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# LIFE AT WHAT COST

## HARD CHOICES IN HEALTHCARE

REPORT



Cover image credits: "This is Axiom" short fiction film, commissioned by Celgene

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## INTRODUCTION

The healthcare revolution is coming. Europe has the money, technology and expertise to make it a reality. But a lack of coordination and communication among authorities, hospitals, drug companies and insurers is holding back progress, leaving patients, like the 1960s sci-fi series *Lost in space*.

‘Life at what cost?’ was the subject of a Friends of Europe debate on 2 May, co-organised by Celgene and the European Federation of Pharmaceutical Industries and Associations (EFPIA). All participants agreed that better collaboration and a focus on the patient can save money and improve access to better healthcare.

“We have the resources,” said [Bettina Ryll](#), Founder of the Melanoma Patient Network Europe and current Chair of the Patient Advocates Working Group of the European Society for Medical Oncology (ESMO). “It’s not sufficient to save, occasionally, a life. This is not good enough.”

Despite rising life expectancy in the European Union, the European Commission has found that the number of people reporting unmet healthcare needs is rising.

“Part of the challenge is walking in each other’s shoes,” said [Lee Heeson](#), Celgene’s President for worldwide markets, inflammation and immunology. “We often have conflicting performance indicators or incentives within each of our relevant areas of expertise.”

The revolution in big data and biotech can aid collaboration, said [Nathalie Moll](#), Director-General of EFPIA. “By 2025, I think that the technology will force us to change the conversation because the patients will also expect to have access to those things, wherever they are, whoever they are.”

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Director-General of EFPIA

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**Penilla Gunther**

Member of the Swedish parliament's Health and Welfare Committee

## LOST IN SPACE

Space is a useful analogy for healthcare. A short film, ‘This is Axiom’, tells the story of astronaut Nozomi, lost in outer space and afraid that she has been given up for dead by her mission chiefs back on Earth. Produced with support from Celgene, the film illustrates the challenges patients face in navigating the health system.

The Axiom mission is “out of time and out of money”, mission director Flight is told by his superiors. “We have the best technicians in the world, we have everything we need right here to bring this mission in,” Flight insists. He refuses to give up, and borrows resources from other active missions to enable Nozomi to ‘hitchhike’ home.

Air traffic control and hotel management are also comparable sectors. Like space and healthcare, they require an efficient allocation of resources to meet fluctuating needs. “Even hotels can see how many beds they have available,” said [Penilla Gunther](#), a member of the Swedish parliament’s health and welfare committee, “but we cannot always see that in hospitals because we cannot organise the surgery or the treatments in the right way,” she added.

All too often, the system fails the patient, with tragic results. “I hope that you will never be in my shoes,” said Bettina Ryll, who lost her husband to malignant melanoma within a year of his diagnosis. “If we lose someone, who then becomes a number or a statistic, the effect on the family, the children and everyone around lasts for years - probably forever,” she said.

But patients’ frustration with the system has not spurred change, with healthcare still operating in “silos” with only limited incentives to work differently. “Now healthcare is organised around the physician, around the hospital or the outpatient service,” said [Professor Gert Van Assche](#), a gastroenterologist and University of Leuven lecturer. Organising it around the patient would be a “major transformation”, he said. “It’s probably not going to be more expensive, but budget allocations are probably going to be different.”

The answer, according to [Renaud Mazy](#), CEO of Belgium’s Saint-Luc University Hospital, is to “reinvent” the system, built on a coordinated “vision” for treatment involving all specialists and payers.

## VALUE FOR MONEY

According to a recent Economist editorial, “universal healthcare, worldwide, is affordable and therefore within reach” - and not only for rich countries. While higher spending on healthcare and longer life expectancy are linked, spending more does not always improve outcomes. The United States, for instance, spends 17.2% of GDP on healthcare, almost twice the OECD average, but has similar outcomes to countries that spend much less, including Costa Rica and Thailand.

And according to OECD research, up to 20% of healthcare spending could be better used, while more than 10% of hospital spending is wasted on correcting mistakes or curing infections caught in the hospital itself.

“The hospital world is one of the most complex that you can find, with so many constraints,” Mr Mazy explained. “You have to make some trade-offs on a daily basis.” Dr Van Assche agreed. “In a highly regulated world like healthcare, there are always budget restraints,” he said. “The caregiver and the patients, they don’t care a lot about the budget, they just think about getting a solution to this problem, so there’s always going to be this tension.”

Medicines, which make up 20% of overall health care spending, are one of the major constraints on payers. Extensive use of generic medicines would save money but the market penetration for generics ranges from 10% to 80% across the OECD.

A shift towards outcomes-based pricing, or ‘pay for performance’ drugs, also offers some hope. According to Forbes magazine, US insurance giant Cigna has struck a deal with the manufacturers of two (very expensive) cholesterol-lowering drugs that will see the drug reimbursed if patients don’t see the results promised in clinical trials.

But pharmaceutical companies need incentives as well as price pressure to change. In 2000, the European Commission began to encourage the development of new, so-called orphan drugs to treat rare diseases, granting manufacturers 10-year market exclusivity and waiving regulatory fees. The move led to a massive upsurge in drug development, with 148 medicines approved to date, up from eight in 1999.

