Public health decisions in a time of uncertainty
The impact of COVID19 on CI services

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(Thanks to Brian Lamb)

PINDROP WEBINAR, MAY 2020

UK and New Zealand: very different in many respects..and…..different handling of pandemic

- 65 million population
- 93 thousand square miles

- 5 million population
- 286 thousand square kilometres
- 110 thousand square miles

But similar problems with hearing care…awareness

- The public and policy makers and funders have little idea of the impact of hearing loss
- Or of today's communication and hearing technologies
- History of CI services has a history of controversy and individuals leading the way –
- With children – parents…

In the UK in the 80's: individuals driving on CI….adults first then children….I was a teacher of the deaf.

- *" an awful lot of people are giving an awful lot of time to this…. I wonder what will become of it.."* A teacher of the deaf in her diary 1987…who?
- Hugely controversial….
- We learnt from Australia- eg Holly and her mum Victoria

- Michael Batt first child in UK.. Parents with a lot of courage..

THE SUNDAY TIMES 15 OCTOBER 1989

The Sunday Times, 1 Pennington Street, London E1 9XW

Bionic ear breaks Michael's silence

WE WERE pleased to see your article on cochlear implants (page A3, last week). It dealt with adults; we work with totally deafened children, who have specific and urgent needs.

When a child loses all hearing, from meningitis or trauma, for example, there is the additional concern that speech and language may be lost and may not develop. This has many social, emotional and educational implications. For a hearing child suddenly to lose the normal route through which language has been acquired so far can be devastating. The timing of help is crucial.

We have worked with the only two children to receive cochlear implants in the UK. An eight-year-old boy received the single-channel, extra-cochlear device at University College Hospital London in November 1987; and a three-year-old, Michael Batt, was given the Australian 22-channel intra-cochlear implant at University Hospital, Nottingham, last March. Both children have needed considerable rehabilitation and support, before and after implantation; but both are making use of their implants in learning to listen again.

We are continuing to use the proven Australian implant, and we already have a waiting list for the operation. However, we are dependent upon charitable donations to continue this work. We are, therefore, delighted by the proposals for six implant centres throughout the country. We hope that this operation will become readily available to children and adults.

Impact of Hearing Loss in adulthood is underestimated: but increasing evidence of its impact

- Hearing loss is associated with **greater use of medical and social services**
- Those with hearing loss have **higher rates of unemployment** and **underemployment**
- In older age people with hearing loss are at greater risk of social isolation and depression and **reduced mental well-being**
- Hearing loss is associated with **dementia and cognitive decline……Livingston et al, 2017, The Lancet**
- A growing awareness of hearing loss as a **critical public health concern. (***Loughry et al JAMA 2017)*
- Growing numbers of those living longer – and hearing loss now the number one cause of Years Lived with Disability in the over 70's (Global Burden of Disease, Davis)
- *Up to date Spend2Save leaflet for the refs.. From* ***www.eurociu.eu***
- ***Dementia briefing document – www.eurociu.eu***

Bridget Shield report (2019): Social and economic Costs: www:ehima.org www:hear-it.org

- Lower quality of life and less productivity with HL
- Health and psychosocial impacts increasing evidence
- Change from 2006 report:
  - Stigma less of an issue in 2018 than 2006 report
  - Stronger prevalence data
  - Stronger evidence for link with dementia
  - Differential between HI and hearing appear to be growing
  - Increasing satisfaction but still sig percentage unaided
- Socio economic costs to Europe of hearing loss exceed 216 billion Euros per year (Shield 2019; www.hear-it.org)

But….The real impact of adult hearing loss is hidden

- For adults at home and work
- *"You lose your self esteem, you don't want to go out- that's what deafness does to you….."*
- *"It was like being put in a box…"*

Pioneering individuals In New Zealand: Ron Goodey,Bill Baber surgeons.First adult CI: Florence Woodward 1986

Adults in the UK: Graham Fraser, surgeon, and Jack Ashley, MP and CI user in 1987, a key figure

But even in 2000 the Federation of Deaf People wanting to "decommission" implants….

Change towards implantation was driven by persistence….

- Those affected by hearing loss – families and individuals have driven forward CI provision everywhere.. with committed professionals
- And change driven by grass roots groups and individuals
- In the UK – 1990 the Dept for Health commissioned a 3 year study on CI…the value of evidence was recognised, including economic evidence
- In 30 years CI has gone from being controversial to being routine in children – What about adults?

Still issues to address

- Consistent public health funding for CI
- Which relies on public awareness of impact of Hearing Loss …
- and of the impact of CI
- Still – after 30 years, much less than 10% of suitable adults receiving implants in developed countries globally
- Why?

Issues of provision for both hearing aids and for CI

- Inequalities of provision for both hearing aids and cochlear implants
- For CI adults: About 5% of adults in UK (Raine, 2013); Netherlands only 7% of implant candidates have received an implant (De Raeve, Hardeveld, 2013)
- Even in Sweden and Finland.. And Australia(2016)
- Hartmann and Kevasdoue, 2017:
- CI : very low adoption, different criteria for eligibility and a great variation between countries
- HAs : According to Eurotrak, the rate of device adoption for hearing care varies from 17% to 96% of the eligible population… the European average is 47%
- Shield (2019) Take up still too low…

Unaddressed hearing loss costs the global economy $750billion annually (WHO, 2017) cost effectiveness

- Hearing aids cost-effective (*Chao &Chen 2008)* Use of hearing aids reduces probability of hospital visits and reduces number of nights in hospital. HA reduces financial burden on health services. *(Mahmoudi et al 2018 JAMA)*
- **Cost effectiveness of CI is well established for adults** (*Bond,2009; Turchetti et al, 2011; Chen, 2014*) and children (*O'Neill et al; Summerfield et al)*
- ***Kevasdoue and Hartmann (2017) in France…***
- **Return on investment** (ROI) for public funds : (Total cost savings) / (direct cost of hearing care) ratio = **10.44**
- **1 euro invested => 10 euros saved** (an estimation close to The Ear Foundation's one in 2016)
- This information changed HA provision in France.

Hearing aids and implants effective and the earlier the better (see Spend2Save)

- Hearing aids improve mental health, physical abilities, cognitive abilities, employability, *(Amieva et al, 2015,2018) Contrera et al, 2015; Saito et al, 2010; Kochkin , 2012; HSE, 2015) Cochrane review, Ferguson et al, 2016; Maharani et al 2018 JAMA)*
- CI in adults improves quality of life, reduces depression, and improves cognitive functioning*, (eg Mosnier et al, 2015)*
- The earlier hearing aids or CI fitted, the greater the benefit *(eg Davis et al, 2007; Mosnier et al 2015)*

So….Why this low take up and disparity??

- Society's lack of recognition of hearing loss and its impact….STILL
- And politicians – the SCIENCE/POLICY divide
- Good to have the evidence –needs to be understandable..
- And It's not just funding when you have it..
- It's awareness eg Virgin photo – they airbrushed out the deaf ballerina's CI.

- Why? What does this indicate?

Virgin Active edited out deaf ballerina's hearing implant for ad campaign

Jen Mills for Metro.co.uk Sunday 29 Oct 2017 3:22 pm

981

How the advert changed (Picture: Virgin)

A deaf ballerina has hit out at Virgin Active after they photoshopped her hearing implant out of the advert she starred in.

