

## **APPENDIX 2:**

### **Focus groups interview schedule**

#### **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.

#### **Introduction**

There is growing interest in the development of a national UK registry of patients that have surgically implanted hearing devices. These devices include Cochlear Implants and Bone Conduction Hearing Implants that work to improve peoples' hearing. A registry is a collection of specific information about a treatment. Registries have been used in other surgical specialties to collect information on who has received treatment, which treatments are best, how patients are faring, if there are any safety concerns and so on.

We are running small discussion groups with patients and their family members to gather opinions and ideas on how to develop this registry. In parallel we have also discussed this with hearing loss professionals. The questions we are asking are based on a review of all the information known on developing surgical registries.

This is an opportunity for you to help shape this future national registry.

#### **Opening questions**

Introduce yourselves and tell us a bit about your hearing loss

#### **Main questions**

1. From what we've said, what are your thoughts on developing a registry of patients that have surgically implanted hearing devices.

- a. What are the potential benefits for patients of the registry and why?
  - b. What are the potential risks/problems of developing a registry and why?
2. How do you think patients could be involved in developing, leading or managing such a registry?
- For example: being involved in setting the aims and direction of the registry, being involved in deciding what information to collection, allocating resources within the registry, being involved in writing the reports.
3. What type of information do you think should be recorded in the registry?
- a. Do you want information about changes in peoples' quality of life to be collected?
4. Would you want to be able to access and add your own information into the registry?
- a. What kind of information would you like to access/add?
  - b. How would you like to access the information?
5. How can we help get patients to input their data and be involved in the registry?
6. Would you like the registry to contain information on results of named surgeons or hospitals? For example a named consultant's/hospital's complication rates following cochlear implantation.
7. How do you think the data should be protected and kept confidential?
- a. Who should be allowed to access your data?
8. Do you have any ideas on who should own the data of the registry?
- a. For example some registries are owned by their professional body. Others are owned by the government, hospitals, private industry, charities.
9. Registries are expensive to set up and maintain. How should the registry be paid for?

- a. For example: The government, hospitals, private industry, professional organisations in ENT.

10. If you could choose the one thing that's most important to be included/thought about for the registry – what would it be?

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