



Robert Mandara

Person Centred Care: Concept V Reality

- Robert was born with hereditary sensorineural deafness, wearing hearing aids before receiving bilateral implants in 2014 and 2016.
- He lives in Finland, working with the Finnish Hard of Hearing Association, is 1st Vice-President of EURO-CIU, the European association of CI users and on CIICA's Communication Group.
- And he always finds a new way of looking at things!



EU
RO CIU

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

Person Centred Care Concept versus Reality

Robert Mandara

EURO-CIU 1st Vice-President



Please note!

I use “clinic” and “clinician” to mean anyone who provides a service to CI users.

Ford Sierra dashboard - design brief.

SIERRA



“Make the driver feel important”
A great concept...

Where are we now?

- **Enthusiastic?**
- **Committed?**

There's no gain without pain.

Is your clinic, region or service already focussed on person centred care?

- ✓ 1. Bilateral implants for adults?
- ✓ 2. Zero age discrimination?
- ✓ 3. Appointments based on patient needs?
- ✓ 4. Relatives of CI candidates involved?
- ✓ 5. 24/7 technical support?
- ✓ 6. Contact with 90-95% of candidates without CI?
- ✓ 7. Person centred care before profit?

Danger of increased tethering



- **CI users must be free to move around, without fearing for their hearing.**
- **Best practices must be adopted globally.**
- **PCC is a global issue, not a local one.**



Who is the judge of person centred care?

- **CI users must be able to judge for themselves.**
- **Clinics must not self-assess on CI users' behalf.**
- **Clinicians only see the tip of the iceberg, not the considerable and cumulative frustration bubbling below the surface.**



How will we measure PCC?

- CI users must be surveyed and asked for feedback.
- Feedback must be taken seriously and acted upon. Changes must be communicated to CI users.
- Audiadvisor[®] application?



What's the solution?

- **CI user view front and centre, not clinic view.**
- **Consider whether PCC decisions are serving CI users or clinics.**
- **If you cannot solve a problem, who can or should?**
- **Recognise that patients are unique, with unique requirements. Flexibility is key!**

Concept versus reality!



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