Population hearing health: Getting it right from the start

Adrian Davis

The Millennium Development Goals Report 2013





Goal 4

Reduce child mortality

Quick facts

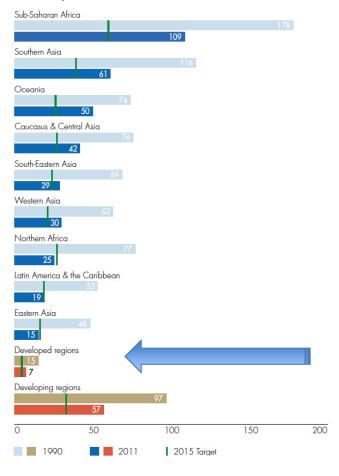
- ► Since 1990, the child mortality rate has dropped by 41 per cent; 14,000 fewer children are dying each day.
- ▶ Still, 6.9 million children under age five died in 2011—mostly from preventable diseases.
- ▶ In sub-Saharan Africa, one in nine children die before age five, more than 16 times the average for developed regions.

INIVALI TIA

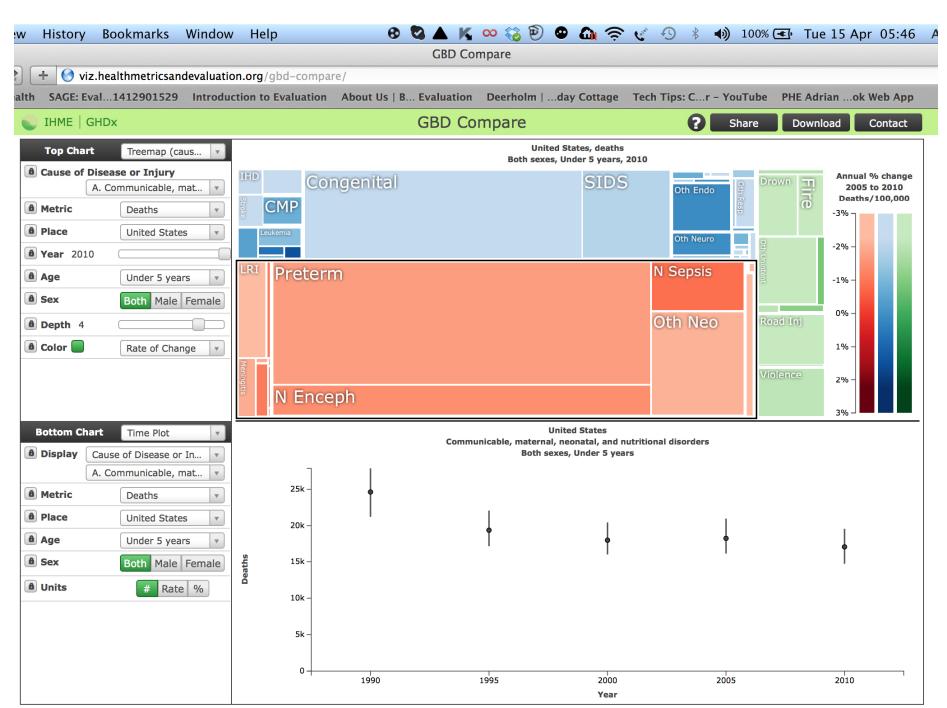
Reduce by two thirds, between 1990 and 2015, the under-five mortality rate

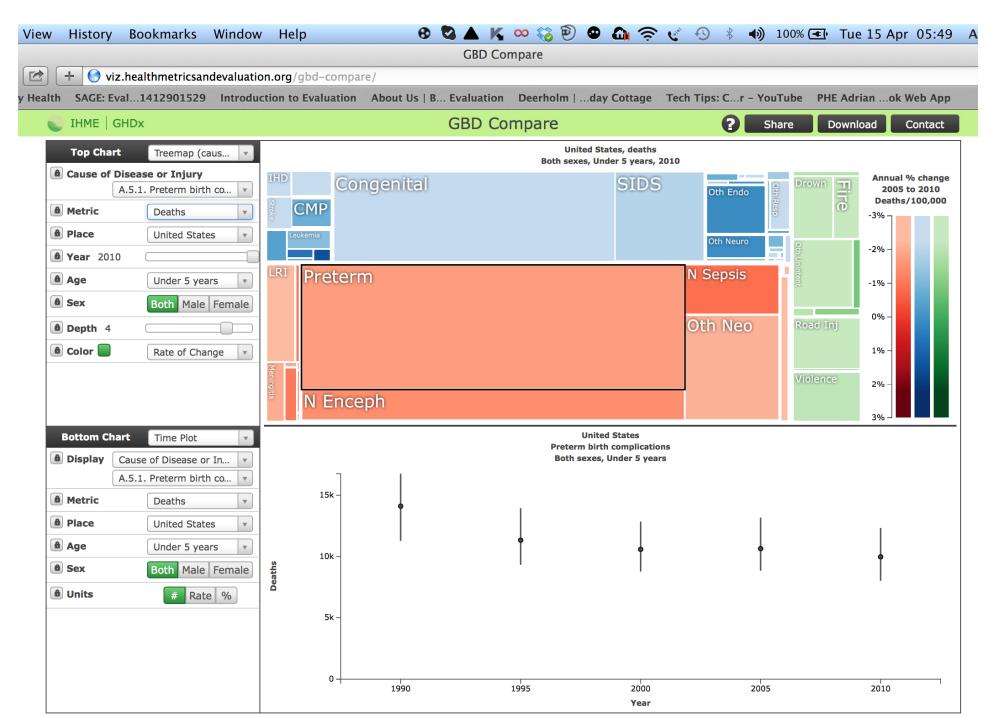
Big gains have been made in child survival, but efforts must be redoubled to meet the global target

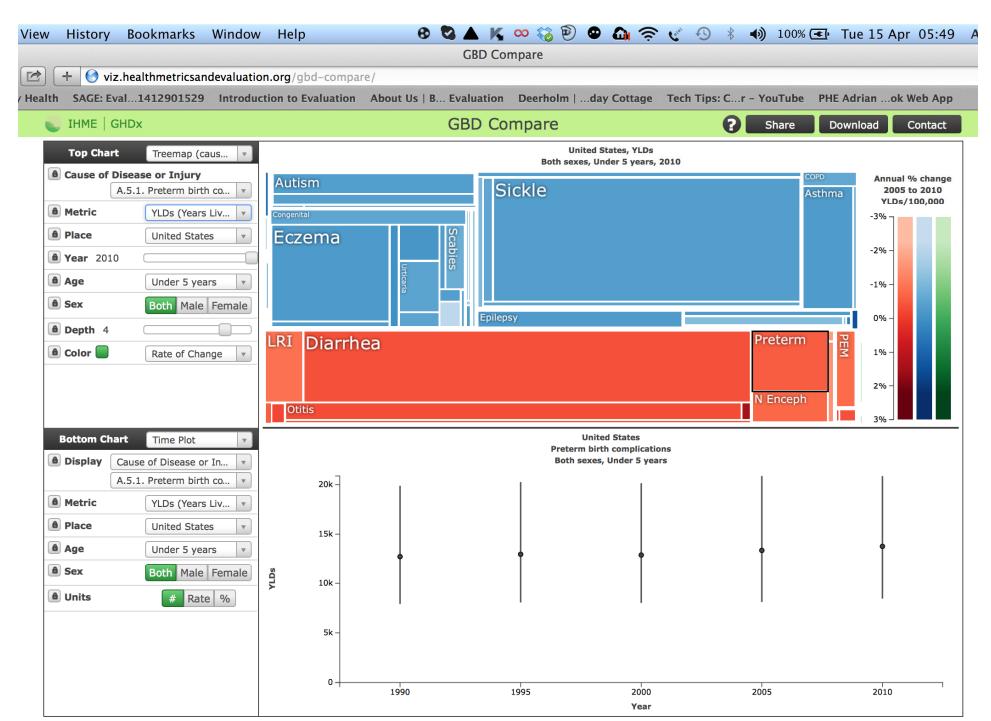
Under-five mortality rate, 1990 and 2011 (Deaths| per 1,000 live births)

