

## **APPENDIX 1:**

### **Semi-structured interview schedule with professional stakeholders**

There is a European and UK drive to establish registries for all surgical implants including for surgically implanted hearing devices. These auditory implants include Bone Conduction Hearing Devices and Cochlear Implants. The current initiatives to collect hearing data on these implants are fragmented and incomplete. In the absence of a national registry of auditory implants it is difficult to regulate the provision of auditory implants and monitor their clinical and cost-effectiveness.

Establishing a registry faces several challenges. We are conducting a series of interviews with professionals and patients through which we can explore the requirements for establishing a successful national registry of auditory implants. You have been identified as an expert on this topic and we would like to schedule a 15-minute telephone interview with you to gain your input. Results will be discussed at a future consensus conference to inform the development of a national registry of auditory implants.

#### **Who we are?**

eidENT is a research team based at the Ear Institute at University College London (UCL). We are dedicated to developing the best research to test and evaluate new and current treatments in ENT hearing and balance.

I am an ENT Academic Clinical Fellow and NICE Scholar

#### **Opening questions**

Please introduce yourselves including your relevant experience/expertise.

1. What are your thoughts on the existing auditory implant registries available? – what are their gaps/problems
  - a. National registry for Bone Conduction Hearing Implants (Ear foundation)

- b. National Paediatric Bilateral Cochlear Implant Audit
  - c. Cochlear paediatric implanted recipient observational study (Cochlear™ P-IROS).
2. Do you think a national registry of auditory implants will be of benefit/do you think registries are beneficial - if so why?
  3. What do you think the main purpose or goal of the registry should be?
    - a. For example: Improve patient care, monitoring interventions, drive research etc.
  4. How should the registry be led/who should make the decisions?
    - a. Should patients be involved in registry leadership?
  5. How should the registry be managed and maintained?
    - a. In terms of the day-to-day functioning.
    - b. Ensuring data is being collected and checking accuracy.
  6. Broadly speaking, what do you think should be included in the dataset
    - a. Should we collect quality of life data and please explain your answer?
  7. What do you think are the main challenges/barriers of establishing such a registry?
  8. How can we overcome these challenges and increase registry participation/ buy-in?
  9. Should patients be involved in the registry and if so how?
    - a. How should patients be involved (for example leadership/steering committee; registry design; registry management; registry reports/publications?
    - b. Should patients be able to access their own data and input their own data? Please explain your answer.
  10. Who should own the data of the registry?

11. How should we fund the registry, taking into account costs for initial set-up and long term maintenance?
  - a. Should government pay?
  - b. Should Industry pay?
  - c. Should contributing hospital pay?
  - d. Should professional societies pay (ENT UK)?
  - e. Should we try and get funding from patient charities?
  - f. Should private individuals/organisations pay when requesting information?
  
12. Should we publish data on specific surgeons and hospitals?
  
13. Overall what do you think are the key factors for making a registry successful?

Is there anything else you would like to discuss about a national registry of auditory implants that we haven't already covered so far?