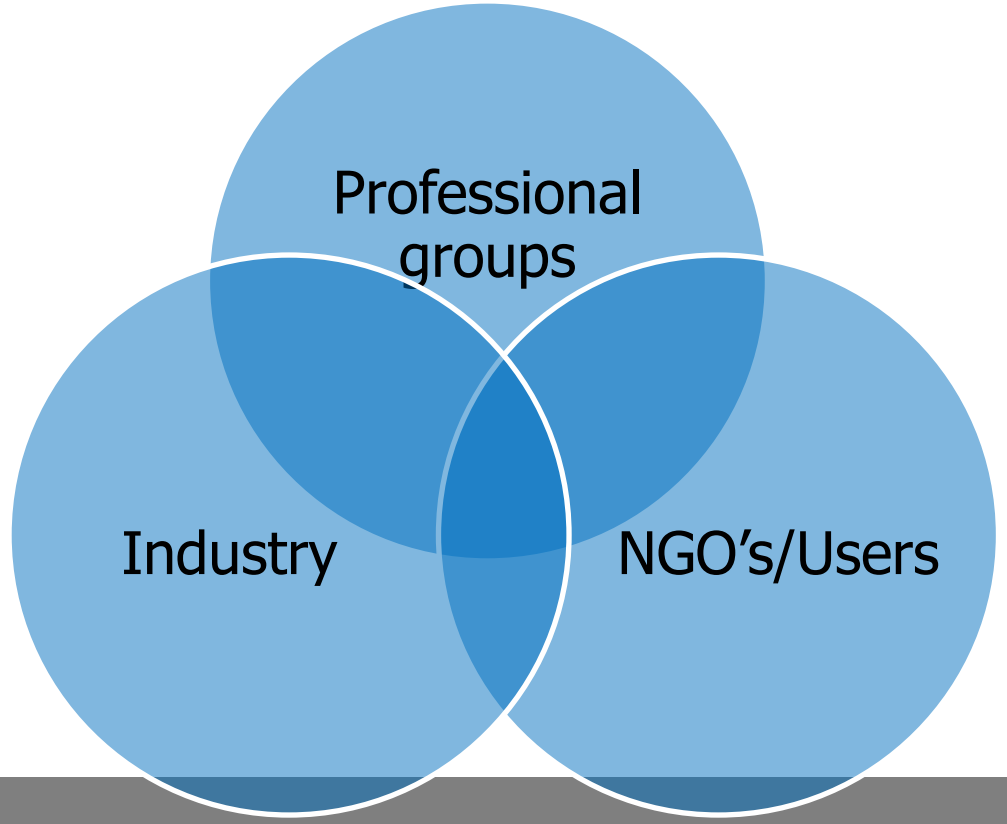
Some global initiatives on Ear and Hearing Care, including CI

- World Health Organisation (WHO): World Hearing Forum
- World Hearing Day (3 March annually)
- World Hearing Report to come
- IFOS work globally
- In Europe – European Coalition, Spend2save initiative
- EURO-CIU organisation
- Uk and Nordic CI action groups
- American CI Alliance
- Global work: International Consensus Statement on ADULT CI

Firstly…..Deafness and Hearing Alliance… England

- Bringing together professional groups, industry and not for profit/user groups..
- To make government aware of deafness and hearing loss
- Speak with one voice about hearing loss and its impact to government:
- How did we manage this?
- Appointed a coordinator: Brian Lamb
- GOAL: To get an **Action Plan for Hearing loss** published by the government…
- (50 iterations… persevere, persevere, persevere…..)

Bringing together



Part of this Alliance… Action group on CI for adults…

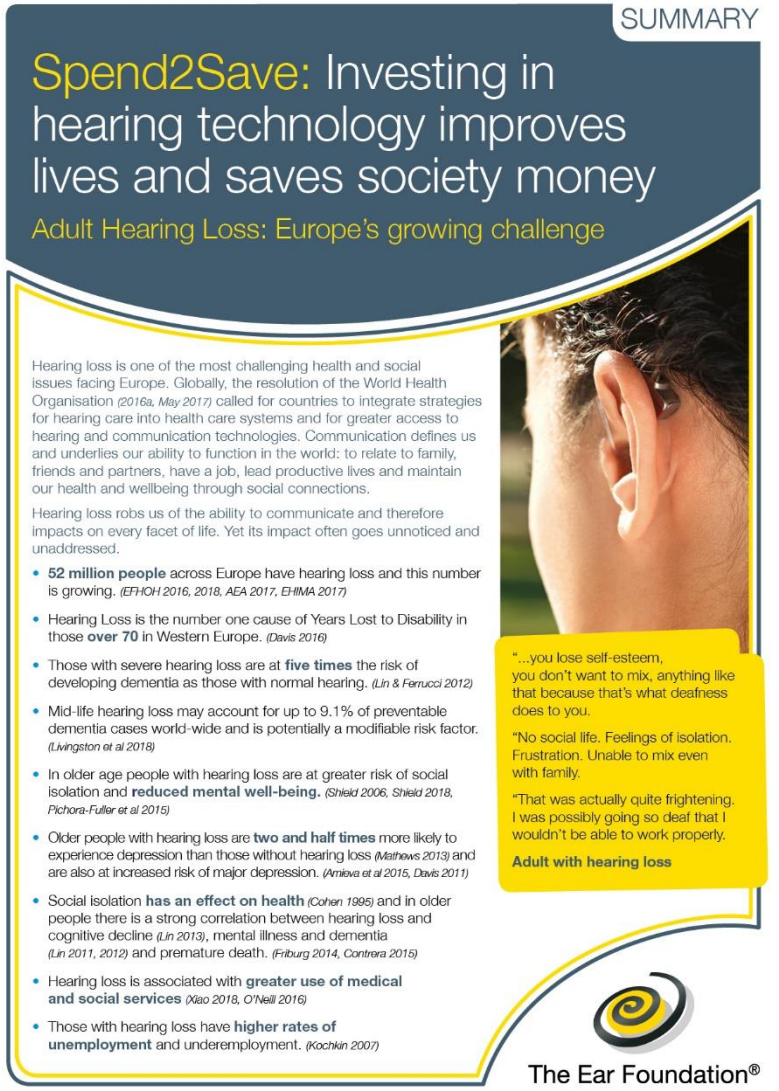
- Began with a change plan…..
- We developed series of reports including literature review, qualitative research, user views, health economics and recommendations
- Launched at conferences and by politicians in our Parliament…
- Understandable and clear and evidence based…
- Available on www.earfoundation.org.uk/research and www.eurociu.eu
- **We changed the story…. From looking at the cost of providing HA and CI to the cost of NOT doing so**
- **And the NICE Guidelines (www.nice.org.uk)were changed last year to be more inclusive**

One resource: Spend2Save- The Ear Foundation : www.earfoundation.org.uk www.eurociu.eu

- Includes Clear Evidence and the user voice
- Up to date references
- Recommendations

- It gives a consistent message
- 19 translations by user groups

- Sent to governments, health funders to change policy



SUMMARY

Spend2Save: Investing in hearing technology improves lives and saves society money

Adult Hearing Loss: Europe's growing challenge

Hearing loss is one of the most challenging health and social issues facing Europe. Globally, the resolution of the World Health Organisation *(2016a, May 2017)* called for countries to integrate strategies for hearing care into health care systems and for greater access to hearing and communication technologies. Communication defines us and underlies our ability to function in the world: to relate to family, friends and partners, have a job, lead productive lives and maintain our health and wellbeing through social connections.