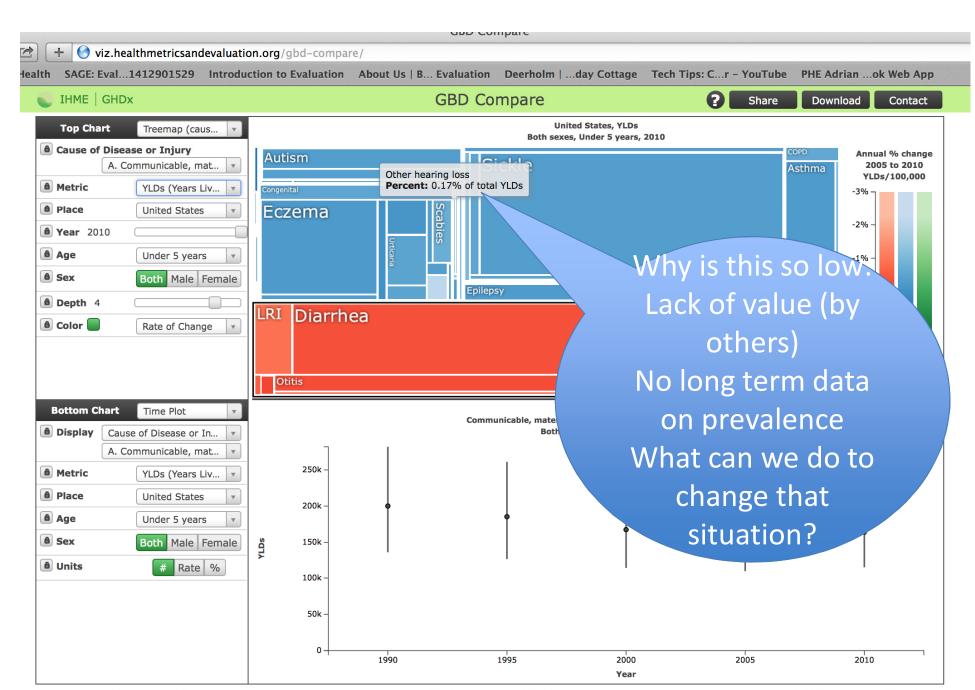


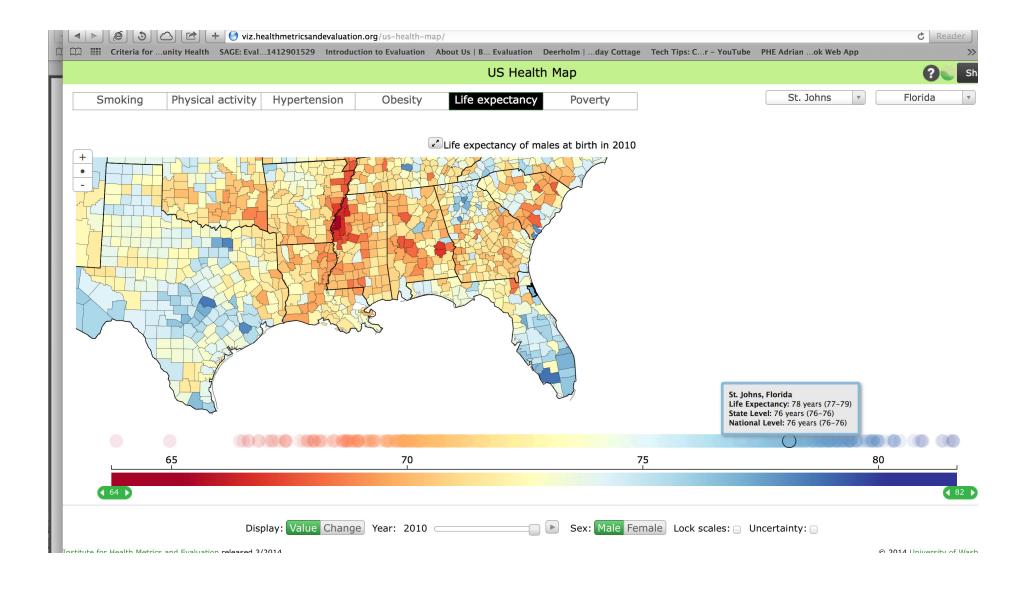
Worldwide, the mortality rate for children under five dropped by 41 per cent—from 87 deaths per 1,000 live births in 1990 to 51 in 2011. Despite this enormous accomplishment, more rapid progress is needed to meet the 2015 target of a two-





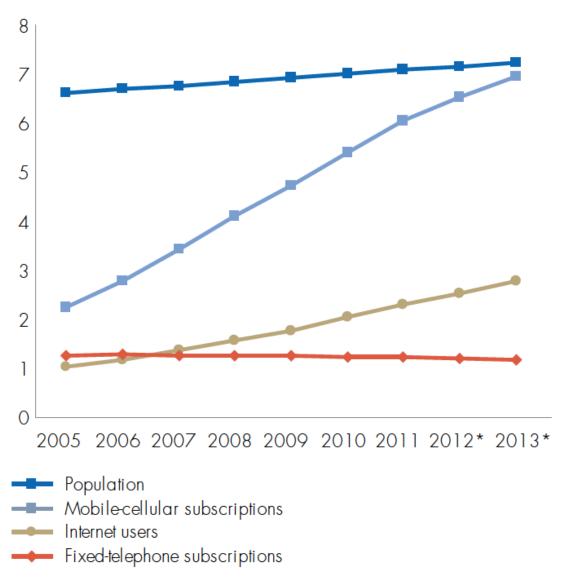






We need this map for hearing and especially for childrens hearing Both in terms of the register of cases and the services they get and outcomes too!

Estimated number of mobile-cellular subscriptions, Internet users and fixed-telephone subscriptions, 2005-2013 (Billions)



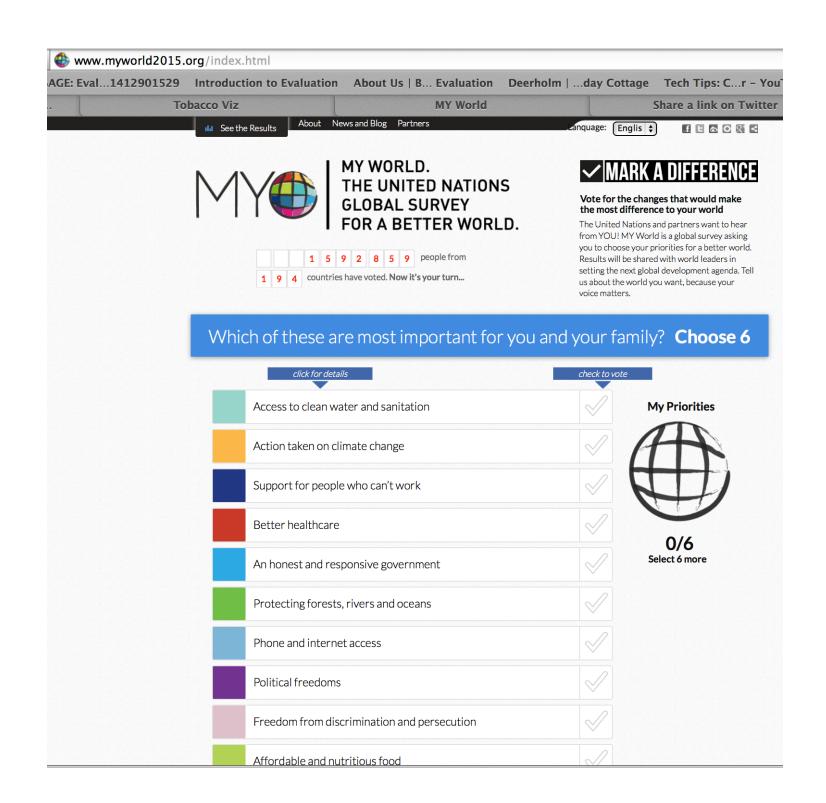
Gives opportunities:

