

Lifelong care begins at the end

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Robert Mandara



In the next few minutes I would like to challenge how you think about lifelong care.

Today's approach

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Although we all have some concept of what lifelong care means, I think most of us are thinking short term. For example, to getting our next processor upgrade or map. Who is paying attention to the far end of the journey where cochlear implant users are completely deaf in care homes

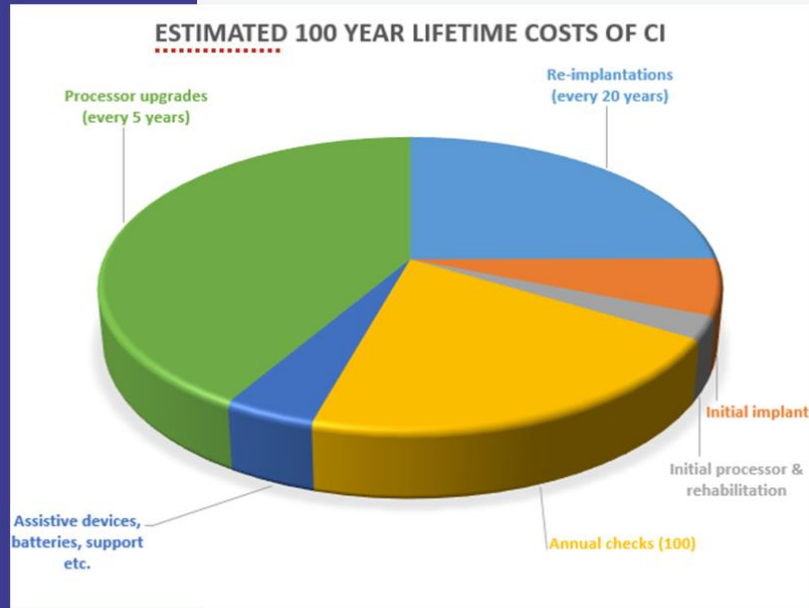
because staff don't know how implants work? Our current chaotic approach is comparable to frantically laying the track just ahead of the train.

In my view, we need to consider the whole lifespan, both of people and of cochlear implants, and trace backwards from there. Once we identify the risks that lie ahead, we can take steps to mitigate them, enabling a clear line of care from cradle to grave.



Some babies who receive cochlear implants today, will still need CI support 100 years from now.

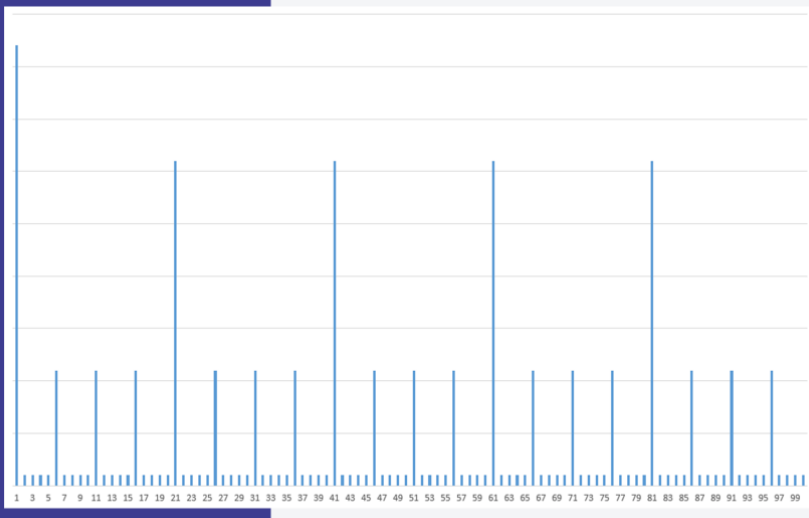
The good news is that we can estimate what support will be needed, when, and how much it will cost per ear, per year. However, because pricing strategies vary so much between countries, I can only show and suggest likely proportions, rather than concrete costs.



The pie chart illustrates that the cost of initial implantation represents only a fraction of the lifetime costs.

