of maximising healthy lives.

Diagnostics and screening for disease prevention

Workshop responsible
Dr Johan Rung, Department of Immunology, Genetics and Pathology, Uppsala University
Facility manager SciLifeLab Clinical Sequencing.

To manage future healthcare needs and costs with a growing ageing population, the firm divide between work life and after work life needs to be challenged. Many people will have to work after 65 years and it will be important to make older people healthy, for work life, to be able to work longer. As an example, musculoskeletal disease strongly impairs the ability to work and is a burden for the workforce. The cost to the European Union each year for lost productivity and sickness absence due to musculoskeletal disease is 2 per cent of GDP (gross domestic product). Interventions that could help these patients to work longer are of great value. How can we more efficiently use early diagnosis and prevention?

When it comes to using advanced diagnostic technologies, we need to first ask ourselves why and what diagnoses should be screened for – cancer, cardiovascular disease, diabetes, dementia? The value for the individual needs to be emphasized, as well as the value for society.

Main possibilities

We are approaching a new era that will revolutionize the genetic knowledge through the Next Generation Sequencing (NGS) techniques. As compared to the standard Sanger sequencing, NGS is substantially faster, cheaper and gives more accurate information. This opens up the possibilities for doing more extensive gene sequencing and giving patients the right diagnosis and right type of treatment. How can new diagnostic technology be developed and brought into healthcare so that costs and quality of care are improved?

All the information and the diagnostic data that the patient might receive from their doctor gives the patient the opportunity to try to more actively understand possible diseases, health risks and treatments. This information can then be the basis for individualized life-style advice.

Critical issues and obstacles

The government in the United Kingdom performed a study showing that if 10 per cent more people with rheumatoid arthritis were diagnosed earlier, this would lead to increased costs for the healthcare, but that the benefit for the working force and money saved at that end substantially outweighed the costs in the healthcare sector. Despite the results from the study, early diagnosis was not implemented – why should one sector pay for a benefit in another sector? Studies have shown that 80 per cent of the patients diagnosed with rheumatoid arthritis want to continue to work. Today the assumption is that if you have these health problems, you are not useful for the work force any more. This assumption must be challenged together with the assumption that prevention and early diagnosis are unaffordable concluded the workshop participants.

The new opportunities given to the healthcare by NGS and other -omics techniques are also associated with challenges. Efficient infrastructures need to be built up to be able to handle the information from large-scale data. In Uppsala, this is done through joint forces between the university, the hospital and SciLifeLab, an infrastructure hosted together by four Swedish universities.

The attitude to early diagnosis is very individual. For many, early diagnosis only makes sense when the condition can be cured. Furthermore, there is not always evidence for screening diagnostics in the elderly. As an example, for mammography there is only data from 40-74 years old. Is it possible to extrapolate from that to patients over 75? Another important challenge is how to communicate benefits from the technology advancements to patients and to find out the needs and desires of individual patients. With the changes in technology and diagnostics and the different high throughput methods coming up, the role and competence of the doctor will need to change. The technological advancements will increase the possibility for personalized treatment and individual dosing.

Today, many patients are also substantially more informed than they used to be, presenting the healthcare professional with a changing situation. The patients of today read about their symptoms on internet and come to the healthcare professional with a diagnosis suggestion and maybe also treatment suggestions.

Conclusions and recommendations for action

For the development of new diagnostic technologies it should not be too difficult to create a driving force in the scientific society by appointing grants, entrepreneurship competitions etc. The more difficult question is how to implement the new technologies in healthcare. Except for the driving force from researchers and healthcare professionals, a strong driving force for implementation can and should be the demands by patients and the informed citizen.

The ethical perspective of new diagnostic technologies was highlighted by workshop participants. Why do we have diagnostic tests and how do we deal with them as well as how do we communicate the pros and cons of diagnostic tests? Before introducing new technologies the needs must be formulated. Robot surgery was brought up as an example that was introduced without the need being formulated beforehand and in the end it was shown to be both more expensive than previous solutions and not efficient enough. There needs to be a deeper and more extensive cooperation between different stakeholders.

Different aspects on how we should use new diagnostic technologies to promote health introduced the workshop on the same theme. From left to right, Andreas Ringman Uggla, Boston Consulting Group; Barbro Westholm, MD, Member of Swedish Parliament; Professor Erik Ingelsson, Uppsala University; Professor Richard Rosenquist Brandell, Uppsala University and SciLifeLab and Professor Stephen Bevan, The Work Foundation and Lancaster University.

Furthermore, there is a need for a general shift in the reimbursement systems from *pay for volume* to *pay for value*. How do you pay for innovations and who should pay? There was an agreement in the audience that the budget needs to be much more integrated and that we need to move away from silo thinking in budgeting for healthcare. In the United Kingdom, a project has been initiated that will evaluate the cost effectiveness of introducing preventive measures to get more older people into work.

The growing amount of data and changes in the healthcare system is a challenge both for the patient and the doctor. The workshop participants suggested that the patients and the clinicians need to work more together and co-create the patient outcome. It was discussed who should define patient outcome – the patient or the patient organizations?

Health communication will become more and more important in the future for all kinds of healthcare professionals. For example, when going through results from a genetic screening, how should risk be explained to the patient in a way that is understood and remembered? A study was referred to where the ability of patients to understand risk had been studied, before and at several time points after counselling. Even a short time after the counselling event the patients did have a reduced understanding of risk as compared to at the counselling. This emphasizes the importance of written information from the meeting but also the need for having, for example, a trained genetics nurse as a longitudinal contact point after counselling. Different aspects regarding health communication should be built into the education of healthcare professionals.

We can see a future scenario where patients do more and more testing at home with help from distributed diagnostic techniques, and doctors can then include more data in their assessments than the information they can gather during a visit at the clinic.



Maximizing public mental health in ageing

– Empowering strategies and determinants of mental health in elderly populations

Workshop responsible

Valerie DeMarinis, Professor of Psychology of Religion and Cultural Psychology; Research Director, Public Mental Health Promotion research area through the multi-disciplinary IMPACT research programme at Uppsala University.