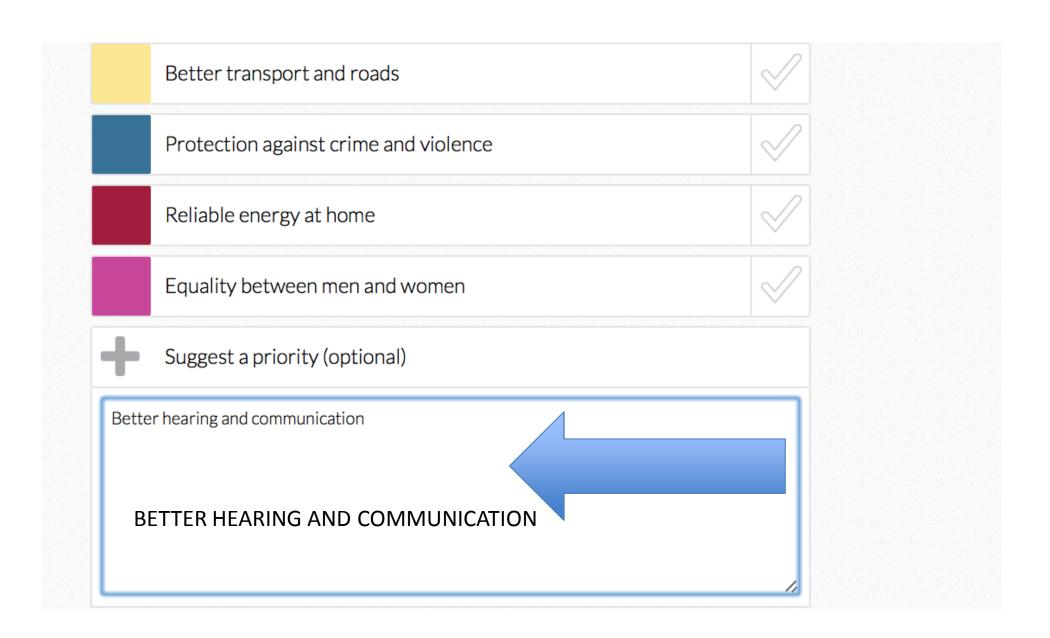
To explore use for Health improvement

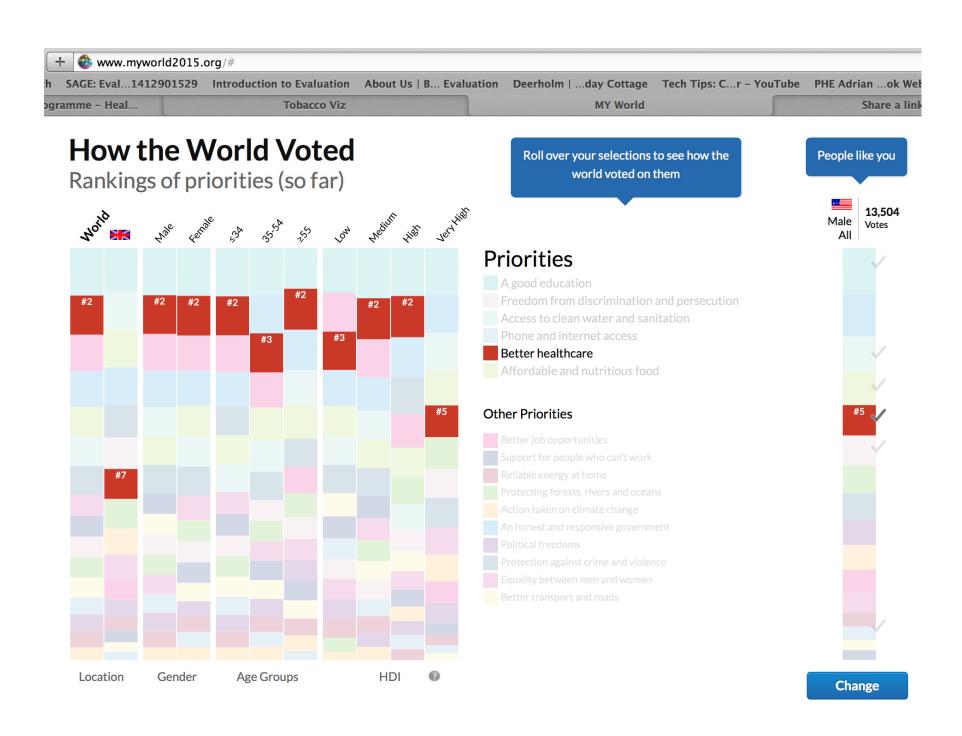
Loss to follow up

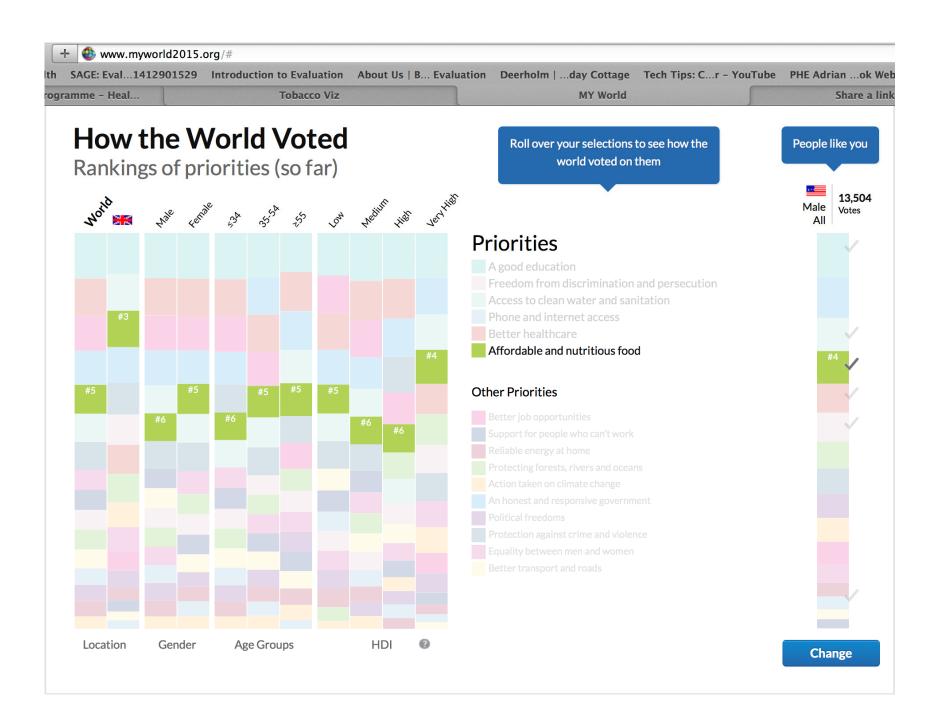
Support from E-hearing health

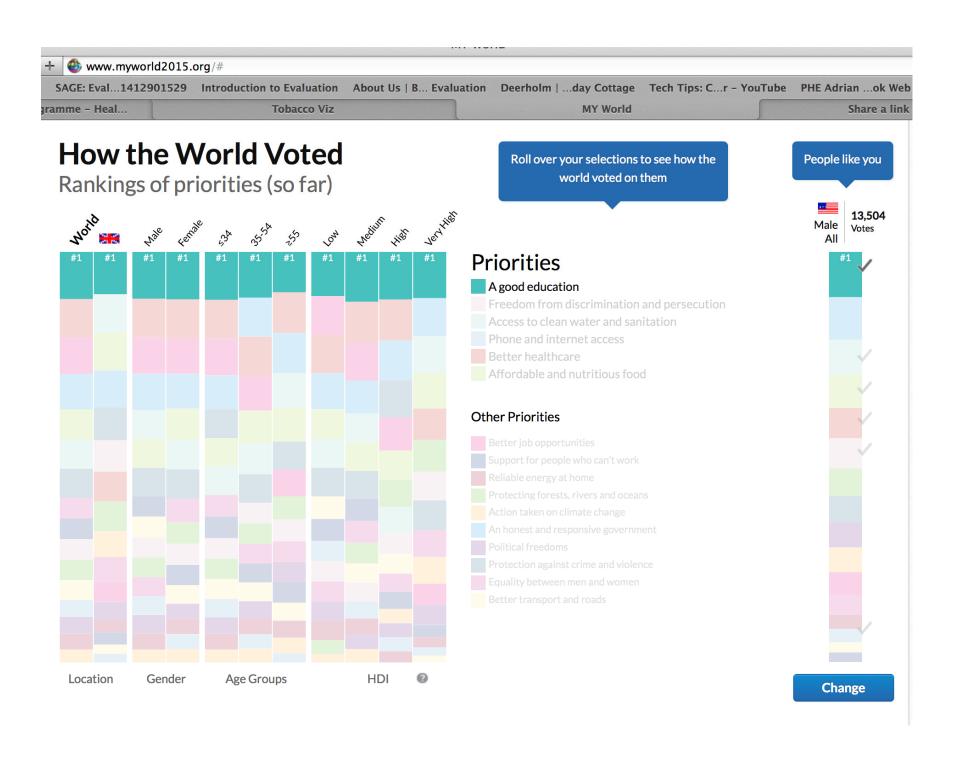
^{*} Data for 2012 and 2013 are preliminary estimates.











SHOULD WE WORRY!

- WHY IS HEARING RATING SO LOW WHEN PREVALENCE SO HIGH?
- YES WE SHOULD HAVE SLEEPLESS NIGHT!
- WHY?
- WE HAVEN'T GOT MESSAGE ACROSS
- HEARING AND COMMUNICATION IS THE GLUE THAT KEEP FAMILIES, SOCIETIES AND THE WORLD TOGETHER

Please don't (only) talk to each other!

Talk to your medical home provider

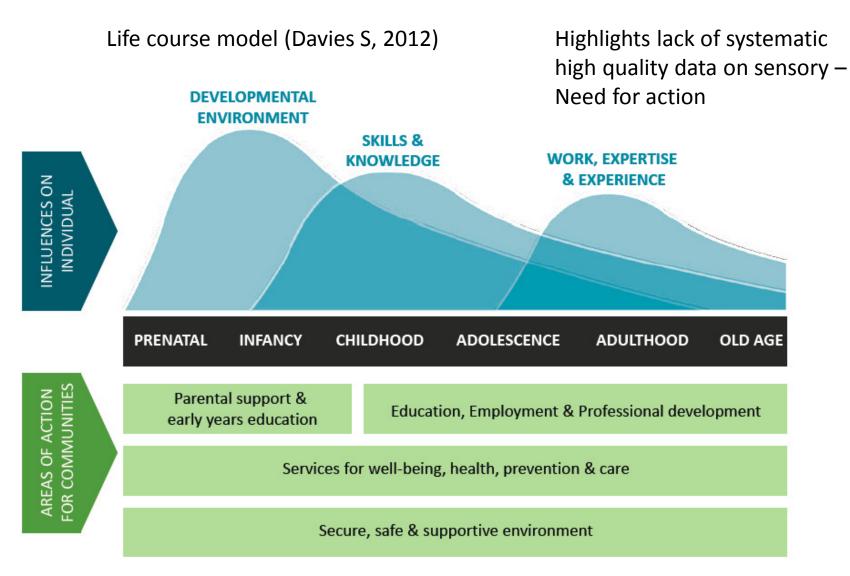
Talk with your local businesses

Talk with the communities and financiers

Talk with other care organisations

Population hearing health: Getting it right from the start

- Systems that maximise hearing health
- Going beyond the process measures
- Integration of services
- Planning for resilience
- Do we need to include others



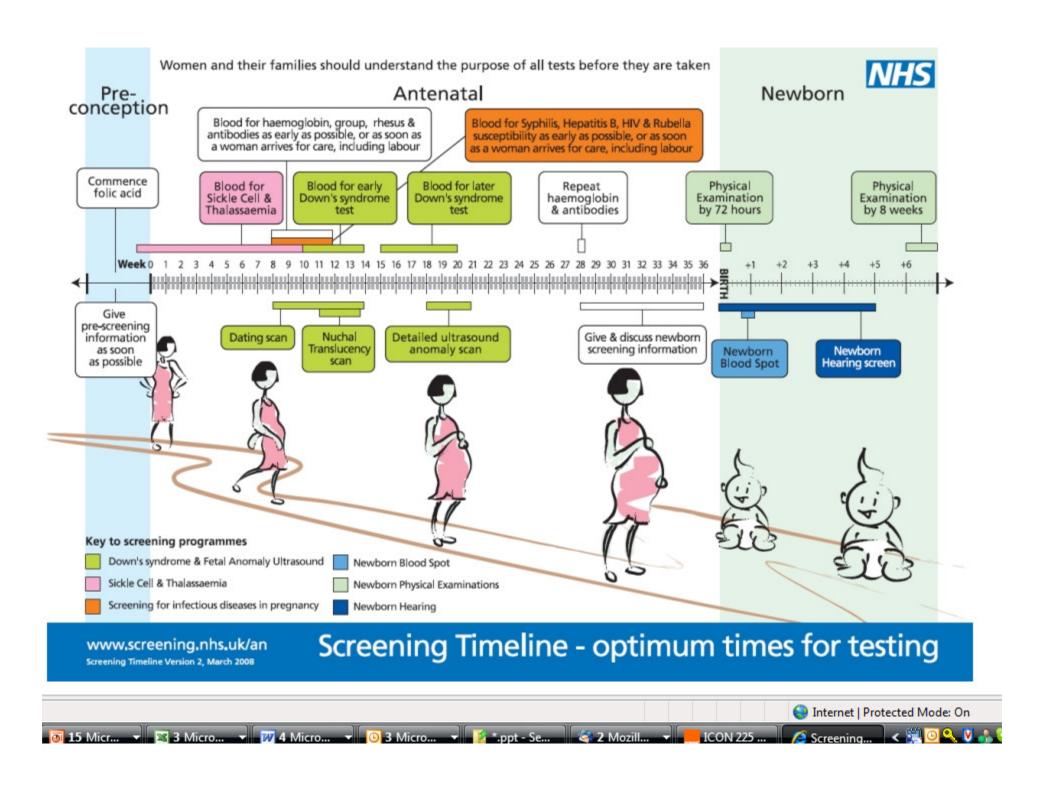
The model shows the need to consider the barriers to and promoters for good hearing and communication outcomes across the life-course and the need to consider both areas for action for communities, organisations and individuals across areas of central and local government

Opportunities to screen (for hearing) in the life-course

- Pre conception
- Ante natal
- Newborn
- Childhood
- School
- When using iPod
- Leaving school
- Entering job
- Leaving job
- Entering retirement
- During retirement
- On demand ??

