3.2 Appendix 3

GIG CYMRU NHS WALES

Pwyllgor Gwasanaethau Iechyd Arbenigol Cymru (PGIAC)

Welsh Health Specialised Services Committee (WHSSC)

The Future of Specialist Hearing Implant Device Services in South Wales Questionnaire

We are seeking the views of patients and other members of the public about how specialist hearing implant device services, such as Cochlear Implants and Bone Conducting Hearing Implant (BCHI) are delivered in South Wales. Your contribution to this is valuable, and helps us shape future discussions. If easier for you, you can complete this questionnaire on-line (at https://forms.office.com/r/s8bSYTaU5K)

Please tick one circle for each question.

Section 1: Please tell us about yourself

1. Are you responding on behalf of a group/organisation or as an individual?

○ **Group/Organisation (please state which group or organisation and move to question 7)**

Audiology Standing Specialist Advisory Group / Audiology Heads of Service Group

○ Individual

2. What is your age?

○ Under 16
○ 16 - 18
○ 19 - 49

- ○ 50 – 69
- ○ 70+
- ○ Prefer not to say

3. What is your gender?

- ○ Female
- ○ Male
- ○ Non-binary
- ○ Prefer not to say

4. How would you describe your national identity?

- ○ Welsh
- ○ English
- ○ Scottish
- ○ Northern Irish
- ○ British
- ○ Other
- ○ Prefer not to say

5. How would you describe your ethnic group?

- ○ White
- ○ Mixed or multiple ethnic groups
- ○ Asian, Asian Welsh, Asian British
- ○ Black, Black Welsh, Black British, Caribbean or African
- ○ Other
- ○ Prefer not to say

6. Please tell us the first four characters of your postcode. (This helps us learn where the answers have come from)

7. Which Health Board area do you come under?

- ○ Aneurin Bevan University Health Board
- ○ Betsi Cadwaladr University Health Board
- ○ Cardiff & Vale University Health Board
- ○ Cwm Taf Morgannwg University Health Board
- ○ Hywel Dda University Health Board
- ○ Powys Teaching Health Board
- ○ Swansea Bay University Health Board
- ○ NHS England
- ○ Other

Section 2: About the Service

8. As a result of reading this information:

- ○ I have a better understanding of how Cochlear Implant and BCHI services are currently organised
- ○ I have no understanding of how Cochlear Implant and BCHI services are currently organised
- ○ **My understanding of how services are currently organised is the same:**

9. As a result of reading this information:

- ○ I have a better understanding of the issues facing the service
- ○ I have no understanding of the issues facing the service
- ○ **My understanding of the issues is the same**

Do you have any comments about the issues facing the service?

The paper does not reflect the significant workforce issues and challenges faced by the Cardiff Cochlear implant service as a result of the Bridgend service being suspended since August, 2019 (due to workforce fragility issues). We understand that funding is still being allocated to CTM for staffing despite only one member of staff from Bridgend working on the CI programme on a part time basis.

The Cardiff and Vale UHB (C&V UHB) Audiology service do not currently have the required estate to see all patients for cochlear implant and BCHI assessments, as

there needs to be a sufficient number of large sound proofed room facilities. This situation has impacted on the current service to patients delivered by C&V UHB. The cochlear implant service issues remain unresolved and the addition of BCHI into the engagement has increased the delay of any decision around funding for the CI service at C&V UHB. As a result of unresolved workforce issues, the service at C&V UHB is now vulnerable due to staff sickness and stress. There now needs to be a clear plan around workforce and accommodation. Failing this, it is highly likely that there will be a subsequent collapse of the C&V implant service.

1) Minimum numbers for BCHI

   a) Section 6 states that 'guidance on standards for bone conduction hearing aids require centres to perform at least 15 procedures per year'. Although the paper then references the commissioning policy from which this minimum number has been quoted with a bookmark, the reference to standards is misleading.

   b) The minimum number quoted in the English commissioning policy has been obtained from professional consensus reached in 1998. It is not clear therefore that this is relevant to services today given the policy, technology and workforce changes that have occurred in the last 24 years.

   c) The commissioning policy referred to in the engagement paper is not the latest version of this policy and appears to have been superseded by NHS England 16041/P (england.nhs.uk) which does not refer to minimum numbers and does reference a more contemporary clinical consensus on standards again with no reference to minimum numbers.

2) The paper does not explain what outcomes are not being met by the current service structure i.e. what requires change and improvement.

3) The paper describes that an implant MDT needs to provide all types of implants. This is not true. CI services need to offer all implants, but the bone conduction commissioning document does not state that BCHI centres have to offer any other devices. This statement in the engagement paper is presumably based on the assumption that the MDT must be a joint CI/BCHI MDT. There are no standards or recommendations for this model, and this is not the model found in most BCHI centres in the UK. The most recent Clinical Commissioning Policy, NHS England 16041/P does not reference a joint MDT but only requires that the MDT must consider which implant is the most suitable for each patient which can be achieved without a single MDT for all implantable devices.