There are different phenomenologies for health and ill health, for example for children, for elderly, for people with different cultural backgrounds, and for different genders. These groups also have different therapeutic needs. Therefore the focus in prevention and treatment of ill health needs to be people-centred with special attention given also to the family and caring network. We need to treat the person behind the symptom, not only the symptom. The quote *nothing about me without me* is very appropriate.

When it comes to the elderly it is not always easy to differentiate between dementia and depression.

Elderly persons can feel that they are not needed anymore, which is a concern on many levels not in the least existential, and can lead to an existential crisis. They can feel a loss of identity and dignity. All these issues are personal and to a large extent culturally influenced. Persons are also always societal beings, in terms of understanding social capital and who is needed and in what way. Furthermore, these issues are part of our healthcare and social service systems, which are also to a great degree shaped by cultural constructions. Existential issues, understood in this way as meaning-making components in every person's life though the expressions of such can

Wolfgang Rutz, MD, Professor of Public Mental Health, Coburg University, IMPACT programme, Uppsala University, in vivid discussions on how to promote public mental health, following the workshop on the same theme.





include a wide variety in content and form, are therefore critically important issues for understanding both health- and illness constructions.

Studies have shown that for psychosocial and for existential development we need: 1) cohesion – and a sense of meaning, 2) control – a sense of mastery, participation, not feeling helpless, 3) connectedness – a sense of social significance, to be cared for and to care for and 4) caseness (personhood) – a sense of self determination, autonomy, integrity, identity, status, dignity and equality.

In terms of the broad range of elderly populations, psychosocial and personal needs vary. Some want strong social contact and activities. Some want and need a connection to nature to relax. Such activities are necessary for healthy ageing and for resilience. As expressions of such needs can vary greatly, understanding diversity is important. Caring, holding, and mindfulness are very important. Societies also need to provide support for family members or others caring for the patient. There must be time to look not only at the patient, but also at the primary caregivers, who may, in certain circumstances, be better able to communicate for the patient. Today you often have to be very healthy to be sick, to make the best use of the healthcare system.

Main possibilities

Access to cultural activities that are valued, such as being in the outdoors is very important for elderly, and especially in cultural contexts such as Scandinavia where studies have shown that nature is an important part of meaning-making processes. In Sweden this possibility is lacking for many elderly. Experiments, like the *health garden* at Alnarp, have shown good results when people with for example burnout, stroke, and depression have had planned access to the outdoors as an integrated component in treatment. The levels of stress were significantly lower after resting time outdoors than indoors. The effect was also greater the sicker the patients were.

In the workshop it was highlighted that we need new metrics to measure the quality of mental healthcare. Today there is no way for healthcare professionals to “tick off a box” for mental healthcare. What can be measured today is what gets done, oftentimes more from the clinic’s perspective than that of the elderly person. This is a big problem. The staff does not want to neglect the elderly, but the system today does not let them help the elderly as they would like to do. Furthermore they usually do not have the appropriate education to be able to help. It should be easy to have a metric for a “20 minute discussion”, for example. This should be an integral part in the healthcare professional’s routine, which it is not

so today. It should also be possible to find ways to test and include other resilience-building and ill-health-reduction strategies for mental health-care that could then be incorporated into the list of things to do.

Despite all kinds of progress, there have been no significant gains in implementing communication technology in mental healthcare. But there is technology that could be used to improve this. For example, information technology could be used to bring families closer together. There are simplified interfaces available for the elderly. There have been lots of successful trials.

Critical issues and obstacles

In the workshop it was concluded that we need visions. What do we want to do? What kind of society do we want to create? We are good at *what to do when people need help*. But we are not so good at what to do *so people don't need help*. How do we put mental health into public health, and with a focus on public mental health promotion?

Mental health problems do not always have common, established diagnoses the way somatic health problems most often do. That is probably one of the reasons mental health often does not get funding for implementation and research.

All activities that prevent suicide are also promoting mental health, and vice versa. We can identify different groups in different countries that are at risk, and we can correlate economic hardships and morbidity.

There is little research on meaning-making process. The models we have are much better for crisis situations, than for building resilience and fostering empowerment in the general population. A big issue here is how we ask the right questions, to the right persons. In a majority culture such as Sweden, which is very secular, assessing meaning cannot be done primarily through religious paradigms. Yet, all people make meaning in some way, and it is access to that information that is important. We have to ask people how they make meaning to get the answers we need. So, how do different people make meaning? This is a relevant public mental health promotion question.

How does academic research end up in health-care? The academic field is often very closed. We, for example, know a lot about elderly and their resilience and well-being, but much of it does not get implemented. Financing is a problem. But also co-ordination. A lot more could be done with planned collaboration and better co-ordination. Today the stakeholders are not working well together.

The education programmes for health professionals contain too little about gerontology.

They learn how many times to wash and clean old persons, but they have little idea how to help them with mental health issues.

Conclusions and recommendations for action

Strategically there is a need to look at people as social beings. We need to raise the awareness of this issue. This work must start in schools, and in the whole of civil society. Societies must also realize that young elderly and old elderly are different groups, with different needs. The end of life poses its special issues. There *are* metrics that could be used, for example metrics on happiness and well-being. Another important issue that was highlighted in the panel discussion is that updated psychological models that differentiate phases in elderly development need to be used in clinical settings and for planning social programmes.

There is a growing need for better co-ordination between the different parts of society. This is true both for the elderly as for others. We also need to develop new competences. We need to learn about how to look at the elderly as a segment of society with different phases and needs, especially with attention to the very old.

Help today is focused on tending to the needs of the body. Staying healthy is not only about such things as eating right and running. It is also about mental health concerns and nurture through meeting people, in giving and receiving respect, to see and be seen.

Bring people into nature. Bring them together. Design cities to be friendly to the elderly, and to be dementia friendly spaces. No group can do this alone. And, most importantly, never forget who the experts are: the ones we are trying to serve.