Hearing loss robs us of the ability to communicate and therefore impacts on every facet of life. Yet its impact often goes unnoticed and unaddressed.

- **52 million people** across Europe have hearing loss and this number is growing. *(EFHOH 2016, 2018, AEA 2017, EHIMA 2017)*
- Hearing Loss is the number one cause of Years Lost to Disability in those **over 70** in Western Europe. *(Davis 2016)*
- Those with severe hearing loss are at **five times** the risk of developing dementia as those with normal hearing. *(Lin & Ferrucci 2012)*
- Mid-life hearing loss may account for up to 9.1% of preventable dementia cases world-wide and is potentially a modifiable risk factor. *(Livingston et al 2018)*
- In older age people with hearing loss are at greater risk of social isolation and **reduced mental well-being.** *(Shield 2006, Shield 2018, Pichora-Fuller et al 2015)*
- Older people with hearing loss are **two and half times** more likely to experience depression than those without hearing loss *(Mathews 2013)* and are also at increased risk of major depression. *(Amieva et al 2015, Davis 2011)*
- Social isolation **has an effect on health** *(Cohen 1995)* and in older people there is a strong correlation between hearing loss and cognitive decline *(Lin 2013)*, mental illness and dementia *(Lin 2011, 2012)* and premature death. *(Friburg 2014, Contrera 2015)*
- Hearing loss is associated with **greater use of medical and social services** *(Xiao 2018, O'Neill 2016)*
- Those with hearing loss have **higher rates of unemployment** and underemployment. *(Kochkin 2007)*

"...you lose self-esteem, you don't want to mix, anything like that because that's what deafness does to you.

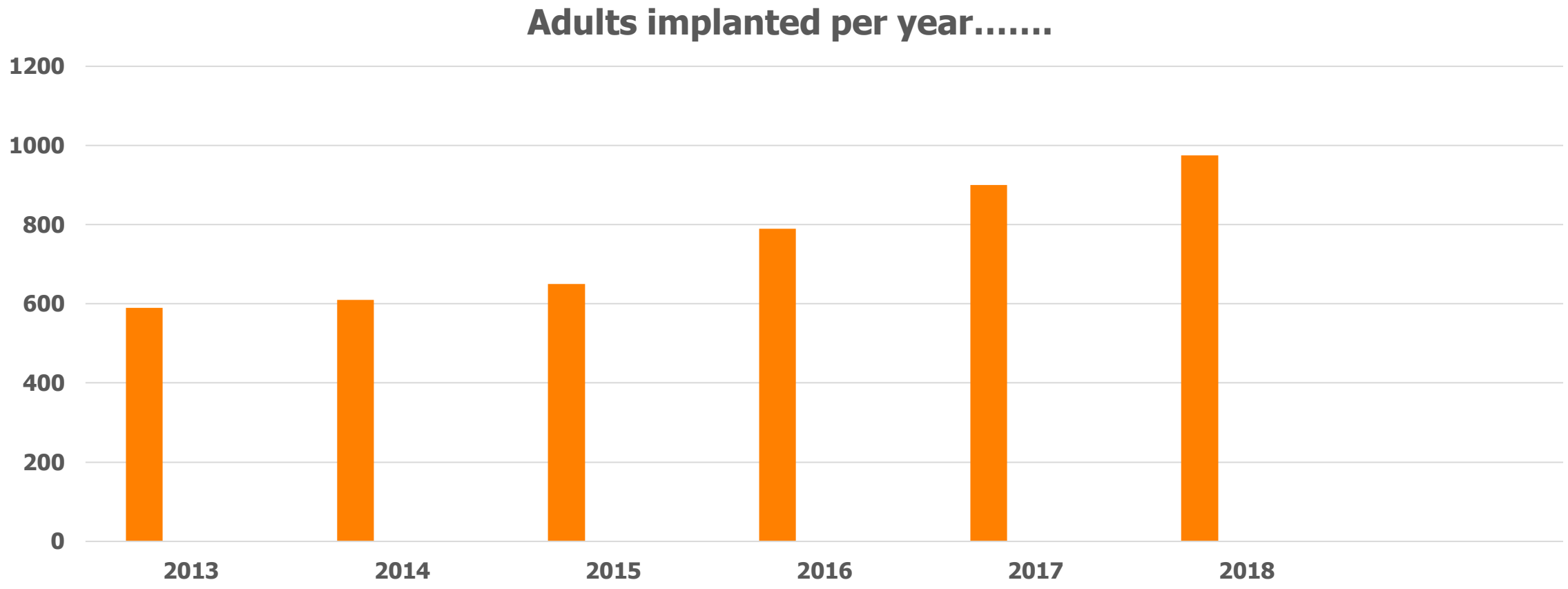
"No social life. Feelings of isolation. Frustration. Unable to mix even with family.

"That was actually quite frightening. I was possibly going so deaf that I wouldn't be able to work properly.

Adult with hearing loss

The Ear Foundation®

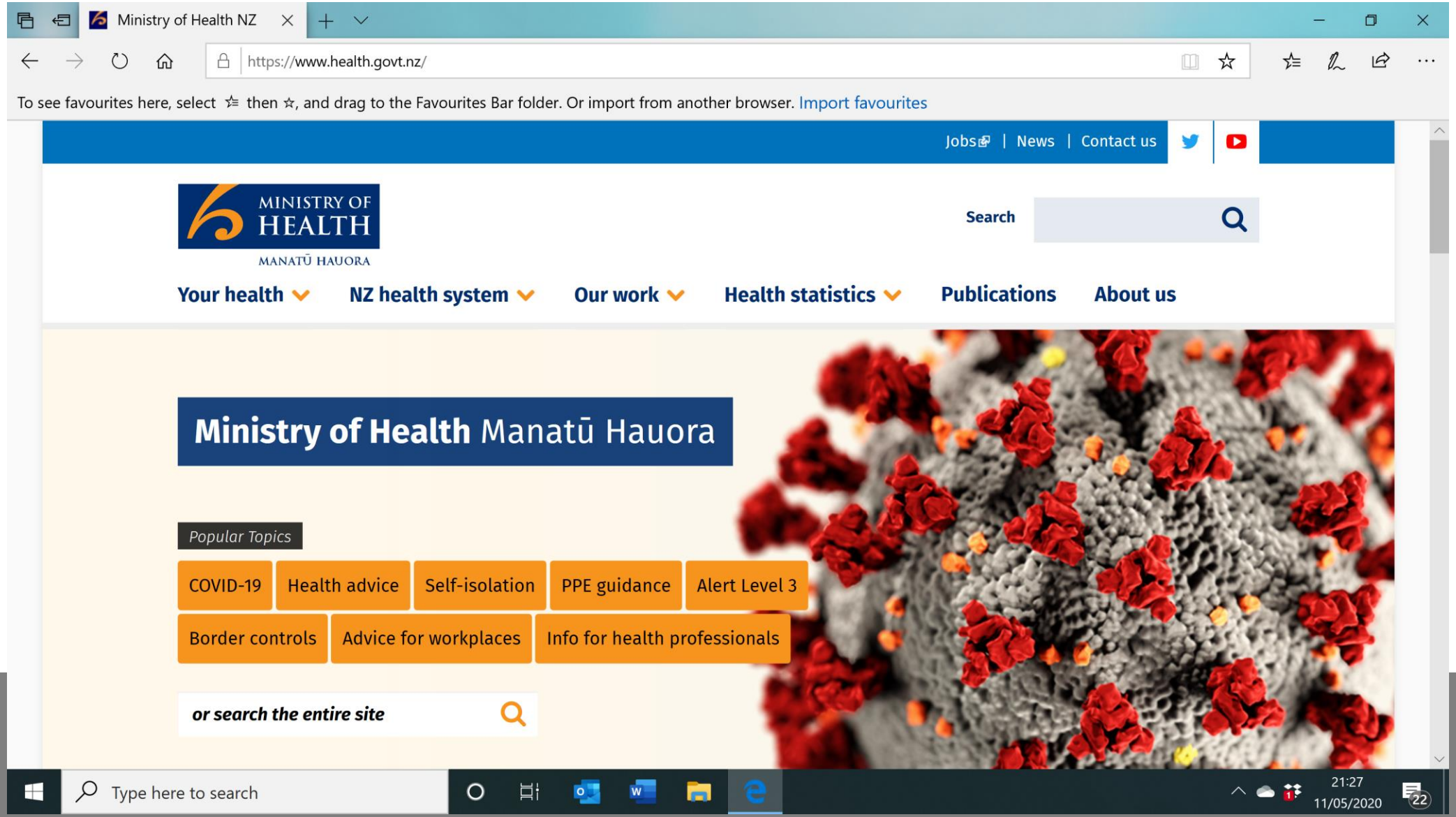
Growth in the UK over time (www.bcig.org.uk)…. Steady growth to support capacity development 12,290 implanted