The proportions are likely to change over time. We can expect that devices will become cheaper, more reliable, and last longer. Nevertheless, the number of implanted ears is rising, so there's a growing need for lifetime funding and support.

Pattern of yearly lifetime costs



Although the lifetime costs may at first appear high and scary, the yearly costs follow a pattern and are low, especially when compared to the cost of other medical interventions, medicines, and the societal costs of unemployment versus working.

Lifelong care requires funding, device upkeep and services. How can we ensure lifelong care?

Lifelong care should be completely uninterrupted. We know that devices will fail and rarely at a good time. Our ears do not work to a 9-5 office schedule, so we need good 24 hour support, 365 days per year. The pre-emptive provision of spare processors and parts would keep us turned on, even when clinics are shut.

We must also ensure that service is not interrupted in situations where we lose independence, for example in care homes, prisons or hospitals.

Somehow, funding for lifelong care needs to be ring-fenced and safeguarded before patients are implanted.

As far as I know, nowhere in the world has successfully ring-fenced money for lifelong care. Where it has been attempted, it has not worked. Ring-fencing funds is something that health services, governments, brands and users are not experienced in doing. Politicians rarely seem to look further ahead than the next election. Our lifelong care challenge is unprecedented. I cannot think of any other medical intervention which remotely compares to cochlear implants.

In my view, it is unethical to implant people without preparing for and committing to full lifelong care. Cochlear implant users who are rendered completely deaf by an unprepared system will be worse off than if they had never been implanted.

50 years of progress

Wish you were ear!

What's next?

EU RO CIU

Let us also consider the endgame of cochlear implants as a technological entity. They will not be around forever. Implants will eventually be superseded by a more advanced solution, perhaps

biological. When that happens, cochlear implants will be on life support and will only remain profitable for a limited time.

Let's imagine that one baby, Zeta, will be the very last infant recipient of Cochlear implants in the world. Zeta is likely to have around 100 years ahead of her. Who will support Zeta for her whole life once the technology is obsolete and the implant companies have fallen by the wayside? What can we do now to ensure that Zeta and existing implant users will get lifetime support?

Undoubtedly there is safety in numbers. The more implanted ears there are, the longer it is profitable and practical to provide support. This is another good reason to reach the 19/20 people who don't already have implants, as well as to bilaterally implant as a matter of routine.

Another issue which we should consider is the divergence of technology between the brands. Initially the brands' implant offerings were so similar that there was little to choose between them. Now there is difference, effectively leaving users to choose which features not to have. We must make compromises, and then live with our choice of brand for life. How can we ensure that brands are inspired to innovate while simultaneously providing the best hearing outcomes to all users? Is divergence really in our best interests?

While I wish all of the brands every success, some WILL eventually fail and leave the scene, just like Philips did two decades ago – negatively impacting existing users. How can we be prepared for when companies fail? I think the best solution would be the adoption of open-source common standards, like we have for mobile phones, to ensure compatibility and interoperability of systems.

Even the best laid plans can unfold. Globally, it stands to reason that over the course of the next century, we will see wars, natural disasters, shifting borders, pandemics, and ever-changing attitudes to people with disabilities. All of these things threaten the safety nets that we create for lifelong care.

On a local level it's all very well to say that a certain city has a really excellent approach to lifelong care. However, that is only useful if the CI user already lives in that city and never wants to leave. Lifelong care should not tether the user to a county or country. Implants are meant to equip people to live normal lives, and that should include the possibility to travel freely wherever and whenever, be it for work, adventure or love.

With that in mind, perhaps we need some kind of central highly-regulated funds, into which one-off lifetime payments are paid at the time of implantation. These would cover all future costs no matter where the recipient lives now or in the future. How such funds would be regulated and not raided, I don't know. But pensions follow that idea and generally tend to work.

Thank you for listening!

- ▶ If you have questions afterwards, please email me: robert.mandara@elisanet.fi
- ▶ <http://eurociu.eu/>



None of us will be alive 100 years from now to see whether we have taken the right path, but I hope that our descendants will be able to look back and see that we at least tried to take the right steps at this end of the journey. Keep your eyes on the horizon and plan ahead!