Investing in prevention for healthy ageing

The first day of the summit focused on how we can make best use of our knowledge and innovations to enhance and maintain our physical and mental health. Three workshops focused on three different aspects of prevention, via life-style changes, from better use of modern diagnostics and through mental health promotion. The conclusions from the workshops are presented separately in this report, pages 7-13.

Following the presentations in plenary of the conclusions from the three workshops, these were commented on by a panel consisting of Meeri Wasberg, member of Swedish Parliament; Bettina Kashefi, Chief Economist at the Swedish Association of Local Authorities and Regions – SALAR; Dr Božidar Voljč founder of the Emonicum Institute of Active and Healthy Ageing and former Slovenian Minister of Health; Dr Malin Hollmark, project manager innovation and growth at Swedish Medtech; Professor Göran Bexell, Pufendorf Institute and Lund University.

Overall, the panel was optimistic about the possibilities to improve the use of preventive measures as a means to strive for healthy ageing. If we can empower the individual and use new technologies, we have great opportunities to improve prevention. Challenges were also mentioned, as how to finance such long-term investments, and how to handle data generated by the new technologies.

Empower the individual, and start early on

Malin Hollmark noted that all workshop groups came together in their call for self-management, self-control and patient empowerment. This can entail supporting the individual person in carrying out and maintaining life-style changes, of being part of a meaningful context or being able to share and discuss health status data with healthcare professionals and other fellow users. The panel agreed that the need for supporting the individual in changing their life-style is crucial, from economic, ethical and equity points of view.

“People can change their life-styles”, and I believe there is concordance on this view, said Göran Bexell. “This is a very optimistic view and a very good argument against determination on self-responsibility!”

Several panellists applauded the much-needed discussion on promotion of mental health. “Mental disorders are exploding, in particular among youngsters. And as a matter of fact, it is the same thing all over the OECD countries”, said Bettina Kashefi. “This is something we have to take care of!” she argued. Göran Bexell mentioned the importance of discussing well-being that creates meaning in life.

The panel saw numerous opportunities to improve prevention by empowering the individual, but noted that we cannot expect this to happen by itself.

Bettina Kashefi underlined that distribution of health and healthcare is very uneven. Poor health correlates strongly with low income. Meeri Wasberg argued for the role that schools can play for health and health literacy. “We will have more impact if we start early on, with our children. We have talked about how difficult it is to change our habits, especially the bad ones. So why do we get bad habits? Why can't we get good habits from the beginning, starting in school?”

Technologies for prevention can help

Technologies, like tools for self-management, genetic tests, whether for prognostics or diagnostics, can have a great positive impact on prevention. The use of new technologies will also generate huge amounts of data, as reported from the workshop on diagnostics.

“If we look at diagnostics on the genetic level, that could provide me with information of an increased risk for lets say cardiovascular diseases, what would I do with that knowledge unless I can control it myself?” Malin Hollmark asked

Panel discussion on the possibilities to improve the use of preventive measures as a means to strive for healthy ageing. From left to right, Professor Göran Bexell, Pufendorf Institute and Lund University, Dr Malin Hollmark, project manager innovation and growth at Swedish Med-tech, Dr Božidar Voljč founder of the Emonicum Institute of Active and Healthy Ageing and former Slovenian Minister of Health, Bettina Kashefi, Chief Economist at the Swedish Association of Local Authorities and Regions – SALAR, Meeri Wasberg, member of Swedish Parliament and Annika Dopping, moderator.



rhetorically. There are over 97 000 apps available today only for health issues, she told the audience, and most certainly we will all be able to find a tool that suit us and our needs.

The panel agreed that the combination of genetics with tools for data-management, for example a simple self-test, is extremely powerful, and could promote both mental and physical health. But the panel also raised some words of warning, and invited a discussion on how to use the data generated; who should be allowed to use them and for what purpose, but also on how to combine self-responsibility and quality in healthcare.

Božidar Voljč advocated for a continuous discussion on how to use gene-technology. We need to discuss what we perceive as misuse, and how to prevent it. He mentioned the possible use of data by insurance companies, employers or if genetic profiles will influence how we choose a future life partner.

Malin Hollmark underlined that we need to discuss who should receive and analyse these data, but she also emphasized that to be able harvest the benefits from the technical development, we need to create robust IT-infrastructures and standards.

Meeri Wasberg also mentioned the need for using technologies in the care for our elderly to be able to free personnel resources, and thus gain valuable time for healthcare personnel.

The most critical issue – financing investments in prevention

Early on in the panel discussion, Meeri Wasberg underlined the urgent need to carefully reflect on how we can get more money spent on healthcare.

Investing in prevention is, the whole panel agreed, a political responsibility that must encompass different aspects such as equity, access etc. How shall societies be able to make such investments, under the current financial constraints?

Bettina Kashefi said that according to SALAR's analyses, there are enough resources in the Swedish welfare system today to cope with the demographic development. "But", she said, "if we get a future development in accordance with the historical development, where we have had a yearly increase of 1 per cent of consumption of welfare, then we have a financial and economic problem."

In the light of the current financial crisis in Europe, this is a challenge. As Božidar Voljč put it, "Healthy choices need also healthy societies and well functioning societies, well organized and well financed with a lot of social capital."

Göran Bexell stressed that this question is about more than money. Who shall pay for healthy ageing, is a fundamental political and ethical question. "How can we combine equality in healthcare with self-responsibility? We must be able to combine concrete consequences of my life-style with equality in healthcare, and that is a great challenge for healthcare and for politicians," he said, while also calling for new economic models including political and ethical perspectives.

"I believe we can construct more research and education projects that are cross-disciplinary. We must combine these different perspectives to develop new models for healthcare.", Göran Bexell concluded.

Main conclusions from the panel discussion:

- Yes, we can change life-styles, but support is needed.
- Start teaching health literacy in schools.
- Use technologies to support life-style changes.
- Invest in standards and data infrastructures to harvest the benefits from the technical developments.
- Maintain a continuous debate on the right use of the data gathered.
- Dare to talk about how to finance long-term investments in prevention.
- Equality and self-responsibility will pose new challenges to our systems.
- We need to develop education and research in cross-disciplinary settings on these issues.