When is it worthwhile

- Evidence base
- Does the evidence generalise EHDI situation?
- Universal newborn hearing screening
 - Follow up of Wessex study (Kennedy et al) shows 0.7SD advantage to screening and early intervention (<9mos for most language based outcomes including sign based getting ++ advantage from early)
 - But that is just an indicator, real benefits also shown to follow through to whole system (Bamford et al 2009 positive support project)



NHS Newborn Hearing Screening Programme

Key successes

Some major shortcomings

NHSP Programme Centre Vision:

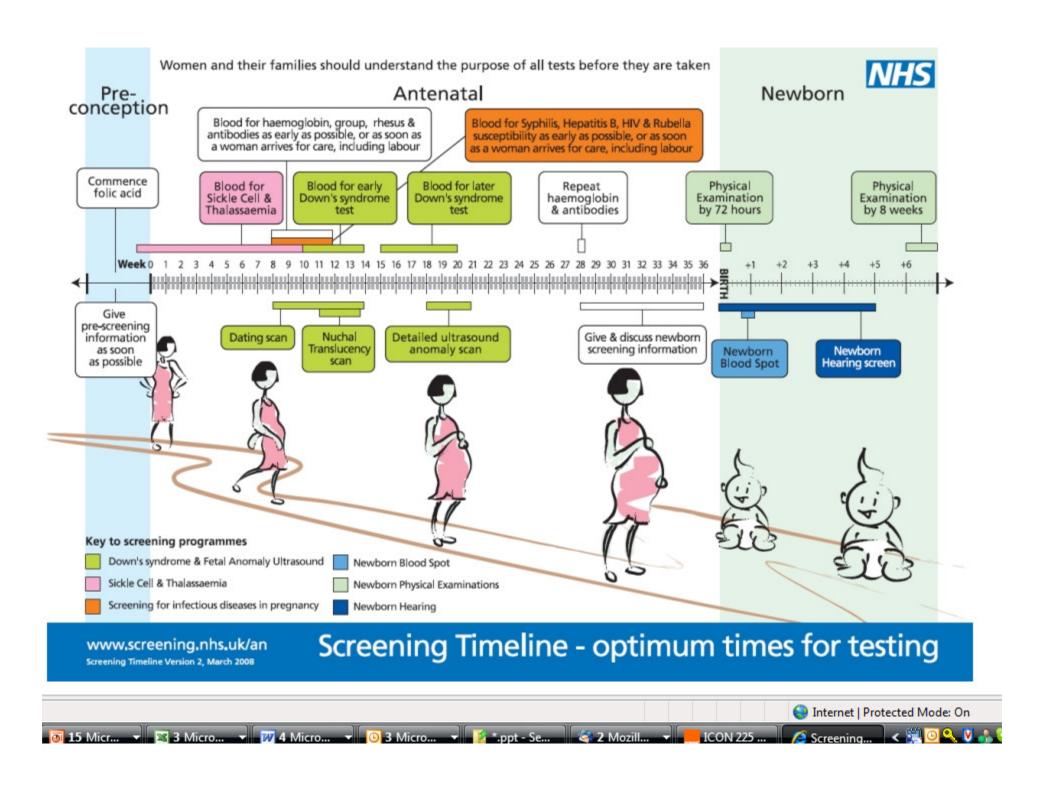
- 'Improving outcomes for every child through a high quality hearing screening programme, safe and effective assessments and family centred early intervention'.
 - This is in keeping with child health strategy, which is for every child whatever their background or circumstances, to have the support they need to:
 - Be Healthy
 - Stay Safe
 - Enjoy and achieve
 - Make a positive contribution
 - Achieve economic well being

NHSP major aim

- To support the vision by identifying all children born with moderate to profound permanent bilateral deafness within 4-5 weeks of birth and to ensure the provision of safe, high quality age-appropriate assessments and world class support for deaf children and their families.
 - To ensure equality of access across England to all screen and follow-up services.

Key success

- NHS Newborn Hearing Screening
- Information system national, integrated and useful
- Programme is holistic and therefore has standards for the parent and child journey & for professional journeys alongside
- Assurance that standards are achieved or not
 - Information for screeners, managers, payers, clinicians, educators, quality improvement – both current and trends over time
 - National register of children with permanent childhood hearing impairment



Integrated Screening programmes

- Need to keep equality of expression and aims across programmes
- Need to have similar process to agree standards
- Foetal Anomaly Screening
- Newborn
- Infant
- Children
- Adult
- Involving parents from the start

Areas covered by standards for all programmes

- 1.Identify cohort
- 2.Inform population
- 3.Invite people
- 4.Tests that work and how
- 5. Minimising harm
- 6. Assessment and Diagnosis
- 7. Intervention/ Treatment
- 8. Outcome
- 9.Staff
- 10. Commissioning and governance
- 11. User experience/ patient journey
- 12. Equality

AN EXAMPLE OF WHAT CAN MAKE A DIFFERENCE

LIFE COURSE APPROACH

 BEST START TO LIFE – HEARING AND COMMUNICATION ASSURED

 BEST EDUCATION BECAUSE HEARING AND COMMUNICATION ARE ASSURED

BEST LIFE OPPORTUNITIES

START OF LIFE

HAVE WE GOT IT RIGHT?

- CAN SCREENING HELP
 - ANTENATAL
 - NEWBORN
 - INFANCY
 - PRE-SCHOOL
- IT IS ONLY PART OF THE SOLUTION AND WE NEED TO MOVE ON!

WHAT NEXT ...

WHOLE SYSTEM

NOT JUST SCREENING

EHDI has a great mission

 And needs to consolidate and learn from what is good and where mistakes have been made

Newborn Hearing Screening in England

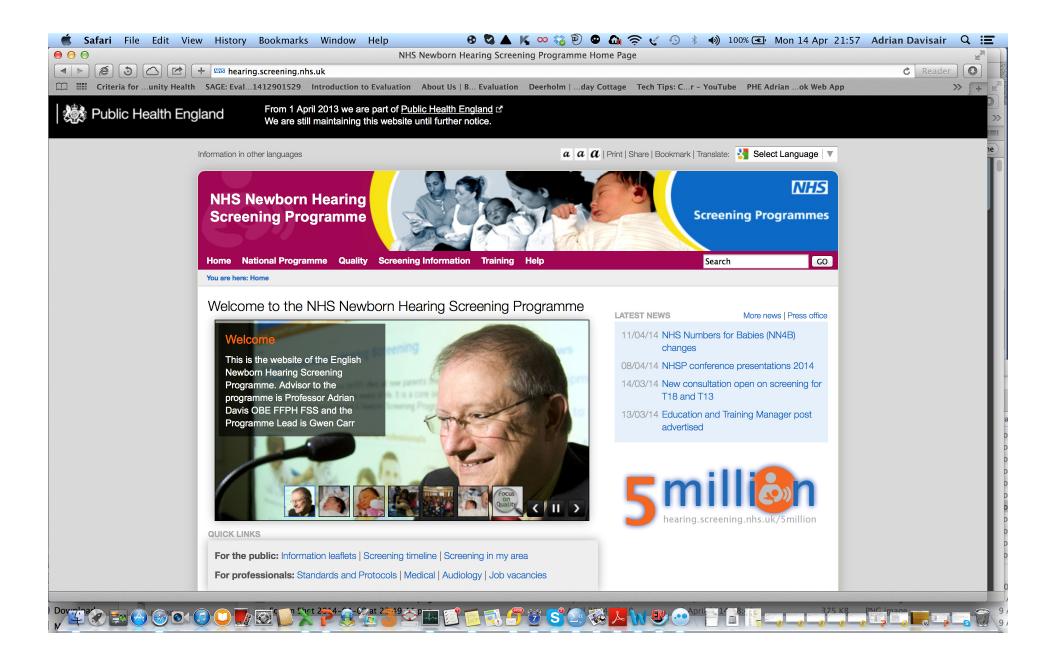
Universal since 2006

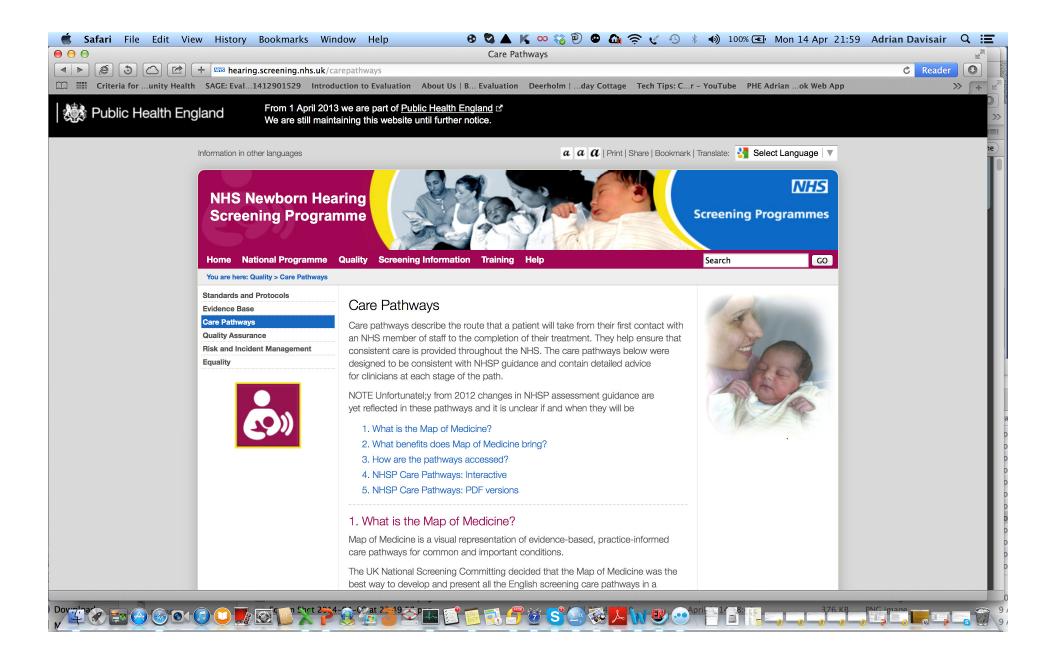
- 680, 000 births per year (>6m screenings)
- 99% of all babies tested