4) In the referenced Clinical Commissioning Policy, section 7 (Epidemiology & Needs assessment) it states that 8-10 BCHI per population of 300,000 is the estimated activity in England and this would translate to in the region of 100 BCHI per year in Wales; of which 75% would be in South Wales. This suggests that there is a large unmet need for this intervention in Wales which may present following removal of 'capped funding' for these devices. Based on meeting the recommended numbers of BCHI fittings there would be sufficient

numbers for multiple centres in South Wales to meet the minimum stated in the NHS England CCP.

ASSAG therefore concludes that the population is underserved, and the recommendation would be to reinforce existing services for BCHI and enable them to meet unmet demand and through agreed National pathways for referral. This would solve the problem of minimum numbers and safety without creating additional barriers for patients.

6) The paper states that a large number of patients would be required to adopt new technologies. Adoption of new technology could be adopted for example middle ear implants could be adopted at a centralised CI service without requiring BCHIs services to be centralised also. Separate BCHI services does not prevent the adoption of new BCHI technologies and so this is not considered to be a case for change.

7) The paper states that a centralised service would deliver an improved service comparable to other regional centres. This would suggest that the services are not currently comparable to those regional centres but does not specify what the differences are. It also makes an assumption that the existing regional services are better than any local services but there is no evidence in the paper for this assumption.

There is no reference related to the statement that procedures carried out at larger centres result in better outcomes.

10. Would you agree/disagree with the following aims for a future Cochlear Implant and Bone Conduction Hearing Implant service:

The service:

- can deliver a safe and sustainable hearing implant device service for the adult and children in South Wales
- has equitable access
- meets national standards
- has staff in the right place with the right specialist skills
- facilitates timely access to surgery

○ **Agree**
○ Disagree
○ Neither agree or disagree

We agree with the aims for the service however wish to make it clear that equitable access should include distance, travel and cost as well as waiting

times.
The paper mentions that some people may not have to travel as far as they do now. As it seems unlikely that any site other than Cardiff would be chosen for the centralised service, we are not aware of any circumstances under which travel to a centralised service would be reduced compared to the current situation

11. As a result of reading this information:

- ○ I have an understanding of the process that has been followed to arrive at the preferred option
- ○ I have no understanding of the process that has been followed to arrive at the preferred option
- ○ Not applicable

Do you have any comments about the process followed?

1) This question does allow for responders to have a partial understanding.

2) It is not clear in the engagement paper which external implantable device centre was chosen to complete the evaluation, what service model is delivered at that centre, why they were chosen or whether stakeholders in that region were also asked to contribute to the evaluation. Evaluation by a single centre could inadvertently have introduced bias into the evaluation. There are two models of bone anchored hearing aid delivery in England. One is single auditory implant centre of which there are 16 in England and the other is a standalone bone anchored hearing aid centre within an audiology centre of which there are over 100. What assurance is there that both models have been consulted?

3) The process does not seem to have considered the Welsh context in which services have run, specifically the current development of All Wales implantable device standards and the close working relationships of all centres in Wales.

4) There is some incorrect information in the engagement documents, which will affect the validity of this engagement process, specifically:

a) In the slide summary (slide 10 of the English version) it states that appointments before the hearing implant and after the hearing implant has been programmed and fitted will take place closer to home. This is factually incorrect for CI and may not be possible for BCIG depending on the outcome of the pathway design.

b) In most versions except the core document, eg slide 7 of the English slide summary, is the statement *British Cochlear Implant Group (BCIG) say that Consultants should undertake a minimum of 10 cochlear implants per surgeon, and that a centre should undertake a minimum of 15 BCHI per year. There are not enough patients to support this across multiple centres.* This is factually incorrect. ASSAG would be concerned that the significance of this statement to the case for change may make the engagement invalid.

12. **Please tell us what you think about the preferred option of a single implantable device hub for both children and adults with an outreach support model.**

- ○ I agree with the preferred option
- ○ **I disagree with the preferred option**
- ○ I have no particular view on the preferred option

Do you have any comments about the preferred option (i.e. why you agree/disagree)?

1) There is no option to partially agree with the preferred option

2) It is not possible to provide a final opinion of the preferred option without more information on the specific models being proposed. It is not clear in the engagement paper what the services will look like and the advantages and disadvantages of each model.

3) Cochlear Implants

   A single site for CI in South Wales would resolve the current and urgent issues facing the cochlear implant service. It would allow for sustainable workforce planning and the development of a full and specialist MDT within the service. Travel for some patients will unfortunately be increased compared to the two-centre model previously provided but this would be balanced by the ability to invest in the best staff, equipment, and facilities at a single centre.