Times are changing fast with a new challenge:

- Me 2 March in Tallin with Epp Muil the parent of first child 20years ago….
- No social distancing…
- Coronovirus??
- A whole new language for society to learn…
- PPE, Social distancing, Lockdown
- A new way of life…

Covid19 NZ Ministry of Health home page – the topic is…



New world AND new language:THE SCIENCE/POLICY GAP

- We are learning public health language
- *"Scientists struggle to explain to ministers and politicians" "blank looks."*
- *Prof Graham Medley, modelling advisor for UK govt*

- For example: **Lockdown** – where did that come from? It's now a global term..
- Non –pharmaceutical interventions
- Behavioural and social interventions

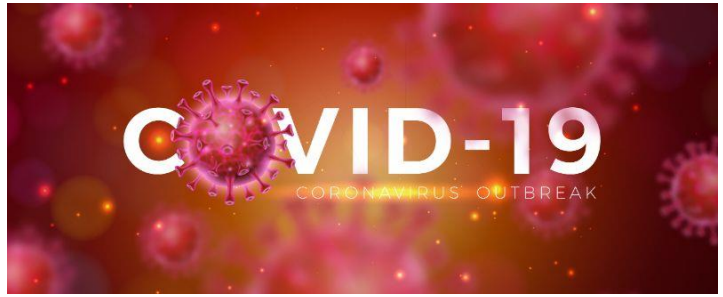
–LOCKDOWN

User and advocacy groups at work in the pandemic

- Updated report on the impact… from EUROCIU
- (rep 27 countries) www.eurociu.eu
- American CI Alliance: CI conference on line….
- https://www.acialliance.org/
- Nordic group
- UK advocacy organisations
- Sharing resources on line , Advocating for telehealth

EUROCIU
EUROPEAN ASSOCIATION OF COCHLEAR IMPLANT USERS a.s.b.l.

Cochlear Implant Users Demand Improved Accessibility to Communication during the Pandemic



Common issues of the impact of the pandemic globally for CI

- CI centres ceasing operating leading to increased waiting lists for both children and adults
- Programming, rehabilitation, upgrades stopped or slowed ……
- Lack of support for CI users and those waiting for longer periods
- Budgets for CI industry and for public health and CI centres hit
- Misinformation: eg being more at risk of COVID19 because wearing CI?
- Suitable masks (they obscure face, and speech) and use of PPE
- Communication in emergency medical situation

New Zealand in lockdown… and coming out..

PINDROP WEBINAR, MAY 2020

Looking ahead… and you are further on than us!

- Managing and funding any back log
- Implementing services with social distancing and safely
- Increasing financial pressures on health care services managing COVID19: conflicts with more money for CI
- Pressing forward with increasing access in a time of changed practice, budget constraints on health care services
- How can we do this in the long term…

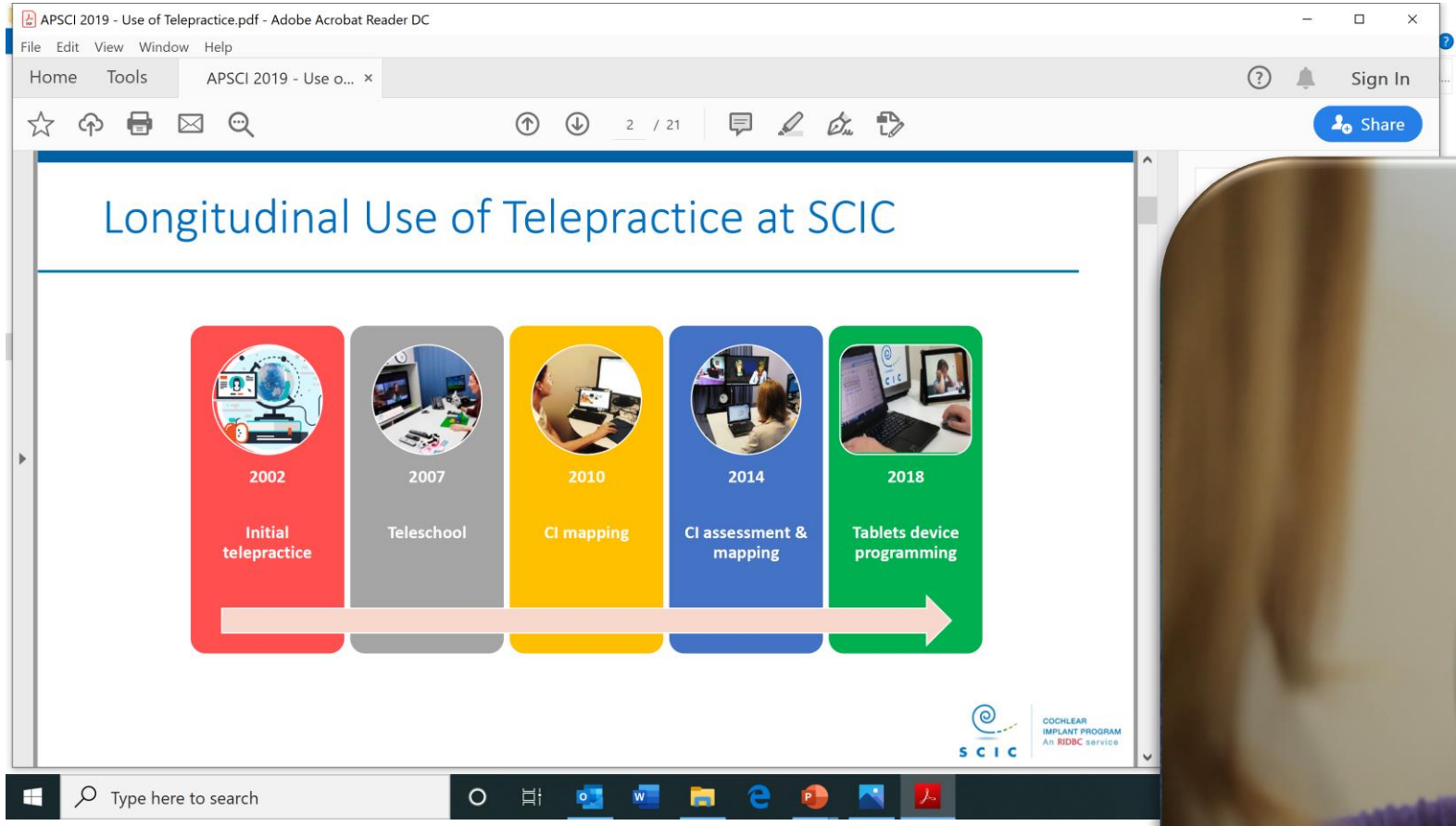
Positive impact of the Pandemic…. for CI services