- 3 stage screen
 - $-AOAE1 \rightarrow AOAE2 \rightarrow AABR \rightarrow assessment ABR$
 - Both ears tested, one ear refer

What is the current organisation

- Currently 114 services across 195 maternity units in the NHS
- Core programme staff work for Public Health England
- Advisors to the programme
- Quality assurance becoming generic
- Quality improvement core and greater investment
- Integrated QA into antenatal and newborn screening programmes
- Single IT platform that access AOAE, AABR, Path labs, Child Health
- Accreditation of paediatric audiology through RCP / UKAS
- Move towards national specification of diagnostic and rehab services
- Integration operation and QA of screening
- Working towards integration of support for deaf children and their families
- Working towards maintaining close working between screening and support services







QA standards for: Training standards for:

Screening Screening

Assessment Assessment

Audiology Audiology

Education Education

Social Care Social Care

Medical care Medical care

How do we implement quality improvement

- Quality standards
- Peer review
- Knowing what good looks like
- Appreciating what your friends wont tolerate
- What you would want for your children, family
- Use routine data, ad hoc data query
- Quality assurance desktop, routine, in depth
- QA visit
- Report improvement cycle

Accreditation of paediatric audiology services

IQIPS accreditation

- Audiology
- Paediatric audiology

 Will become the major route to assure services meet standards and are independently asessed Standard Site

Interpreter available when needed

Antenatal information written and verbal given in appropriate language

NN4B numbers entered into eSP by midwives within timescales

Written and verbal information before and during screen in appropriate language

Coverage offered, started and completed within target

Started

Completed within target

Decline screens within target

Refer rates within targets

Screening outcome set by 3 months of age on 99% or more of cases

Data to be archived onto a secure location every 6 weeks

Results entered electronically onto eSP where possible and within targets for hospital sit

Data to be checked against national validity reports or the CDC

Checklist issued for screen/assessment completed or declined

Clearly defined pathway for screen fails to be referred to audiology within time targets

Babies seen within 4 weeks of screen refer

Babies confirmed with PCHI in target times

Explanation of assessment and result

Explanation of deafness and support mechanisms

Referral for aetiological investigations and paediatric assessment

Informing Education

Early support and common assessment

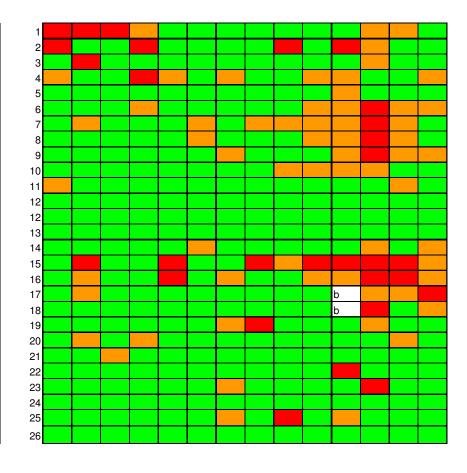
Key working/lead professional function

Hearing aid fitting offered for confirmed cases of hearing loss where appropriate

Parents to be informed and supported with respect to developing early communication w

Family care assessment (as part of a single assessment) and support offered

Confirmation of additional family and social care



Standards and specification

Equipment

False negatives

False positives

Transparency and openness in algorithms

Please don't (only) talk to each other!

Talk to your medical home provider

Talk with your local businesses

Talk with the communities and financiers

Talk with other care organisations



Getting the best hearing and communication for all:

building skills and systems for the future

Adrian Davis

Muir Gray

A good start in life secures hearing for life!

Getting the best hearing and communication for all children

- Good hearing and communication are essential across the life course for the individual, their family and for the population. Getting the best outcomes for children, families and our society depends strongly on development of learning, social and emotional skills and competences and then on using these to fulfil their potential. The changes in commissioning and in the health and social care system give us a unique opportunity to stand back and discuss how children and their families can be best supported by the health, social care, education and other services where there is a manifest need.
- A clear signal that these services should look to integrate their support around the child and family has been given by government and plans are slowly coming together in some areas of care! There is a clear need to develop a narrative at the local level about how this might happen in terms of providing the best value services, how they can be networked, peer reviewed, provide innovative solutions for children and parents, integrate health, education and social care needs and technology.

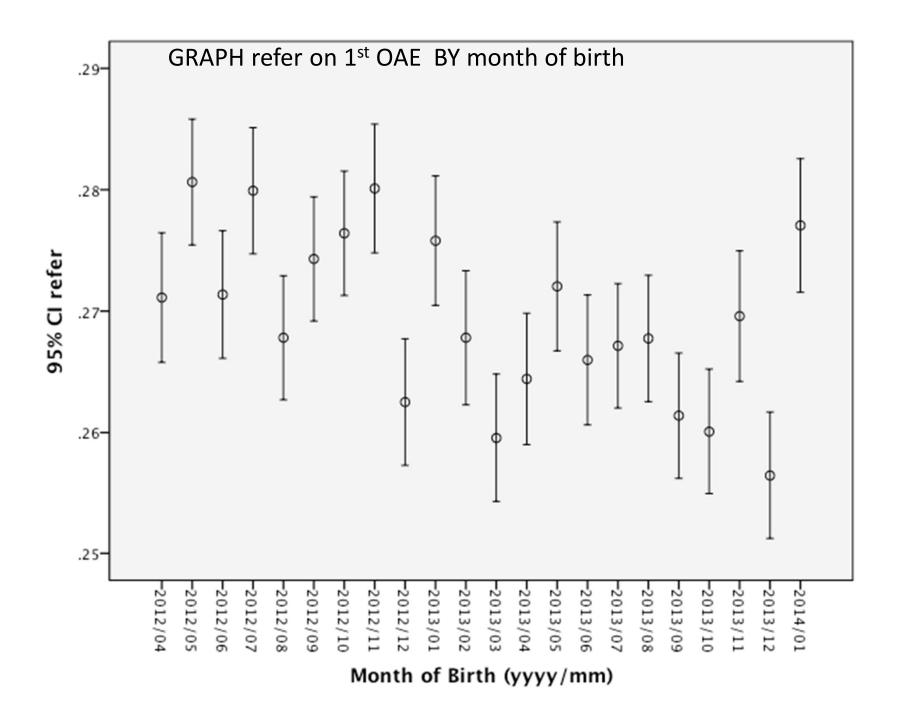
National system

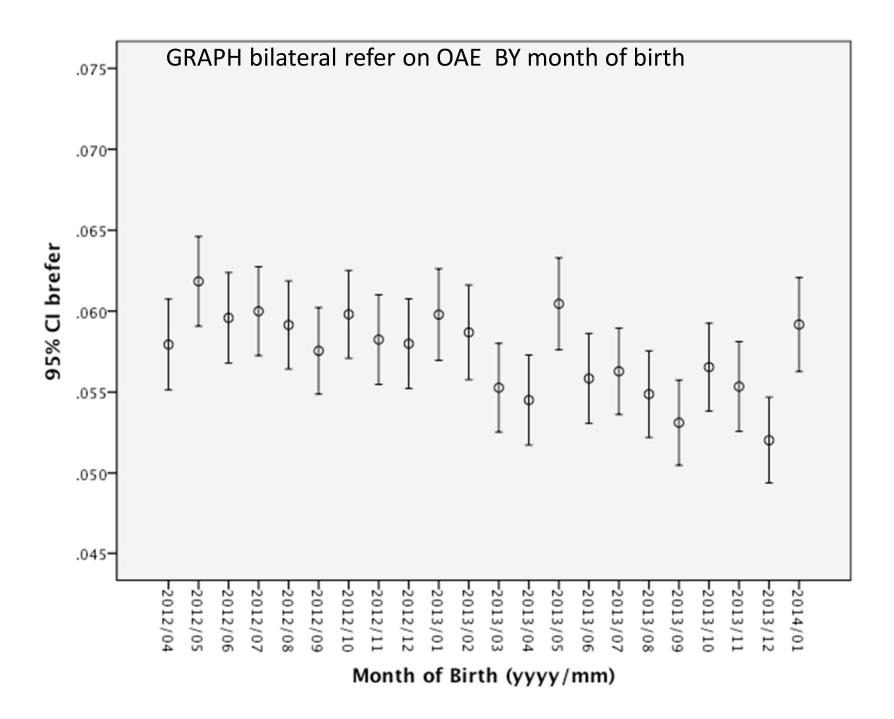
- Child health (→ life long) health and well being
- What is the vision for the future
- Health and well being improvement, resilience, sustainability in culturally appropriate way
- Hearing and communication integral part of healthy child vision
- Guiding principles addressing inequity, improving services to be fit for purpose in all respects

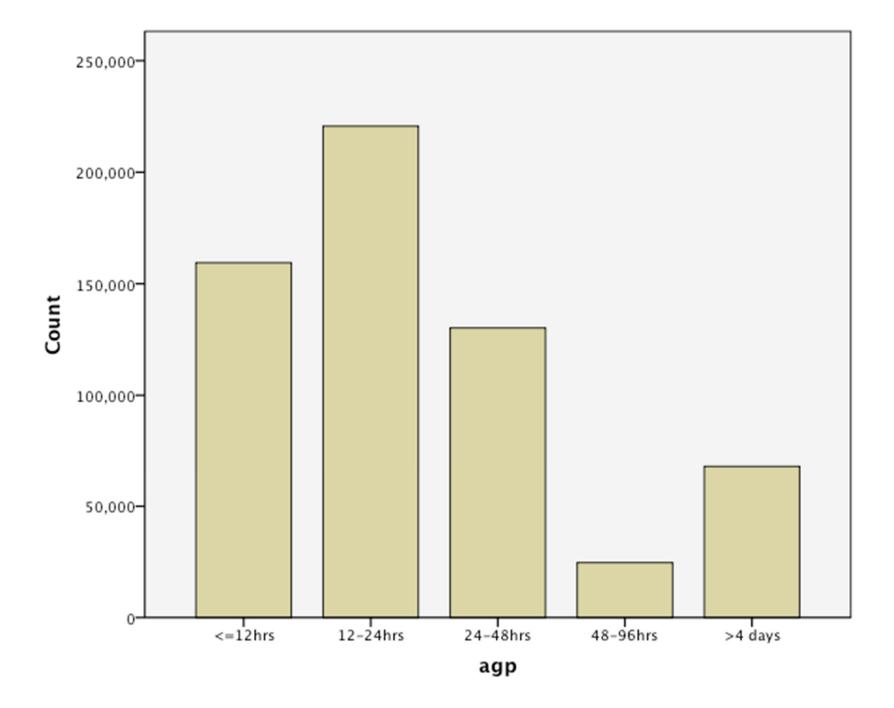
Pathway 1: the screening test should have reasonable referral rates