“We have incredible innovations coming through that will last healthcare for the next millennia, but the challenge is, in the short term, the budgets at a hospital level,” said Celgene’s Lee Henson. “We’ve got to be prioritising today what patients will need in the future,” he added.

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**Lee Heeson**

President for Worldwide Markets,  
Inflammation & Immunology at Celgene

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Founder of the Melanoma Patient Network Europe and current Chair of the Patient Advocates Working Group of the European Society for Medical Oncology (ESMO)

**ACCESS ALL AREAS**

But costs are only one of the constraints patients and caregivers face.

Often, access to the best treatment depends on where you live. “When I look across Europe, it is a few hundred kilometres either westwards or eastwards that decide whether you get a chance to live or whether you will die,” said patients’ advocate Bettina Ryll. “If we talk value, it has to be value for everyone, not just for the rich.”

Access also comes down to education and support systems. “The people we have seen faring best are the ones who understand their condition well and, ideally, have someone else - often a spouse or partner - advocating on their behalf,” Ryll added. “If they’re in a position where they’re weak and can’t demand, having someone that comes with them and insists that certain things are done - for example, that a pain specialist is pulled in, or they get psycho-social support - makes all the difference.”

Access can also come down to who you know, according to Celgene’s Lee Heeson. “I felt like a patient navigator a couple of weeks ago,” he explained, after helping an ex-colleague get information about trials for a new leukaemia drug. “The challenge we have in our system is that we don’t often have that ability to network and really get access,” Heeson said.

But we shouldn’t knock the situation in Europe, cautioned Gert Van Assche, who said access to healthcare is more equal here than in the US. “In North America it is survival of the fittest, people that have advocates for themselves and have a very good [insurance] plan get better care than others.”

“Universal healthcare access is affordable and doable, and that’s something, in theory, that we have in Europe,” said [Tamsin Rose](#), senior fellow at Friends of Europe, “But clearly we have a mismatch between demand and resource allocation.”

## COLLABORATION

Managing strained budgets and improving access to healthcare requires collaboration, networking and a focus on the patient and the goal, all participants agreed.

Some, like Swedish MP Penilla Gunther, said more direction should come from the EU - for example, countries that have failed to present action plans for rare diseases should be made to do so. The European Commission has tried to tackle disparities across the bloc through legislation, with the 2011 cross-border healthcare directive allowing patients to travel and be reimbursed for care.

“Do we have an Erasmus in health? Yes, we do, the European Reference Networks,” said [Andrzej Rys](#), European Commission Director for Health Systems, Medical Products and Innovation at the Directorate General for Health and Food Safety. “These are 24 new virtual centres of expertise, connecting specialists and patients with rare or complex diseases. I am in contact almost every day with the leaders of these networks and I see their potential. Almost one thousand clinicians around Europe have started cooperating - knowledge is already travelling.”

Hospitals are also pioneering new ways of working together, Renaud Mazy pointed out, with Saint-Luc introducing treatment coordinators and multi-disciplinary teams. “Now, if you have cancer, the team, oncologist, radiotherapist and surgeon, take the decisions together - on which pathway is the best for you,” he explained. Penilla Gunther had a multi-disciplinary team - including a doctor, nutritionist, psychologist and physiotherapist - around her when she had heart surgery 11 years ago. “Everyone should at least have the access to these kinds of professionals,” she said. “As a patient, you should know that there are some people out there for you.”

But Gert Van Assche cautioned against mission directors hindering “entrepreneurship” among doctors. “Patients need physicians to be entrepreneurial because otherwise they will not look for solutions,” he said. “It’s not going to be one-size-fits-all. Optimising flow can help allocate resources better, but what you should not forget is that every patient is an individual.”

EFPIA is working with the International Consortium for Health Outcomes Measurement (ICHOM) and pharma companies to standardise the way health is measured in the EU, with the aim of designing the most cost-effective treatment for all kinds of diseases, including chronic conditions such as diabetes. The European health data network, funded by the EU, is also helping to standardise data for diagnoses, lab results or procedures to enable better analysis.

## “Do we have an Erasmus in health? Yes, we do, the European Reference Networks”

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European Commission Director for Health Systems, Medical Products and Innovation at the Directorate General for Health and Food Safety

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**Renaud Mazy**

Chief Executive Officer,  
University Hospital Saint Luc, Belgium

Bettina Ryll compared healthcare to US space agency NASA, which has worked hard to improve internal collaboration in its 60-year history, including setting up a ‘centre of excellence for collaborative innovation’. “This is something we’re missing in healthcare,” Ryll said. “You can’t expect to have a specialist in every tiny little hospital, so I would like to see a collaboration between centres,” she said. “If we put incentives on that collaboration, that can be as cheap as an email.”


## **CONCLUSION**

The healthcare world is a complex and vast one, and the suggestions to improve it are many. But a number of themes emerged during the ‘Life at what cost’ debate, centred on improved collaboration and patient-centred care. As Renaud Mazy put it: “It’s not about making links within the hospital, or within the oncology department; it’s really how we are building together a vision of the future.”

“We can’t avoid changing what we do because what we do now is not good enough,” said EFPIA’s Nathalie Moll, “or because the things coming down the line for health are so revolutionary that we will have to do things differently.”



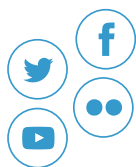


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