Francesca Cerreta, Geriatric Medicines Strategieist at the European Medicines Agency, was one of the delegates at Uppsala Health Summit 2014.





Care for autonomous ageing

Reports from Workshops
June 4

Workshop D Food for Ageing

Workshop E Care for the person not for the system

Workshop F Technologies for healthy ageing

Workshop G Respecting the elderly's need in medical- and economic
evaluations of drugs

Panel discussion

Food for ageing

– Individual and societal perspective

Workshop responsible
Professor Tommy Cederholm,
Department of Public Health and
Caring Sciences; Clinical Nutrition
and Metabolism, Uppsala
University.

Dr Rikard Landberg, Department
of Food Science, Swedish Univer-
sity of Agricultural Sciences, Affili-
ated researcher at the Nutritional
Epidemiology Unit, Institute for
Environmental Medicine (IMM),
Karolinska Institutet.

Diet related issues are top-contributors to the global burden of disease. Although education might not be the single answer to the question of improving dietary habits, education is without question an important marker for inequalities in health and lifespan. A well-educated woman has an eight year longer life expectancy than a low-educated man. We are getting healthier but inequalities in health are growing, largely due to differences in dietary habits, including alcohol consumption.

Ageing per se is inevitable. But with a more plastic approach to/view of ageing we can put effort in reaching a successful ageing, meaning a delayed ageing or ageing without disabilities. Today health measurements focus on mortality rates and BMI (Body Mass Index), but are these good markers for health in elderly? Should we instead be looking at optimal function ability, knowing that both low fat free mass and high fat mass increases disability? Many elderly suffer from a vicious circle of sarcopenia (loss of muscle mass with age), decreased physical activity and decreased energy intake – how do we break the circle?

Improved diet quality and life-style changes have an enormous potential in preventing public health disease. This is evident both from observational studies and intervention studies –still we end up taking pills instead of changing behaviour and dietary habits.

Professor Tommy Cederholm had prepared the workshop Food for Ageing in collaboration with Associate professor Rikard Landberg from the Swedish University of Agriculture.



We can continue to produce evidence and new knowledge on healthy diet and life-style, but what we really need is to implement our knowledge, what we already know, in the society.

Main possibilities

From the revision of the Nordic Nutrition Recommendations (NNR) we learned that although elderly largely have the same dietary requirements as younger adults (except for vitamin D) they do need a higher protein intake, in aim to preserve muscle mass. Therefore, we need to work for maintained protein intake in the elderly. Since elderly also have a lower energy requirement there is less food on their plates. This food has to be nutrient dense to fulfill elderly's needs as there is in the elderly less room for empty calories.

The Swedish National Food Agency is already working on translating the NNR into food based recommendations and will initiate a campaign to promote healthy dietary habits. All stakeholders need to make an effort to change policies in their respective arenas. The involvement of different actors but also the importance of concordance among actors is important. Doctors (and health-care employees) should know the NNR and be allowed to promote dietary changes only in accordance with the recommendations.

In the workshop it was emphasized that prevention has no upper age limit and there is a great possibility for improvement. Decreased sedentary time and increased physical activity could battle obesity rates and promote retention of muscle mass to lower sarcopenia and frailty among elderly.

Critical issues and obstacles

An obstacle for improving diet among elderly is the fact that as we get older we experience a loss in taste and we might not perceive food as before, which might lead to loss of appetite. This can however be compensated with good cooking habits. This in addition to the fact that many



Of course, all meals served at Uppsala Health Summit were carefully prepared in cooperation with researchers from Uppsala University and the Swedish University for Agriculture, to meet standards for healthy ageing.

elderly eat their meals alone, or in an environment that might not promote *joyful* eating complicates the situation even further.

Together, different stakeholders, need to promote healthy foods; by labelling, by increasing the variety in healthy foods etcetera. The Danish wholegrain project, resulting in a doubling in the Danish wholegrain consumption, was brought up as an example of a fruitful co-operation between the academy, the public sector, NGOs and the industry. We need to make the healthy choice easy and accessible for the customer. The keyhole symbol is another good example. The Swedish National Food Agency has, in collaboration with other Nordic food agencies, developed the keyhole symbol in order to help consumers make healthier choices.

It is essential to include the aspect of inequalities in health in the discussion and plan for targeted interventions to reach critical groups where unhealthy dietary and life-style habits cluster together.

To motivate changes on a political level there is a need for health economists to provide the numbers, costs and benefits, of promoting healthy food choices. But what if disease prevention does not lead to economic benefits? If we are to live (even) longer we need to decrease the years of unhealthy ageing, at the same time increasing the years of healthy ageing free from disabilities, disease and healthcare costs/burden. Otherwise,

the price tag for society will be overwhelming. However, by changing to a healthy diet and life-style our increase in lifespan would equal an increase in healthy, productive years. Societies also need to battle the inequalities and inequities in health and healthcare to close the gaps of health and wellbeing in the society.

Conclusions and recommendations for action

We need to inspire eating among elderly. A proposition was to focus research on the palatability of foods and preferences of foods among elderly. This could, together with the knowledge on healthy food habits, be a starting point for the industry to produce new products with maximized positive features, which would encourage healthy eating also in older ages.

How can we improve the quality of meals? Food could be delivered from nearby restaurants, cooked by skilful chefs, or the industry could be motivated to provide tasty, nutritious and adapted prepared meals for elderly. The importance of vitamin D fortification and of promoting protein intake among elderly was highlighted.

Supported by public sector initiatives, the industry should be encouraged to increase the availability of healthy foods. It would be valuable if the industry saw an opportunity in engaging in healthy food habits to promote their own brand. A similar trend to what we have seen regarding the industry's commitment to the environment.

Communication on food choices and messages from researchers and agencies also need to focus on *do's* instead of *don'ts*, to reach out to the population. If feasible, we need to include nutrition on the agenda in the whole society, not least in schools. Moreover, we need to take into account that we live in a multicultural society where diverse intervention strategies might be needed to reach different ethnic and cultural groups.

The discussion with politicians needs to separate *healthy* from *unhealthy* ageing and the engagement of health economists is needed to confirm the economic benefit of diet and life-style changes concluded the workshop.