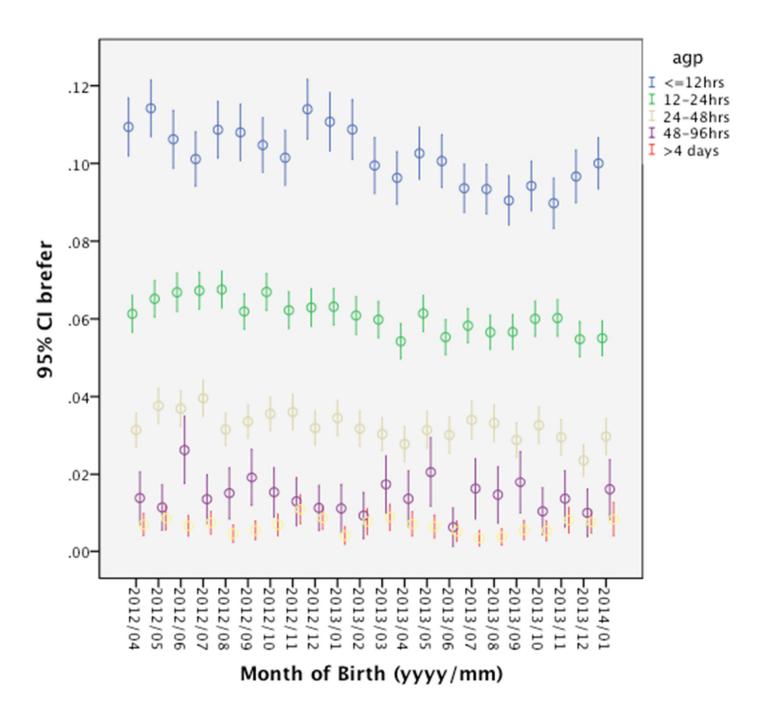
March 2014

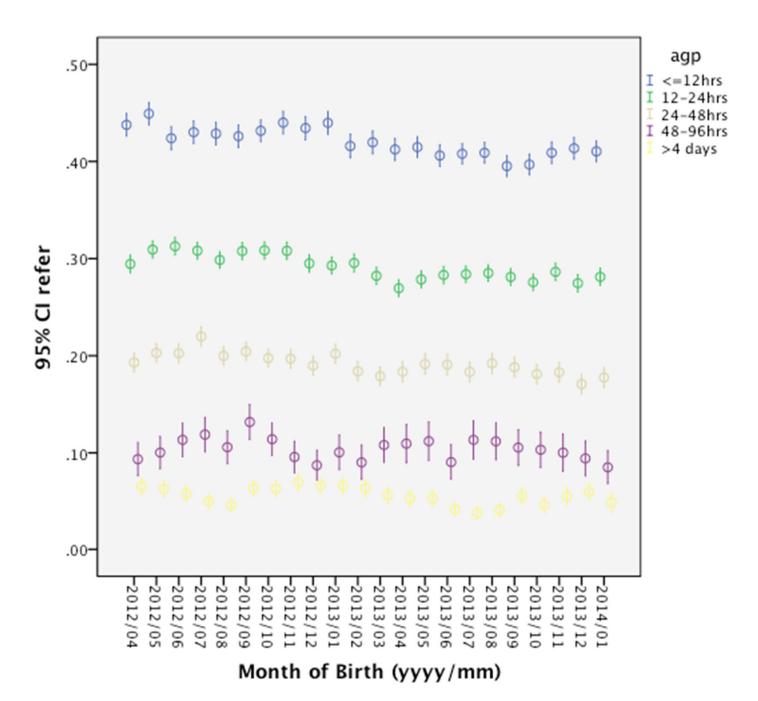
Adrian Davis

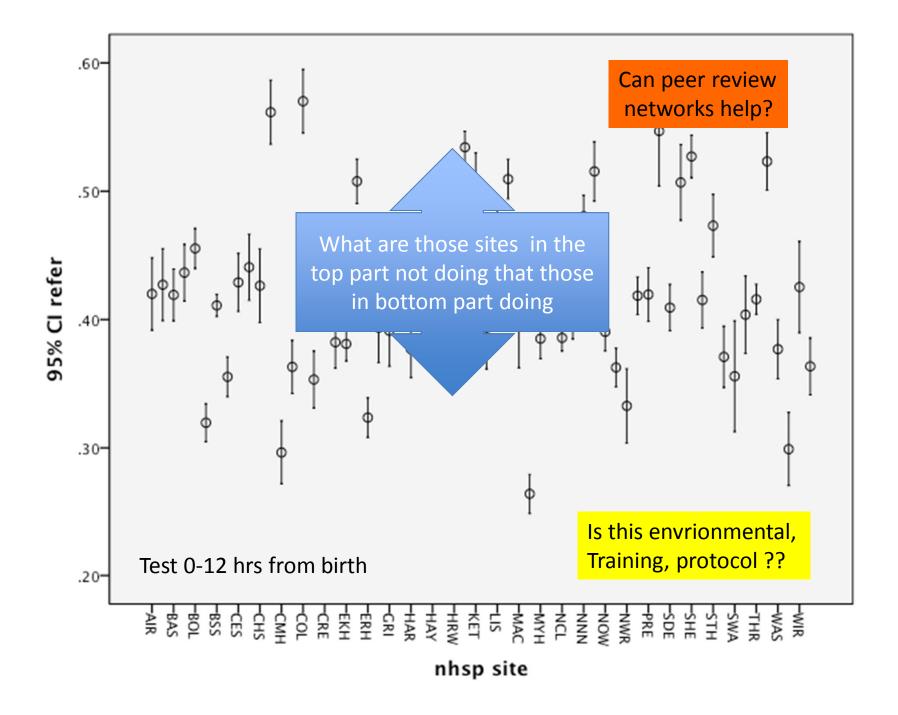


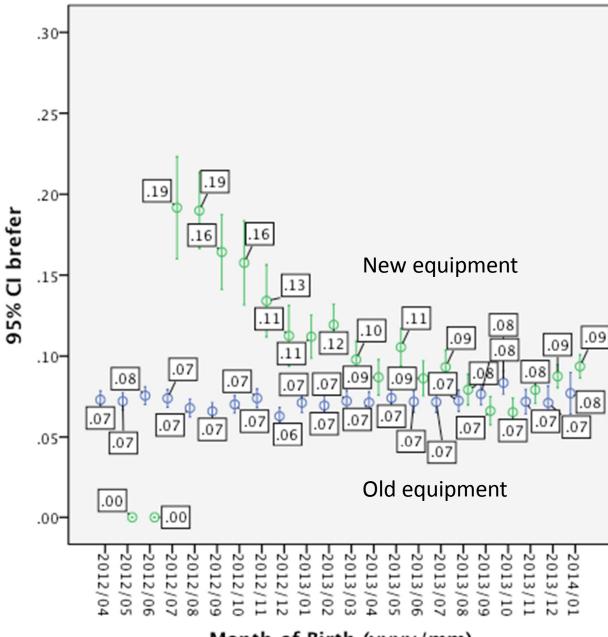










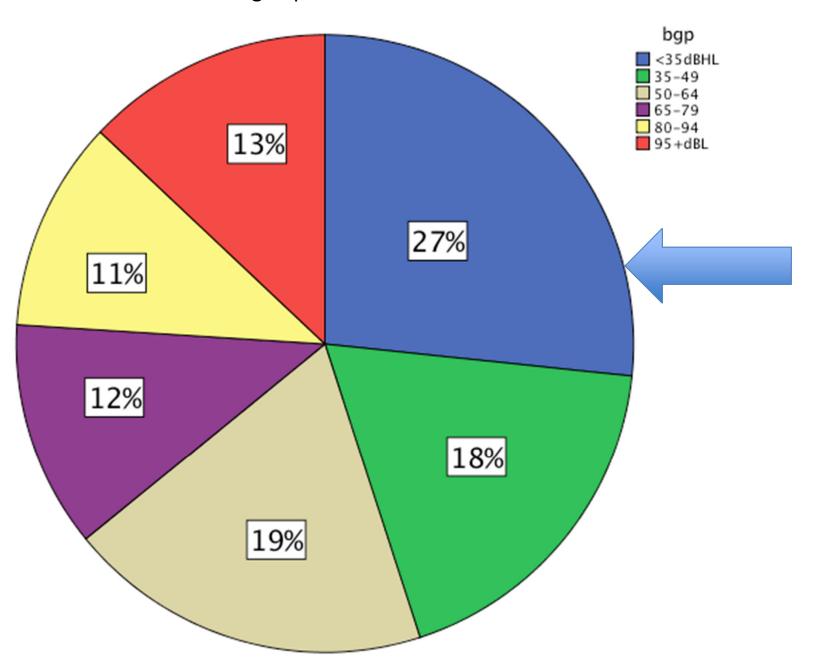


Month of Birth (yyyy/mm)

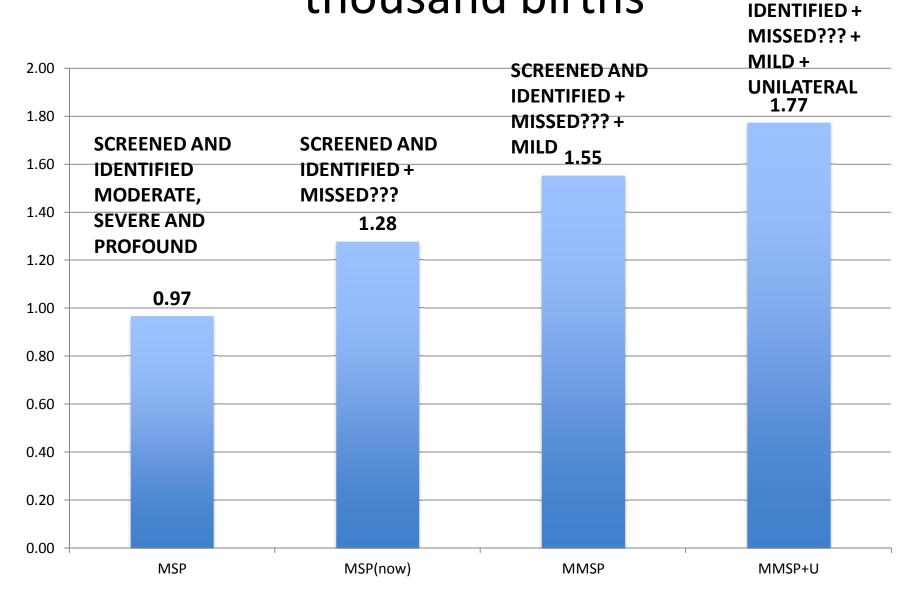
Pathway 2:

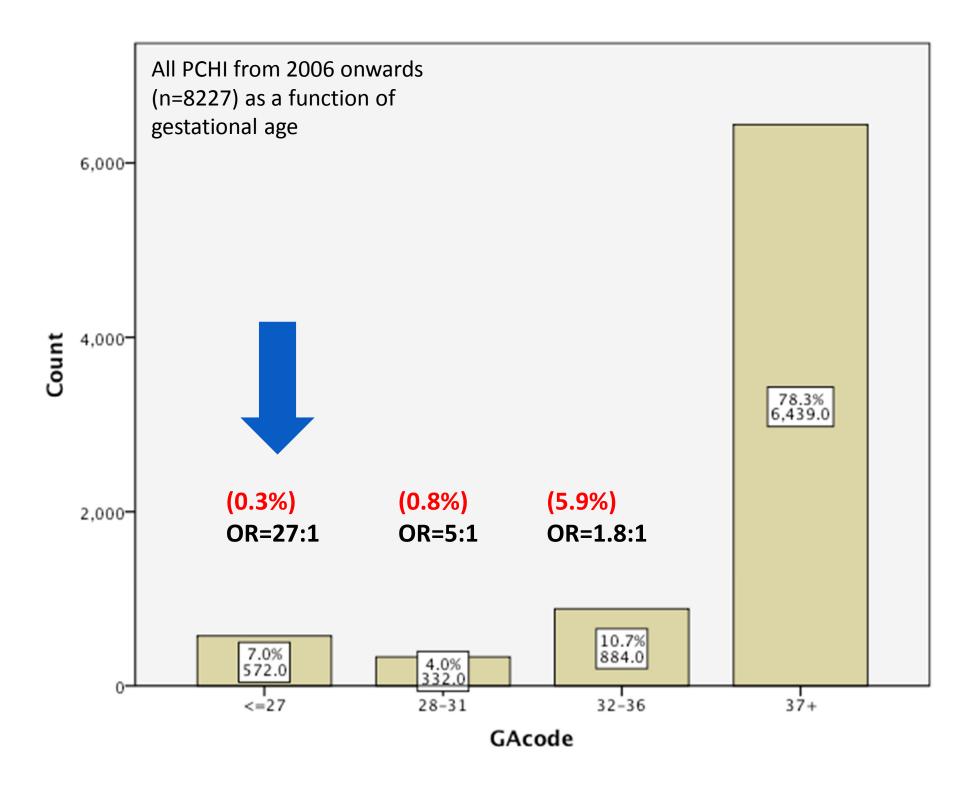
Key elements of screen are understanding yield, interpreting time at referral, assessment, diagnosis and support

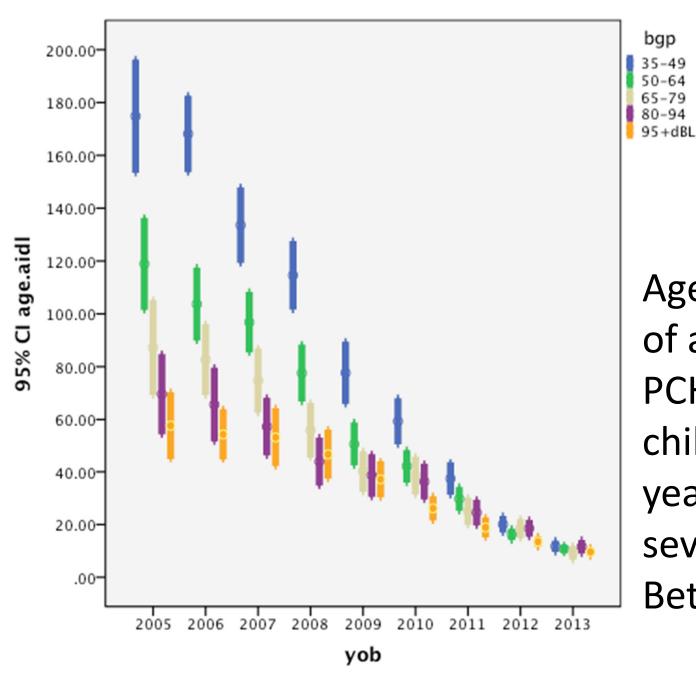
Distribution of hearing impairment on better ear for those with PCHI