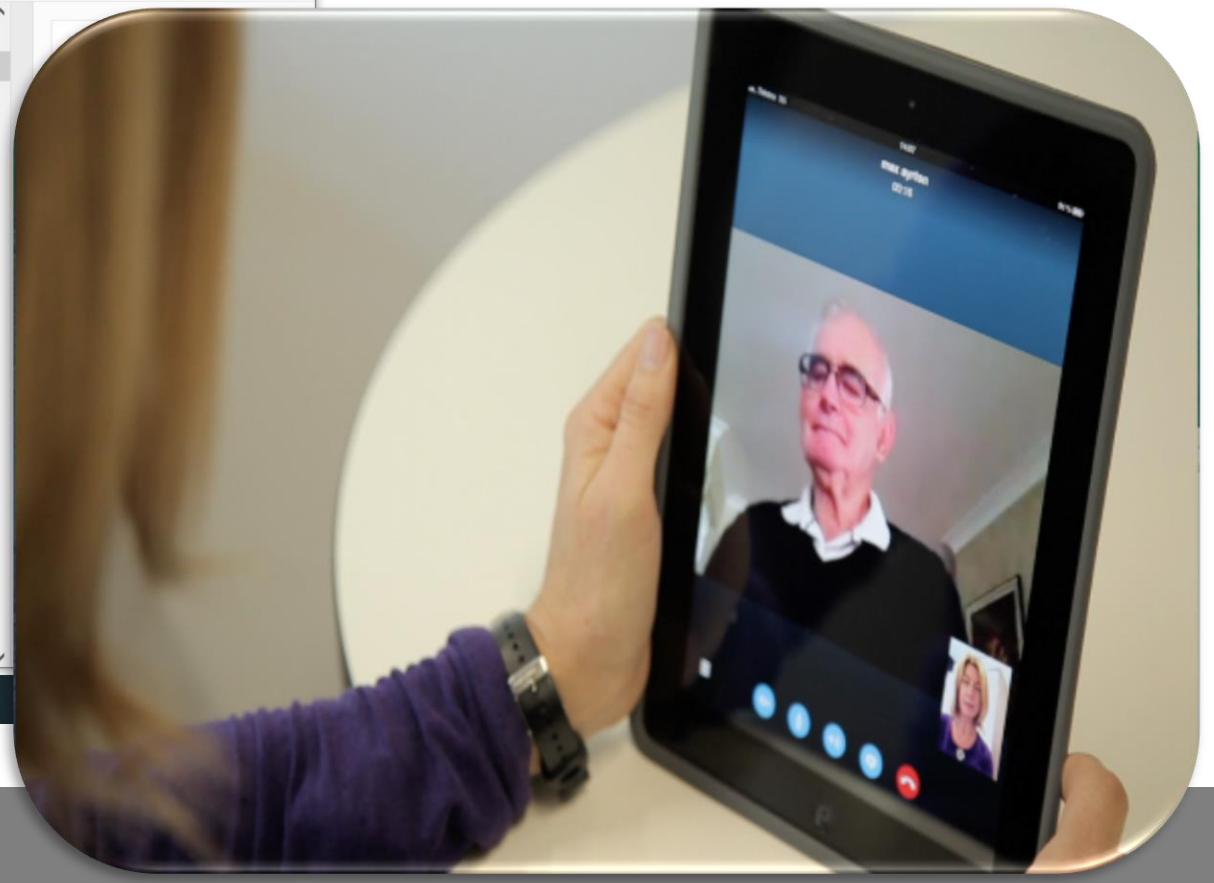
- We have better understanding of public health language
- Greater awareness of the importance of communication and need for mental and social care
- From NZ Ministry of Health: *"Care and support workers and providers will get a clear signal that the funding is there for the long-term"*
- We have greater confident use of technology
- Greater awareness of the potential of on-line services of all kinds
- (Zoom, Skype, Facetime, Whatsapp, Microsoft Teams, etc…..)
- **Learnt new ways of working**

Social distancing and working safely…..
We have some answers for these public health issues

- Growing use of Telehealth: Remote care and technology is available
- Growing use of remote rehabitilation and services in New Zealand
- In Australia – Cathy Birman in Sydney at SCIC
- Helen Cullington in the UK at South of England CI service with CHOICE