There should be no doubt that nutrition is a good investment!

Care for the person not for the system

– A person centred perspective on the
co-operation between care and healthcare

Workshop responsible

Dr Barbro Wadensten, Senior lecturer, Department of Public Health and Caring Sciences; Quality of care and safe care.

Dr Susann Järhult, MD Emergency Care, Department of Medical Sciences, Uppsala University and Uppsala University Hospital.

Dr Åsa Muntlin Athlin, Researcher, Department of Public Health; Quality of Care.

Many old persons have multiple medical problems. They need services and advice from a multitude of healthcare professionals. When co-ordination fails, and when the old person becomes a pawn on a chessboard rather than a full social creature, consequences can be substantially negative for the person's mental and physical health as well as for societal costs. When co-ordination fails, visits to the emergency department may be a consequence. These might have been avoided if the person's needs were better met by healthcare or social care providers.

When you assess the relationship between users (in this case the old person and the people in their social vicinity) and services, you find that the users want to influence and participate. They want engagement and shared decision-making. The challenge is to achieve better care for older persons by experience-based co-design and to integrate healthcare and social care.

There is a need to examine all healthcare and social care, and redesign it to put the person in the centre, to create person-centred care. Doctors and nurses need to understand what this really means and it requires a change in attitude from a focus on the system to a focus on the individual. Many caregivers believe they are working patient-centred, but they are not. Currently, the main challenge is lack of definition and agreement of what patient-centred care is. Implementation yet another.

Financial incentives currently have a large effect on how elderly care is provided. Almost all reimbursement models today are such that the less autonomous the patient, the higher the reimbursement. Reimbursement is often tied to the number of hours and days of care needed, rather than to quality measures. For example, rehabilitation is extremely important but there are no solid quality metrics for base-level, rehabilitation potential or progress of the old individual.

There is also a need for increased sharing of knowledge. Building definitions, targets that are transparent, as well as results that are publicized and publicly available. In addition, financial incentives need to be transparent. The economic models used to steer care do not necessarily steer the care towards patient-centeredness. Co-ordination of, and "measuring" quality and efficiency of care around old people in the emergency department is complex. The persons (medical) history and multiple illnesses as well as multi-medication and the acute illness and/or social insufficiencies need to be sorted out in a short time span. We need to develop better tools for risk-screening and evaluating these persons. More research is needed to evaluate level of care needed and outcome of interventions, both medical but also co-operation between in-hospital-care

Kaiser Permanente is a health-care provider that over the years has developed systems for integrating prevention in its healthcare program. Mary Durham, vice president Research at Kaiser Permanente, gave an overview of strategies and results.





and municipalities and homes. What happens when patients are rushed to the emergency department? We do not have a good method of measuring how co-ordinated the care is in the emergency department.

An important area that was highlighted in the workshop was the need for metrics for person centeredness that can be captured, followed, and changed. There are no generally accepted definitions for what quality is, because it involves subjective concepts for the patient. The definition of autonomy varies between persons and is hard to measure. At the same time there is a need for useful comparisons to incentivize providers appropriately. If change is going to occur you need to be able to show you are getting more value for the money. Healthcare providers also need guidelines and recommendations on how to include the family perspective and the informal caregiver perspective. All elderly persons may not be able to make their own decisions, and then we need the family involved.

Main possibilities

Solutions are often driven by healthcare professionals, who do their job, who listen, who respond, and create improvement strategies.

However, another path would be striving for more active involvement by patients. For example by listening to their stories and storytelling. Experience-based co-design is anchored in the management of nursing home and social service. They use films and internet applications for storytelling. There have been cost-effectiveness studies of this.

The older person is the key but the family must be included. It is essential for families to get good care. Relatives have an important and demanding role. They should not take over care but they can be supportive participants, for example to help with communication. Successful person-centred care requires that relatives be treated as the key parties that they often are.

In Sweden, one of the best tools to assess and improve care is by use of quality registers. However, nothing will improve without better financial incentives pushing toward patient centeredness and without data that can increase effectiveness.

The comparative high numbers of elderly patients in the emergency department is the most difficult area and should be a core focus area. Lidköping, a medium sized city in Sweden, has successfully

Mentometers captured the audience's opinions on different topics discussed.



improved quality of care by applying person-centred care. Unnecessary use of emergency care has been seen to decrease. Now patients are taken to the emergency department only when they really need it.

Critical issues and obstacles

To accomplish person-centred care, there are several different challenges that need to be addressed. For example, how can the patient be asked to tell his or her whole story to every provider at every healthcare encounter? The cost of medical specialization; are doctors too specialized, leading to fragmented care with too many encounters? The traditional holistic approach is partly lost (at least in Sweden). Others problems include high staff turnover, changes in care providers.

All taken together this is logistically challenging. Many informal caregivers find their situation rewarding, but there is a cost. Studies have shown that the more care they give, the worse they rate their own health status. There are also economic consequences for the caregiver, they reduce work time or quit work to be a caregiver. Also, relatives often feel taken for granted, they feel that their involvement is not taken into account, they may feel invisible and that their needs are ignored.

Another important issue that was highlighted is how one gleans the needs and preferences of older people with challenges in communication (such as language, dementia related, cultural issues,

difficulty in hearing or speaking, etc), and that family or next of kin can play a helpful role in these situations.

Conclusions and recommendations for action

It is important to find a common definition of person-centred care that also entails its relation to for example integrated care. What is the relationship between integrated care and person-centred care? How are these two concepts related?

When examining outcomes, consider using classifications of a person's function and health, rather than classifications of disease state. Contact various healthcare organizations and providers and find out if they are providing what they consider to be person-centred care. If so, what does this entail for them? Perhaps there are some best practices out there that could be centrally gathered and analysed. There is also a need for guidelines and tools.

Another important issue that was highlighted in the workshop was that it is imperative to educate relatives so they know what is happening, what is to be expected, and what to do in case of an emergency.

Provide economic arguments concerning why person-centred care is better. Draw on the experiences of municipalities in improving care for elderly and the need for them to see it as cost-effective. The municipalities need to be able to show results.