   The other advantage of the CI team would be to assist in the robust and efficient management of the cost of this service. This also fits with the model being provided in England. Our view is that middle ear implants would generally fit within an auditory implant programme as per the English model rather than in a standalone centre.

4) For bone conduction implants the advantages of a single centre are less clear.

There is ample precedence of safe and effective standalone centres working within audiology services for bone anchored hearing aids in England with clear cross referral pathways to a tertiary implant centre where required. There are no standards requiring bone anchored hearing aids to be done in large regional sites or for services to be provided only in those providing other implantable hearing devices.

With regards to the creation of a single MDT the advantages of including bone conduction implant services in a single centre **may** provide additional staff resilience and promote the consideration of potential for middle ear implants however, there is no evidence that this is currently or foreseen to be an issue and it is not required in any recent policies or professional consensus. If bone conduction services remain standalone, then the recommendation would be for mitigations and safeguards such as joint MDTs for patients meeting the criteria for more than one type of device (likely to be very few) to ensure equitable access.

The disadvantages of a single centre are the increased travel and cost for patients which ASSAG do not feel are balanced by any advantages for patients requiring this type of device.

13. If the preferred option was progressed, what do you think the impact would be?

1) The impact of the preferred option for bone conduction hearing aid patients is of decreased access, particularly as the level of service to be provided in centres 'closer to home' is not defined in the paper.

2) The impact of the combined MDT which allows for all options to be offered to patients is not obvious as, patients who are candidates for bone conduction hearing aids are generally not candidates for cochlear implantation and vice versa. Robust cross referral pathways are the norm across multiple disciplines in the Welsh NHS.

3) The impact on quality and outcomes of a centralised service for BCHI's is not clear as the issues and required quality improvements required are not clear in these documents particularly as BCHI surgery is significantly less complex than that of cochlear implantation.

4) A move to one centre would require significant investment in facilities, for example large sound-proof clinical rooms, to avoid an ongoing detrimental impact on the core audiology service. This would require a significant capital investment. The need to provide for both CI and BCHI on a South Wales basis may impact on the site's ability to provide the facilities required for CI.

5) Removing the BCHI service from Swansea Bay UHB may have an impact on the South Wales microtia service, as the advice of surgeons with knowledge of BCHI placement and surgery is important in the management of Microtia.

ANNEX B – GLOSSARY OF TERMS

Term	Definition
Audiology	The branch of science and medicine concerned with the sense of hearing.
Specialist Audiologist	A Specialist Audiologist specialises in the diagnosis, analysis and treatment of human auditory disorders such as hearing, tinnitus and audio balance deficiencies.
Bone Conduction Hearing Implant	A Bone Conductor Hearing Implant (BCHI) is a hearing aid which uses bone conduction to help sound get to the inner ear. Note many people also call a BCHI a BAHA.
Clinical Child Psychologist for children	Clinical Child psychologists work with children by assessing, diagnosing and treating children and adolescents with psychological or developmental disorders, and they conduct academic and scientific research
Cochlear Implant System	A Cochlear Implant is an implanted electronic hearing device designed to produce useful hearing sensations to a person with severe to profound nerve deafness by electrically stimulating nerves inside the inner ear.
Hearing Therapist	A Hearing Therapist offers counselling to help with hearing difficulties
Multi-Disciplinary Team (MDT)	A Multi-disciplinary Team is a mixture of team of named healthcare professionals (eg Doctors, audiologists, nurses etc) who are responsible for discussing and arranging facilitating communication and coordinating care for patients.
National Institute for Health and Care Excellence (NICE)	National Institute of Clinical Excellence – sets standards and guidance for services
Paediatric Anaesthetist	Paediatric Anaesthetists are responsible for the general anaesthesia, sedation, and pain management needs of infants and children

Qualified Teacher of the Deaf (QTOD)	Qualified Teachers of the Deaf (also known as QToDs) are qualified teachers who provide support to D/deaf children, their parents and family and other professionals who are involved with a child's education.
Specialist Nurses	Specialist Nurses are dedicated to a particular area of nursing; caring for patients suffering from long-term conditions and diseases.
Specialist Radiologists	Specialise Radiologists are medical doctors that specialise in diagnosing and treating injuries and diseases using medical imaging (radiology) procedures (exams/tests) such as X-rays, computed tomography (CT), magnetic resonance imaging (MRI), nuclear medicine, positron emission tomography (PET) and ultrasound.
Speech and Language Therapist	A Speech and Language Therapist provides life- changing treatment, support and care for children and adults who have difficulties with communication, eating, drinking and swallowing.