Thanks to Cathy Birman, SCIC, their remote service

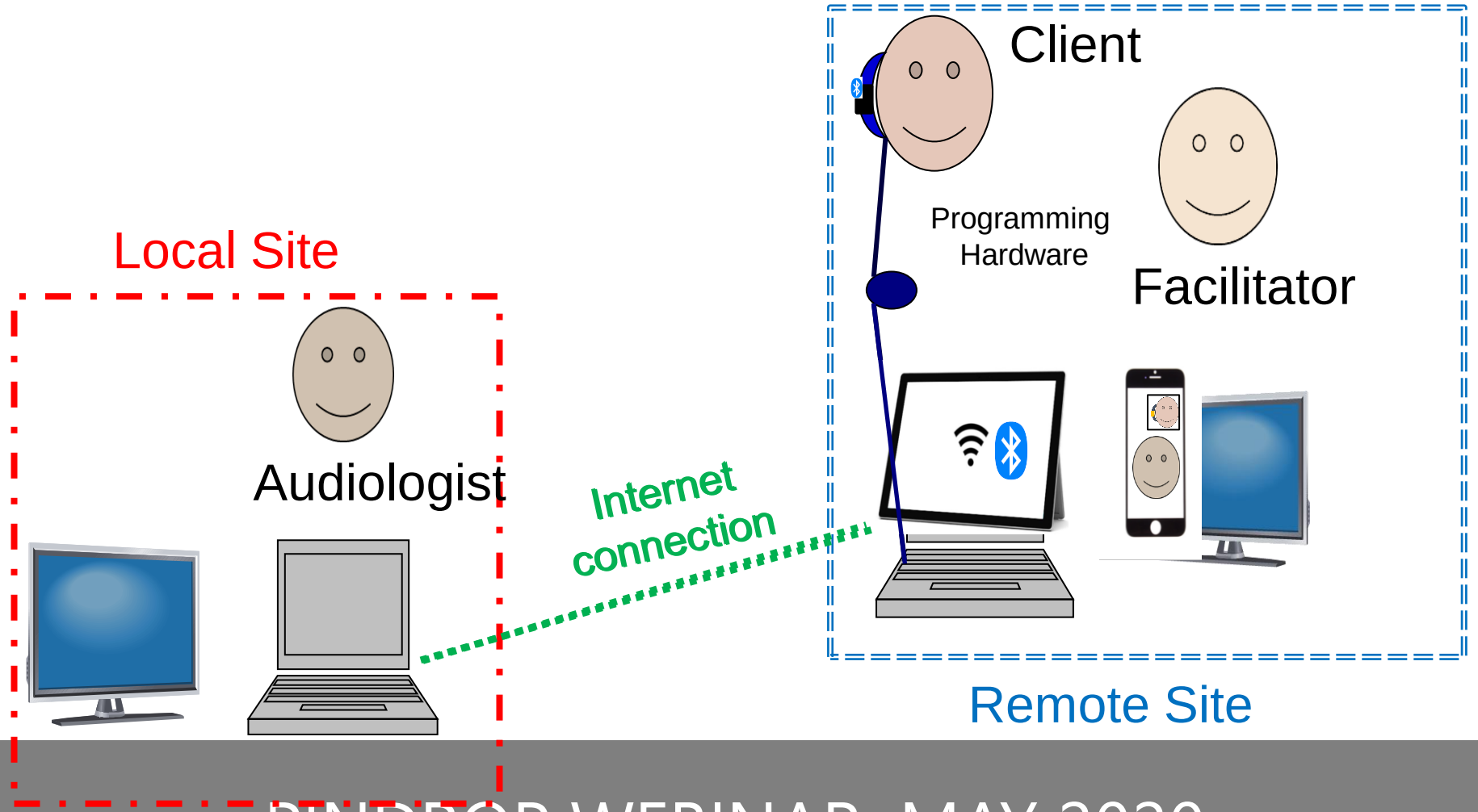




The Wireless Programming Kit – Mapping Cochlear Implants

- Wireless pod + tablet computer + instructions couriered to family
- Tablet contains - Skype/Polycom (video conference), Teamviewer (allows control by remote computer) and Custom Sound/NFS loaded with client's mapping file
- Kit returned to clinic, CDX uploaded to database, troubleshooting

Remote Mapping Components



Telehealth in action –CHOICE in the UK (Helen Cullington, South of England CI Centre)

CHOICE gives patients CHOICE

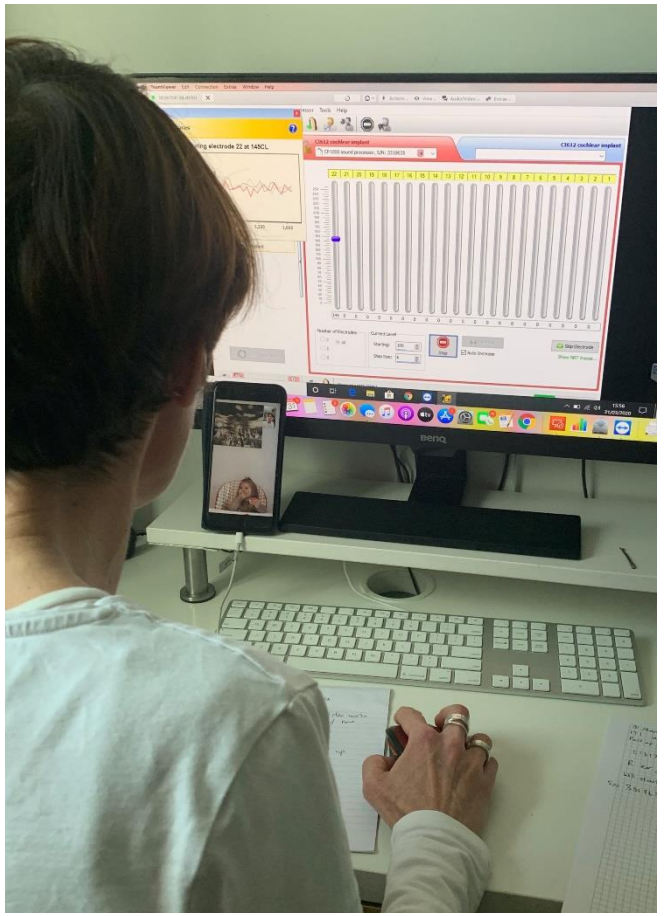
Used in 7 CI centres in the UK

People like it

“exciting to be testing one’s hearing and even a little programming at home..”

Growing numbers now…

Research evidence



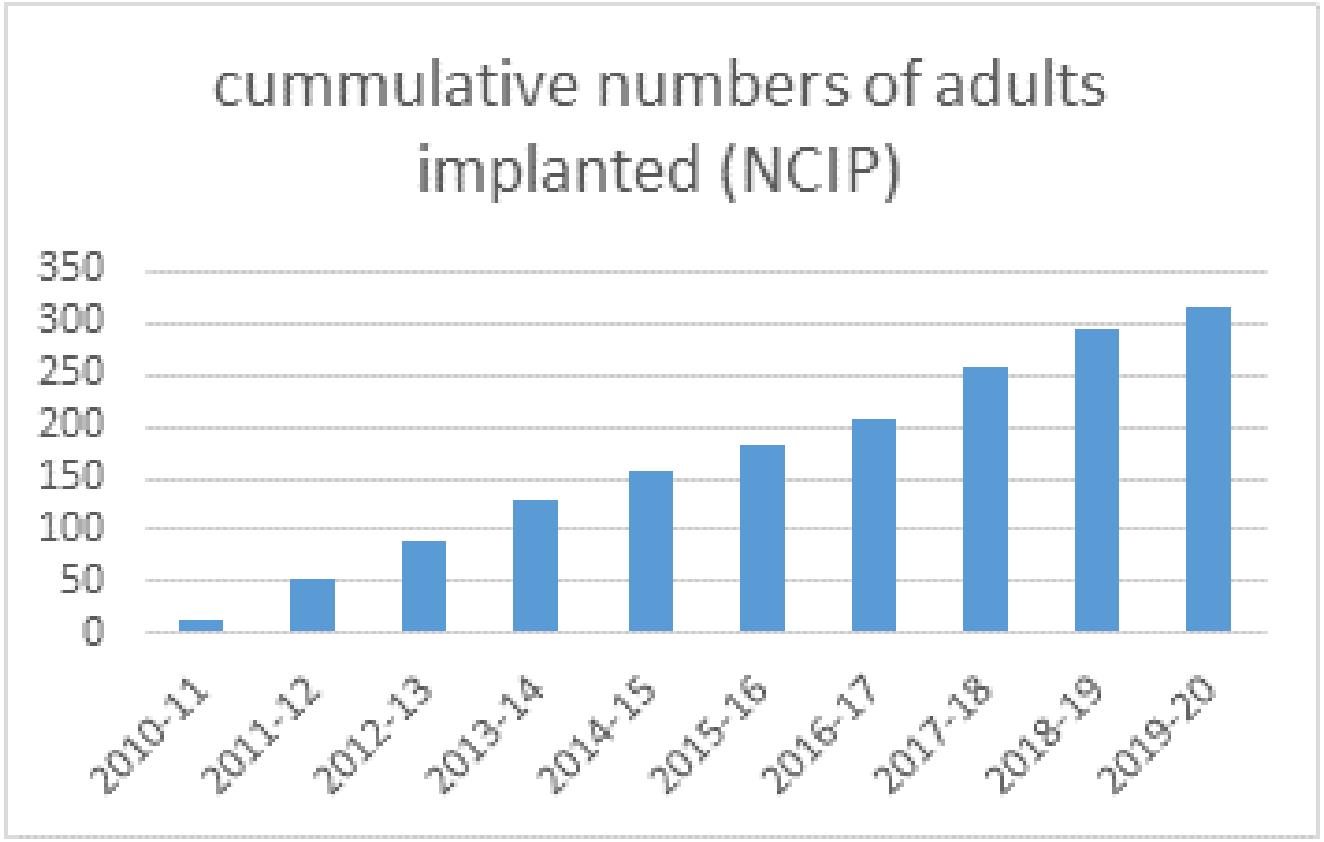
PINDROP'S Development of consumer advocacy