Technologies for healthy ageing

– Implementation of technical aids in home care and nursing homes

Workshop responsible
Dr Johanna Ulfvarson, Programme Manager Life Science, VINNOVA – the Swedish Innovation Agency, Karin Eriksson, MSc, VINNOVA – the Swedish Innovation Agency.

The development seen over the past years in population ageing also means that the demands on delivery of care and services are changing. An ageing population, an increasing prevalence of life-style diseases, new treatments, drugs and medical technology drive demand and healthcare spending.

Furthermore, consumers are becoming a stronger force and their expectations are changing. Better-educated, increasingly well-informed and increasingly mobile consumers place new demands on healthcare providers. There is an increasing awareness that proactive behaviour, such as exercise and diets, leads to a healthier life. Power is also given to patients as consumers of healthcare.

The workshop on technologies for healthy ageing had a practical focus, which included demonstration materials and the opportunity for discussions with innovators, providers, decision-makers and users.



Main possibilities

Technologies, tools like walkers or different types of eHealth solutions, offer a great potential for the individual to increase the degree of autonomy and to address the pressing needs of governments to reduce costs and increase quality of care as well as meeting consumers rising expectations on quality and availability.

Consumers have access to an information and communication infrastructure that can vastly increase the reach of healthcare services. The prevalence of personal technology, especially “smart” mobile phones, creates opportunities for new ways of delivering healthcare services and for service integration.

Another important aspect in the ageing debate, is to not only see demographic change as a burden on society, but rather an achievement to be celebrated and the path to opening new social and economic opportunities. A wide variety of sectors can profit from this new *silver economy* – amongst them public services, health, new media, telecommunications and financial services. This suggests that scientist, innovators, and businesses need to think more broadly about the business opportunities and the service sector of an old people’s market and about what this market needs.

Critical issues and obstacles

One of the main challenges that needs to be addressed is the common feeling of being ashamed of a disability or age. This affects the willingness to accept the help and aids that can hugely advance the individual’s sense of autonomy.

There is also a need to address design as well as function. Walkers improve access to the outdoors for the user, increase independence and provide the user greater possibilities to stay physically



Using available technologies to increase autonomy is crucial for perceived welfare, advocated Anders Ekholm, deputy director at the Institute for Futures Studies.

active. But, it is also important that the walker has an appealing design, otherwise you will be less prone to use it in public.

A substantial problem that was highlighted in the workshop was that the elderly often have little or no choice beyond the standard product, but also that they often do not know what technical aids exist. There is a need to increase the information to users and payers what products and services there are (or should be) available for elderly. Another challenge is that it also differs a lot between municipalities which technology products are offered the inhabitants.

A main issue that needs to be addressed is that subsidizing and funding by healthcare is decreasing, and that the costs for the new technology (products or services) will only be offered to a few if the users cannot pay themselves.

Conclusions and recommendations for action

It is important to involve the users from the beginning when designing and developing products and services. Involve the personnel; they need support and education when new products and services are implemented. Partnership with the users is essential as well as empowering the users.

Studies have shown that relatives are willing to take greater responsibility for the elderly when using ICT (information and communications technology). Internet is a very good tool, not only for paying bills, but also for social support. An important action is to educate more elderly to use computers and social media.

Education about elderly and technologies for healthy ageing is needed for all actors; users, personnel, politicians, relatives, county councils, municipalities and companies.

Another important conclusion from the workshop is what connotations come from how items are portrayed. For example, sell the walkers in bicycle stores. Lets bring the walker from being seen as a handicap aid, to becoming a walker that users actually desire. Just like when buying a car or a bicycle, you can choose between different models, upgrades and accessories, all according to your personal preferences and preferred activities. This is could also be applied for other products, not only the walker.

Finally, respect the user's privacy, especially when you are implementing technology in elderly homes. Also, see a robot as a tool or device for communication and security, it cannot replace a human being and should therefore not look like one.

Respecting the elderly's need in medical and economic evaluations of drugs

Workshop responsible

Dr Sophie Langenskiöld, senior lecturer at the Department of Public Health and Caring Sciences, Uppsala University,
Dr Eva Arlander, Head of Unit Use of Medical Products, Medical Products Agency,
Aina Törnblom, BSc Pharmacology, Director R&D, LIF – the Research Based Pharmaceutical Industry.

The importance of providing the right incentives for developing drugs for the growing elderly population and of making sure that the elderly's innate conditions are accounted for in the documentation and evaluation of medical treatments were the focus of the discussion during this workshop.

Drug authorization – how and when to gather additional data

Today the oldest old are practically absent from clinical trials. In a study conducted in Sweden researchers found that 55 per cent of the oldest old, i.e. between 77-100 years old suffer from two or more diseases simultaneously. However, in a systematic review, other researchers found that age and two or more diseases are exclusion criteria in 39 and 81 per cent respectively of the surveyed randomized controlled trials. This shows that the way clinical trials are conducted needs to be adjusted or they need to be complemented with other studies, especially if there are reasons to suspect that the benefits and risks of treatments differ for the oldest old, i.e., those who in the majority of cases suffer from co-morbidities. Otherwise, doctors risk prescribing drugs of unclear value to the elderly population at a cost to society as well as the elderly.

So, the workshop concluded that additional data *shall* be collected regarding the elderly especially if their benefit/risk ratio is expected to be different. How and when depends on the drug, i.e. should be decided on a case-by-case basis. On the one hand, workshop participants emphasized that the aim, in principle, should be not to delay the introduction of important medicines, that it in many cases is better to collect additional data afterwards. On the other hand, participants expressed a need to have this information at the time of authorization, especially if the drug will mainly be used by the elderly.

In the case of collecting information after authorization, the possibility of using patient registers was discussed. The main challenge with registers is that they do not contain “perfect” data and the patient registers need to be improved. However, the patient registers are seen as a great resource that should be more frequently used. Also, randomization within registers should be considered a possibility for collecting additional data.

It is the health economists' responsibility to demonstrate efficient allocation of resources

The methods used to estimate cost-effectiveness of healthcare interventions, can seem to leave the elderly at an obvious disadvantage. Avoiding a death in an elderly population results in fewer life-years gained than the same risk reduction in a young population, which leads to worse cost-effectiveness in the elderly. Further, health-related quality of life is lower in the elderly, so each life-year gained is valued lower. In addition, the elderly have higher medical costs; each life-year saved is associated with a cost for related and unrelated medical expenses, which is higher in elderly than in the younger – again leading to higher ICERs (incremental cost-effectiveness ratios) for treatments in the elderly. If productivity costs are included, this favours interventions in younger age groups. Finally, the practice of

Dr Eva Arlander, MPA, during workshop discussions.





Dr Sophie Langenskiöld, senior lecturer at the Department of Public Health and Caring Sciences, Uppsala University, welcomes the delegates to the workshop on elderly's need in medical- and economic evaluation of drugs.

including net productivity in added life-years clearly puts interventions in post-retirement age at a disadvantage.

So, should we take all these costs into consideration, i.e. take the societal perspective? Is that not sheer discrimination against the elderly? The workshop participants all agreed that the societal perspective should be used in health economic evaluations, because it is the health economist responsibility to demonstrate efficient allocation of resources. It is then the politician's responsibility to prioritize, i.e. to make the tough final decisions, which for instance involves weighing the efficiency goal against the equity concerns.

Moreover, the politicians need to be explicit, i.e. transparent, in the weight they give to the elderly in order to provide the best incentive for innovation of drugs for the elderly. If you want to prioritize the elderly, because the elderly benefit more or suffer more, that's OK according to one participant at the workshop. They are the big consumers of the drugs. However, this needs to be transparent.

One problem that was highlighted during the workshop was that there is hardly anything to gain for a politician in discussing prioritizations. They can only lose, thus it is hard to encourage them to do it productively. The question is how to engage our politicians in these discussions? Prioritization is about choosing what *not* to do, to say *no*. It's a value judgement, and it is difficult to say no and at the same time win votes.

Conclusions and recommendations for action

We need to adjust the way pivotal trials are conducted or complement these trials with other studies on the oldest old in order to truly understand the benefits and risks of treatments for the elderly, especially if the benefit risk ratio is expected to differ for the oldest old. In the workshop it was concluded that both pre- and post authorization data should be used. There was a call in the workshop for developing a strategy for when and how additional data should be collected to ensure that the elderly's innate conditions are accounted for.

In the workshop it was highlighted that maybe RCT:s (randomized clinical trials) are not always the best way to collect this data. If not, this would entail a paradigm shift. Traditional end-points in health economic evaluations are mortality and morbidity. However, these end-points need to be supported by other end-points more uniquely related to the disease under evaluation. As elderly are a heterogeneous population, you may otherwise not know if the true effect is related to the effect you are measuring.

The gap between regulatory and reimbursement evaluations needs to be bridged. There is a need to be more transparent about decisions and prioritizations – both in regulatory decision-making and HTA decision-making. Prioritizations are already made today but not transparently.

The ethical discussion should not be decisive for how health economic evaluations are conducted. In that case, the results will be misleading. The trade-off between efficiency and equity cannot be avoided; attempts to conceal the issue may mislead decision-makers and lead to suboptimal use of resources. An important discussion has been initiated in this workshop.

Care for autonomous ageing

Uppsala Health Summit's second day focused on how we can assure and afford years of health and autonomy for senior citizens. Subjects covered during the morning's four workshops were elderly's nutritional needs, the use of technical aids, person-centred care and the development of new treatments for elderly, often suffering from multi-morbid conditions.

Conclusions from the four workshops are presented on pages 18-26.

The panel convened to discuss the workshops' conclusions consisted of Anders Blanck, Director general LIF, the Research Based Pharmaceutical Industry in Sweden; Professor Göran Lantz, former Director General of Ersta Sköndal Institute for Healthcare Ethics; Nicola Bedlington, Director general at the European Patients' Forum; Professor Barbro Westerholm, Member of Swedish Parliament and Petter Odmark, Chief analyst at the Swedish Ministry of Health and Social Affairs.

A call for autonomy and recognize the opportunities

In several of the workshops, the notion of autonomy had been brought up. Autonomy as an integral part of healthy ageing turned out to be an aspect that the panel discussed at length. The panel was also overall quite optimistic about the current development.

Ben van Hout, professor of Health Economics at the School for Health and Related Studies of the University of Sheffield, UK, engaged the audience in his presentation on how economics can help estimate the value of new treatments, as well as the limits of economics.



"We need to find a way to embrace the future. This is a fantastic development that we see these last couple of decades. It can't be a problem that we live longer lives!", said Anders Blanck and initiated a discussion on how to turn the demographic challenge into a possibility, mentioning as one example that US pharma companies have over 400 drugs in the pipeline that can improve conditions for elderly. "Is that a problem or a challenge?", Anders Blanck asked, calling for a discussion on what changes are needed on the system's level to channel such opportunities.

The individual's or the patient's perspective was in focus during the panel discussion, also this second day of the summit. Petter Odmark expressed some discomfort with the title of the summit. "Healthy ageing", he said, is a bit disturbing. "Autonomy is a tool to make sure that I have the opportunity to control my life in a way that gives *me* value.", adding that this choice may perhaps not be the healthiest of all life-styles. "There is a tendency to disregard the value of autonomy", he concluded.

The panel agreed that autonomous ageing is a more relevant goal than merely healthy ageing, though the latter is often a prerequisite. Thus, on a societal level, we must be able to provide opportunities for healthy lives, but it is up to the individual to make the choice of what advice to follow, and which to disregard.

The need to see the individual person

The panel underlined the need to see the individual person, as the person he or she is, with his or her background, needs and wishes. The workshop on person-centred care had discussed the model of experienced-based co-design, inviting the patient or the elderly to tell stories about themselves and their needs, as a good example of how to work with a patient-centred view.

It will be a challenge for care-givers as well as for societies to deliver care aiming to strengthen autonomy, and not only physical health, the panel agreed.