- consumer groups
- participate in publicity
- lobby electorate MPs
- Health Select Committee
- petition (11,000 signatures)
- party political conferences
- participate in seminars
- advocacy training workshops

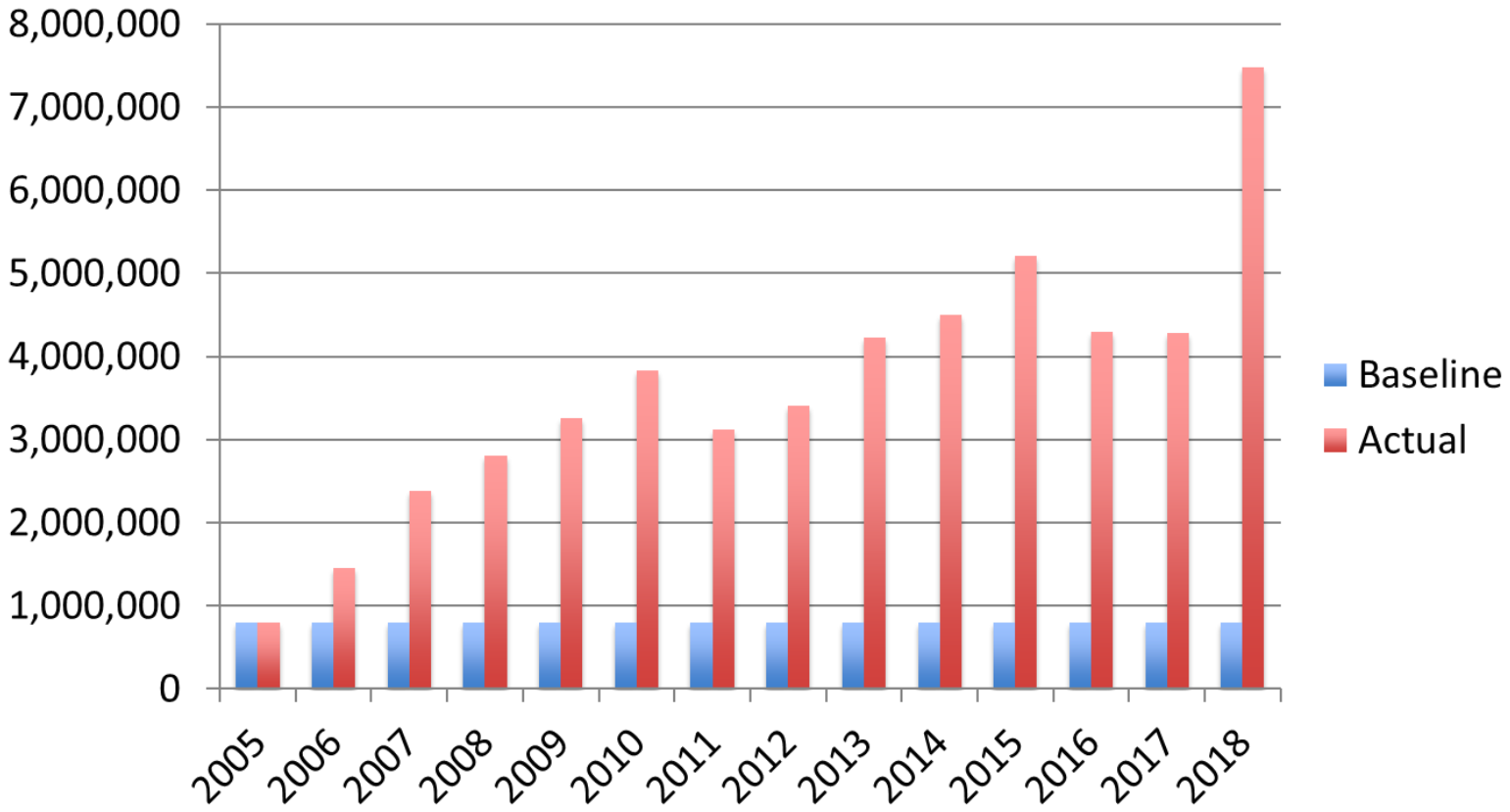
New Zealand access to cochlear implants….

- 880,350 people with HL (18.9%) (one in six)
- 40 adults a year are funded to get implants in the baseline
- But….
- Two hundred people a year meet the criteria for the surgery annually
- Waiting lists growing – these sums don’t add up..

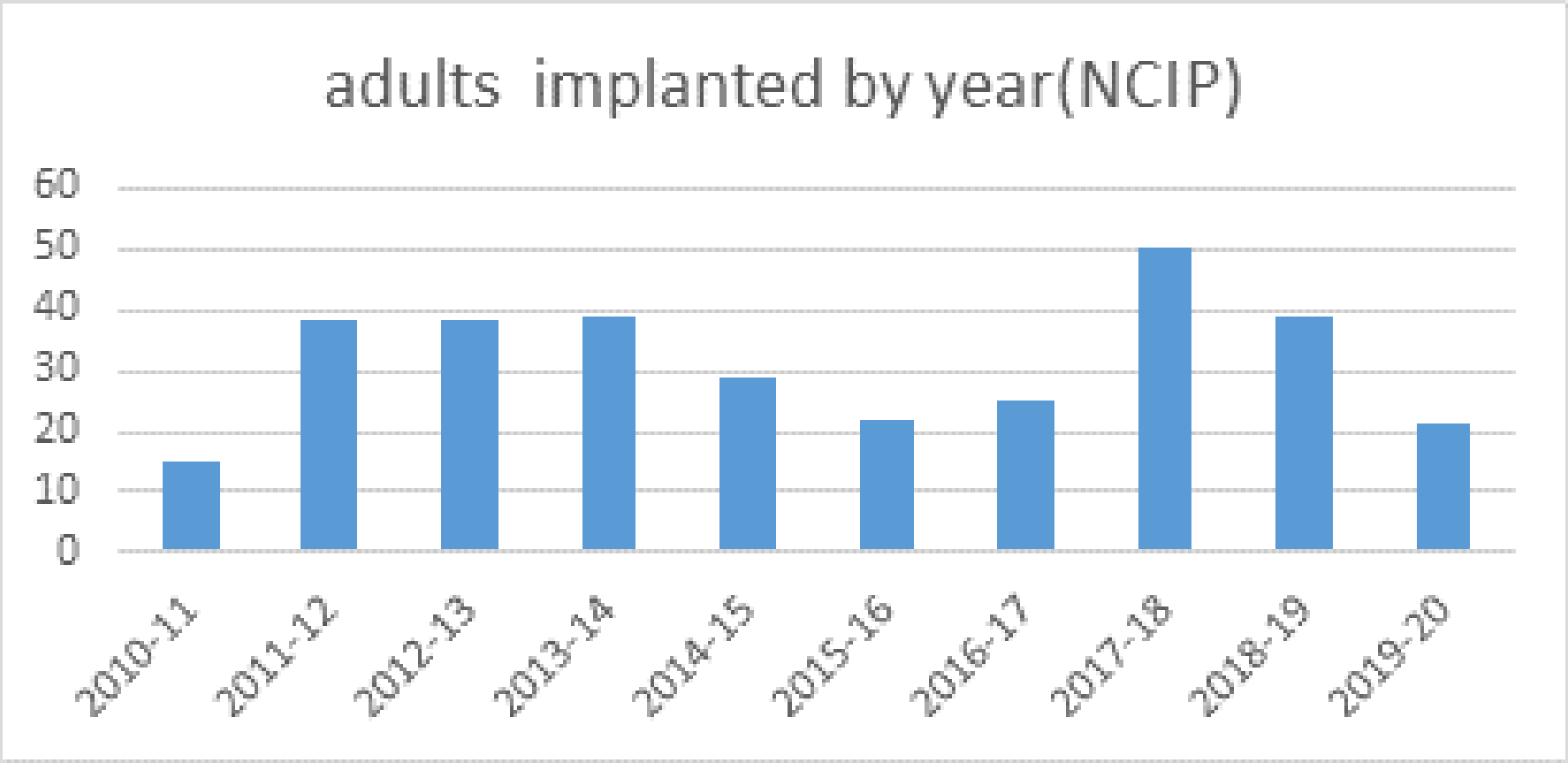
Cumulative numbers of adults implanted (NCIP) (thanks to Ellen Giles)