Moderator Annika Dopping led the hearing of the panel's views on the workshop conclusions June 4. In the panel, from the left, Mr Anders Blanck, LIF - the research-based pharmaceutical industry; Nicola Bedlington, European Patients' Forum; Petter Odmark; Swedish Ministry of Health and Social Affairs; Barbro Westerholm, Member of Swedish Parliament; Göran Lantz, former director of Ersta Sköndal Institute for Health Care Ethics.



“Everybody is not just this body with its physical and medical characteristics”, Göran Lantz commented, “basically, we are a story, a huge story including many life years and experiences. That is our identity, in a more basic sense than our bodies”.

The panel had a lengthy discussion on how we can change attitudes, not only among individuals, but also on a system's level.

“We need to find ways on how to build patient-centred care, and we need to have choices and listen to what people want, but how do you do that in the models we come from in Europe?”, Anders Blanck asked. “We try to build societies that are equitable, and it must not cost more money,” he continued, “and I think that this is the real challenge! We need to be able to discuss the systems, the models, the reimbursement systems, the tax system. As long as we don't do that, we don't discuss the real priorities!”

Petter Odmark pointed out that this would be a matter of priorities and political decisions, mentioning that this summit had highlighted huge possibilities to improve peoples' lives. It may be that some of the measures we propose will lead to higher costs for society, at least in the short term. “It might be a good idea to embrace the fact that yes, this may cost more money. Considering the

amount of increased human autonomy and dignity we can gain, this may be worth spending, this may be worth looking at not only from a cost perspective.”

Following a comment from Barbro Westerholm on many senior citizens' expressed need for social networks, rather than e.g. physical training, Petter Odmark mentioned that policy-makers might not always see the value of small, not so costly initiatives, e.g. creating arenas for networking. “Public policy initiatives may actually lack these small initiatives that can make a big difference during the part of your life when you need assistance, but you are not so sick that you need a nursing home or similar.”

So while the panel called for a discussion on priorities and needs for a strategic discussion on systemic changes, they also agreed that a lot can be done already as we speak.

Barbro Westerholm had earlier proposed to involve elderly in development of various treatments and technical support, designed to increase autonomy. The user, the target person, may see things quite differently. “We, the politicians, may think that a camera in the bedroom is a no, no, no, while 92-year-old Olof thinks it's great, because I will not be disturbed by healthcare personnel.”



Petter Odmark mentioned experiences from a Swedish municipality where persons who had opted for having a camera in their bedroom felt it increased their integrity, while at the same time the measure saved costs for society. But when presented as a measure that saved money, not as one that could increase integrity, the idea completely lost ground.

“From my perspective, the elderly people and the patients are not the problem but part of the solution”, Nicola Bedlington underlined, “Our knowledge and expertise is probably the most underused resource in the social system”. Nicola Bedlington also highlighted that different types of innovations – technical, pharmaceutical, social – are often developed isolated from each other and from the patient.

Value elderlies’ contributions to society

The risk for age discrimination was a subject raised in a few workshops, notably in the discussion of evaluation of new treatments addressing elderly with multi-morbid conditions.

A distressing sign of our attitudes to elderly in society is the low status attached to jobs in care for elderly people. “That it is very difficult to engage young people to care for the old, the lack of staff, is a sad thing that I heard mentioned at this summit”, Göran Lantz said. His analysis was that this was due to both an underestimation of the profession, and of old people.

If all the old people who do unpaid voluntary work today would go on strike, Barbro Westerholm said, the society would fall together. Somehow we have to show that all people are a resource. “We who are older are responsible for being role models”, she continued giving examples on how elderly contribute to society in many ways. “Don’t ever say –I’m *only* a pensioner!”, she urged the delegates.

According to Nicola Bedlington, we lack coherent strategies for how to empower people, aiming to improve health literacy among people. “If there could be more thinking about a coherent strategy, either here in Sweden or preferably from a European perspective, I think that would be fantastic!”

Main conclusions from the panel discussion:

- Autonomous ageing is a relevant goal with consequences for healthcare systems.
- Autonomous ageing is not synonymous with healthy ageing.
- Work with attitudes on age!
- Involve the users – patients, senior citizens etc – in development of technologies and in decisions on care and healthcare solutions.
- Start discussing coherent strategies for patient-centred care, and the priorities that need to be made, in order to embrace possibilities for many autonomous life years.

Governance



Richard Bergström, Director General, European Federation of Pharmaceutical Industries and Associations, EFPIA

Göran Bexell, Senior Professor of Ethics, The Pufendorf Institute, Lund University

Anders Olauson, Founder of the Ågrenska Centre; Member of United Nations' ECOSOC; Member of Swedish National Board of Health and Welfare's Advisory Board; President of European Patients' Forum

Dr Ingrid Wüning Tschol, Senior Vice President, Health and Science, Robert Bosch Stiftung

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Madeleine Neil, MSc Ba and Econ., Uppsala University

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Antibiotics and antibiotic resistance in focus at Uppsala Health Summit

2-3 June, 2015

Antibiotic resistance is one of the great threats to health globally, a threat that needs urgent coordinated action on a global scale.

WHO underlines in its 2014 report "Antimicrobial Resistance – Global Surveillance" that if not dealt with, ordinary infections that we today consider treatable will kill again. A growing burden of antimicrobial resistance will increase mortality among frail groups as patients suffering from other diseases, and even simple surgical interventions will once again become interventions of high risk. The World Health Assembly has called for a global action plan against antimicrobial resistance, to be coordinated by the WHO.

At Uppsala Health Summit 2015, we will focus the dialogue on how we can use our current state of knowledge and innovations to take steps forward, on global, national and local levels, to reduce the threat from antibiotic resistance. Issues to be discussed in workshops and in plenum will cover:

- measures for rational use of antibiotics for human and veterinarian purposes
- environmental issues
- business models for innovation and release of new antibiotics
- prevention of infections

Uppsala Health Summit invites decision-makers, opinion leaders and experts throughout the world to meet 2-3 June 2015 to discuss consequences of actions and of non-actions for people, animals and the planet.

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