Funding of CI in New Zealand over time…this is NCIT……in 2019, a drop in funding



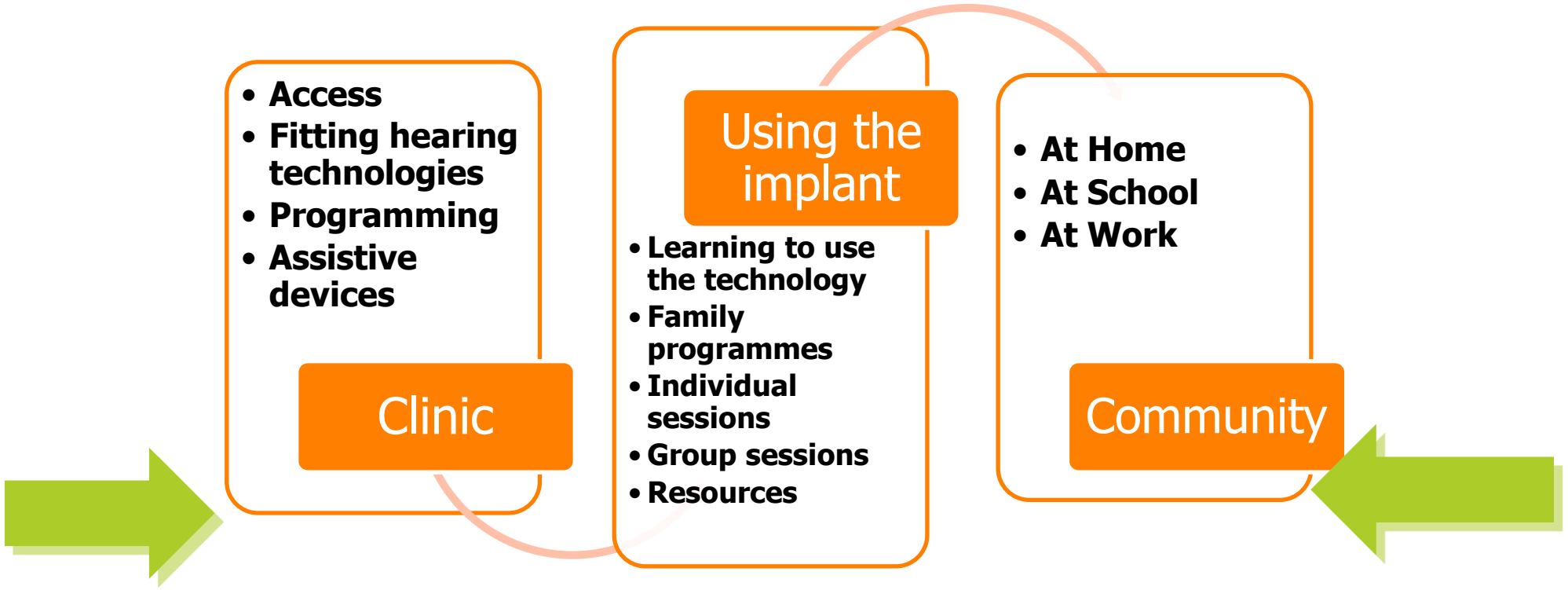
Adults implanted by year (NCIP) thanks to Ellen Giles



Role of user groups at this time? Influencing public health care and decisions…

- Mutual support and practical support
- Demanding up-to-date information - not misinformation: captioning, signing
- Working with ci teams towards sustainable life-long services
- Making case for sustainable funding not one offs…
- Gathering clear data see www.bcig.org.uk as example
- User and advocacy groups may be the best people to convince public health decision makers… combine the story and the evidence..
- And to ensure long-term services : its not just about access

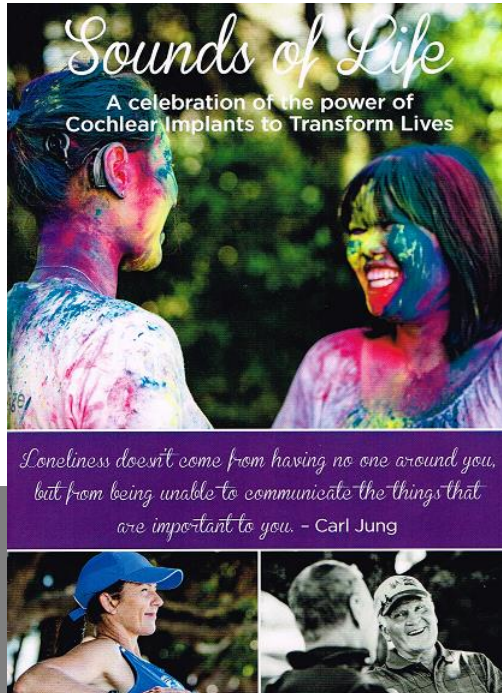
While thinking about improving access to CI … don't forget…making the technology work in the community…for a lifetime



Don't forget the longterm management and its funding

BUT: THE DIGITAL DIVIDE…

- With increased reliance on technology for services, communication, education
- The digital divide is growing…
- What about those without access to technology or without the skills
- And it's not just an age thing! The silver surfers
- We need to empower people not disempower them
- Put the user in the driving seat- literally!!
  - Drive through service programming…
  - Click and collect repair services

Circumstances change…but he (she) doesn't (Machievelli)

- The pandemic has meant we are now all more involved in public health issues
- People have understood more about value of communication
- Greater awareness of isolation and mental health issues
- We have grown to understand the public health language and messages
- We have been hearing it for several months
- Now we can get re-energise our message about Adult CI
- Our global world has changed…
- but the case for CI is stronger than ever.