Overall prevalence of hearing loss, per thousand births SCREENED AND IDENTIFIED

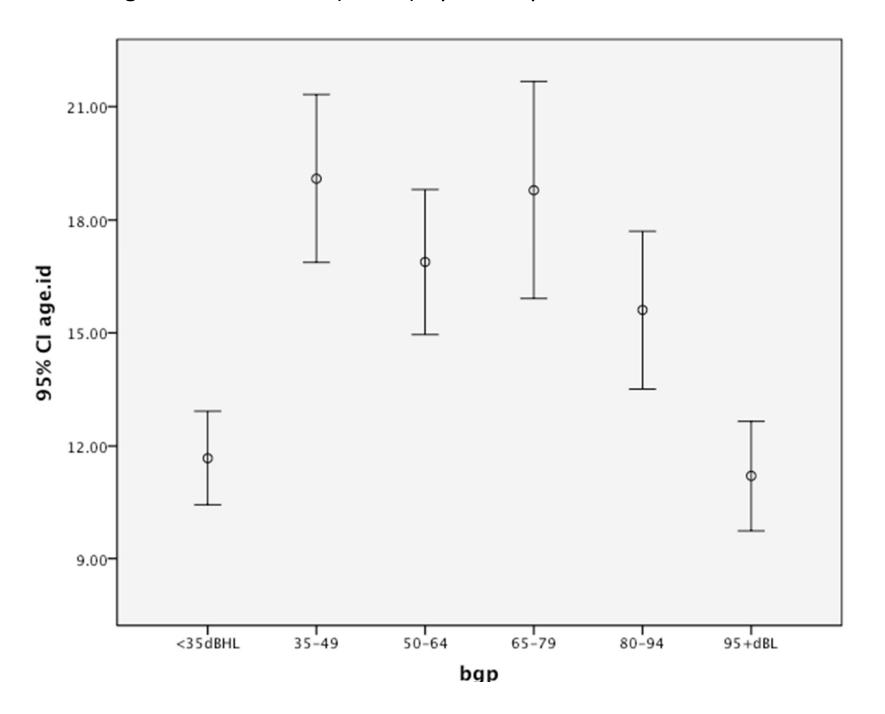


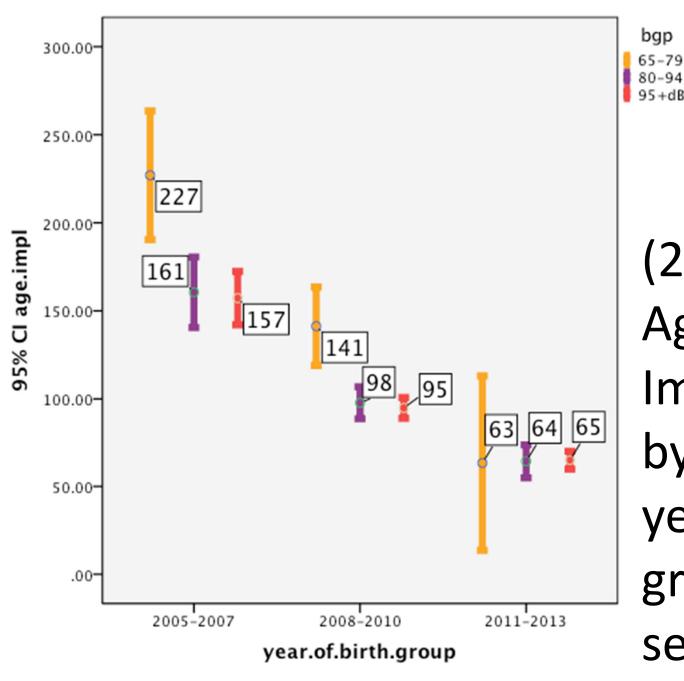




Age (weeks) of aiding of **PCHI** children by year and severity on Better ear

bgp

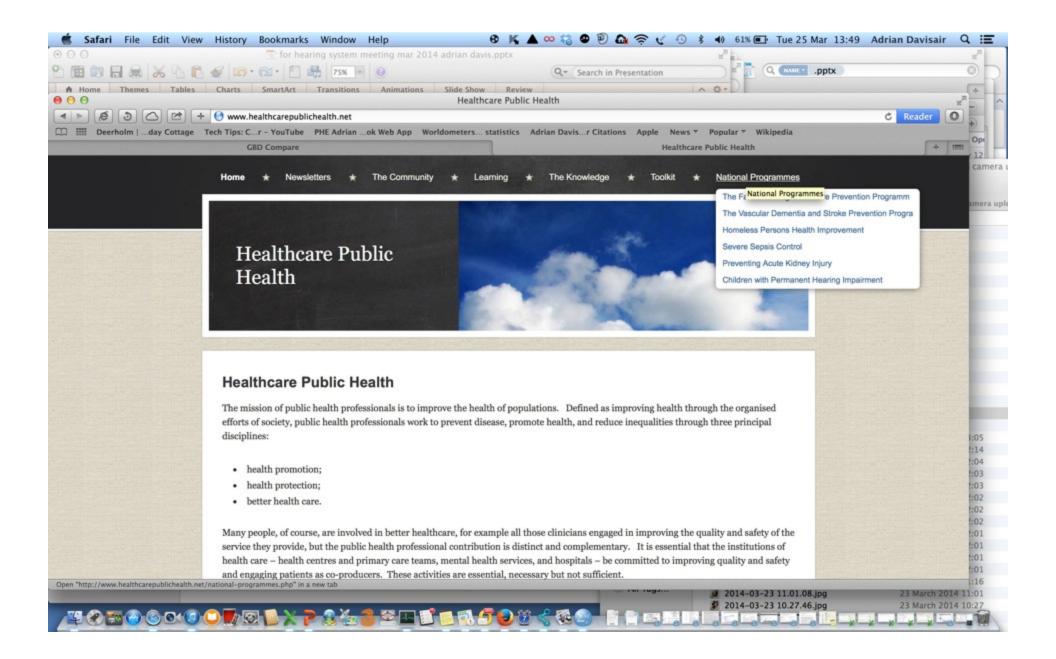


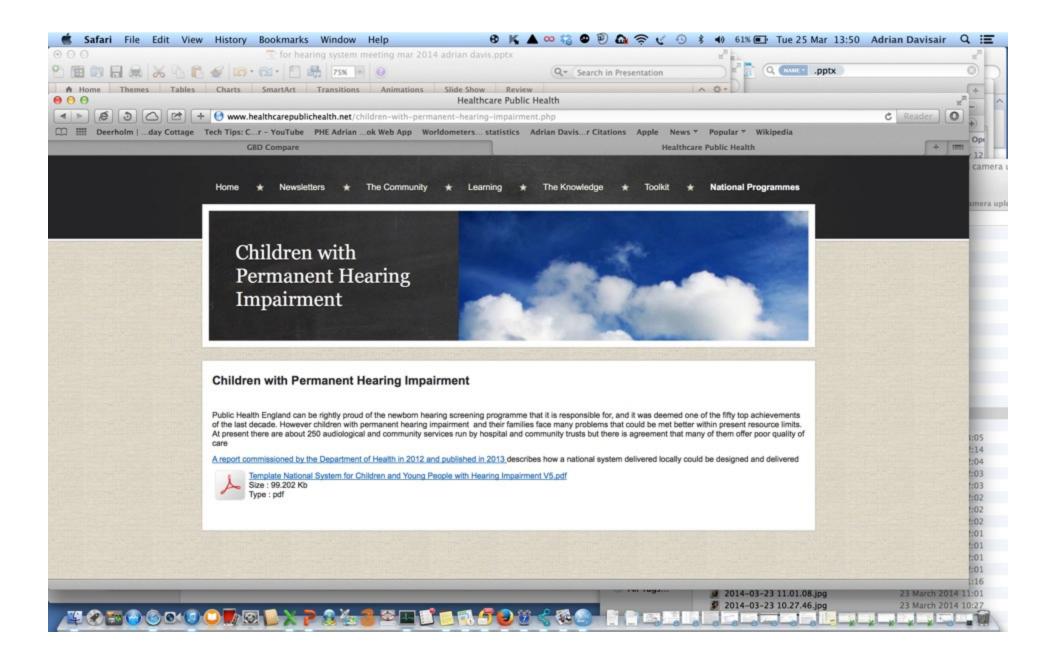


(2011-13)Age (wks)at **Implant** by year group and severity

Working together Right care Population Health Science

Muir Gray, Adrian Davis





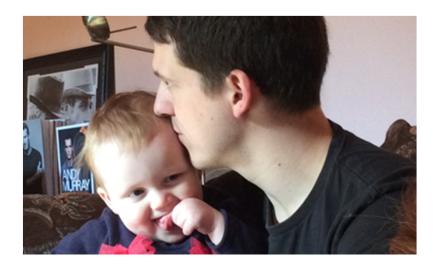
DRAFT
NATIONAL SYSTEM FOR CHILDREN AND YOUNG PEOPLE WITH HEARING IMPAIRMENT

1.	Scope of the system	The system is designed for children and young people in England with all degrees of hearing impairment up to the point of transition to adulthood and adult services (which should occur before the age of 25). All stages in the management of children and young people with hearing impairment and support for their parents should be included: screening, assessment, differential diagnostics, and all aspects of subsequent management including education and social support. This also includes temporary or recurrent episodes of temporary, hearing impairment, unilateral, conductive hearing losses and other specialised paediatric audiological services such as auditory processing disorders, auditory neuropathy/spectrum disorder, and children with complex needs. The system does not include paediatric balance disorders, which should be covered by a separate system.
2.	Population served	The system covers the whole population of England with care being delivered through local systems which have an annual birth rate of between 15-30K.
3.	Aim of the service	The aim of the system is to enable children and young people to fulfil their social, emotional, communicative and educational potential, by maximising their use of auditory sensory information. Central to this is the facilitation of confident communication. The importance of non-speech environmental sound awareness was also acknowledged, as are the needs of sign language users.
4.	Objectives of the service	 To identify children and young people with hearing impairment through screening and other pathways as early as possible. To confirm the nature and degree of hearing impairment accurately and quickly. To provide effective medical and surgical assessment and management of hearing impairment and appropriate technical assistance including implantable devices. To prevent preventable permanent hearing impairment. To provide integrated multidisciplinary cross-organisational support. To provide support and information to the child or young person and their family and support them through transition to adult services. To enable each child to develop effective communication skills. To develop the skills of all staff involved with children and young people with hearing impairment. To mitigate inequity. To make the best use of resources. To promote and support research and the adoption of innovation. To provide an annual report to the population served by the system.

The scope of the system

• Elodie, Ni, Elsa and their families





5. Developing criteria and performance levels

Objective	Criteria	Levels of performance for quality standards		
 To identify children and young people with hearing impairment through screening and other pathways as early as possible. 	A NHSP programme is in place across the system. School screening programme in place which may include a school exit screen, and online self testing in schools.	The programme is delivered to defined approved national standards. 95% coverage; records to include date of assessment; record of loss; and record of intervention.		
 To confirm the nature and degree of hearing impairment accurately and quickly. 	A comprehensive range of audiological tests and a full audiological assessment is carried out appropriate for the child's age and stage of development and taking into account the presence of additional and complex needs.	All referrals are investigated using appropriate testing for the child's age and development. All staff with the clinical responsibility for the child must have a specialist qualification in paediatric audiology.		
	The tests that are carried out accurately measure the child's hearing. The tests are undertaken in a timely fashion.	2. a) The equipment used in the assessments is serviced and calibrated at least annually in accordance with the periodic verification of audiometric equipment specified in IEC 60645-1 and ISO 8253-1. b) All children should be assessed in a family friendly, sound proofed room complying to DH Technical memorandum 2045 and ISO 8253. 3. 80% of children with PCHI of any degree have their hearing loss confirmed within 3/12 of referral with 98% confirmed within 6 months.		
	4. A full explanation of the assessment and results is given to the parents or carers. 5. A full explanation of hearing loss, deafness and the available management and support is given to parents and carers. 6. A system of active "watchful waiting" is available for children with "glue ear".	 4. a) All parents and carers accompanying the child are given an appropriate verbal explanation of the assessment results on the day of the assessment. b) All parents and carers accompanying the child are given details of the next steps on the day of the assessment. c) All parents and carers accompanying the child are given information and contacts for sources of support. 5. All parents and carers accompanying the child are given an appropriate explanation and information about hearing loss and deafness including written information about "glue ear" or permanent hearing loss, to include the Early Support information and details of the multi-agency support available. 6. All children with "glue ear" are offered an audiological assessment following the period of active "watchful waiting". 		
Objective	Criteria	Levels of performance for quality standards		
To provide effective medical and surgical assessment and management of hearing impairment and appropriate technical assistance (including	Referral for aetiological investigation and paediatric assessment.	All parents of babies and children with confirmed hearing loss to be offered referral to appropriate medical consultants in a timely fashion – evidence based or informed by professional guidance. 2.		

		_			
	implantable devices).	2.	Provision of appropriate amplification as required:	a)	All appropriate cases offered hearing aid fitting within 4 weeks of
			Hearing aid fitting offered for confirmed cases of		confirmation of hearing loss, unless delayed for management
			hearing loss where appropriate.		reasons.
				ь)	Appropriate hearing aids are fitted according to MCHAS
			 b) Hearing aids fitted to match the amplification needs of 		guidelines and programmed with appropriate features using real
			the infant in order to provide effective amplification.		ear measures and prescriptive fitting rule.
1				c)	Robust ongoing audiological care including regular checking of
			c) Provide support for hearing aid use and monitor hearing		hearing aids, hearing aid settings, and use in the home is carried
			aid function.		out. This information is shared with colleagues to form part of
					each child's integrated support and audiology care plan.
				3.	90% of profoundly deaf children identified through newborn
					screening whose parents wish for implantation to be implanted
		3.	Referral for cochlear implant assessment is offered where		before the age of 12 months.
			indicated.		-
4.	To prevent preventable permanent	1.	Promote awareness of preventable causes of hearing	1.	Information available in all healthcare settings.
	hearing impairment.		impairment.		
		2.	Raise awareness among healthcare professionals of the	2.	Reduction in number of children with preventable hearing
			preventable causes of hearing impairment.		impairment per 1,000 births.
		3.	Provide robust evidence to support epidemiology of hearing		
			loss.		
5.	To provide integrated multidisciplinary	1.	Cross organisational integrated care from multidisciplinary	1.	
	cross-organisational support.		teams is available to support children and their families.	a)	A written agreement (with terms of reference) which details how
					different service providers will give integrated support across
					disciplines and organisations is available.
				ь)	The universal Health and Development review process is used and
					reviewed every 2 years.
				c)	Education Health and Care assessments (detailed in the Children
					and Families Bill) are delivered through appropriately
					commissioned joint arrangements.
		2.	Develop a common approach to pathway support and the	2.	Data is available to, and shared across all partners providing care
			data needed to assure the pathway.		to children and their families. The system is working towards
			•		shared data systems.
_		-			•

Ob	Objective		Criteria		Levels of performance for quality standards	
6.	To provide support and information to	1.	Availability of reliable evidence based, age, cultural and	1.	All families are given information in appropriately accessible form	
	the child or young person and their		language appropriate information (for children, young			
	family, and to support them up to and		people and their families); access to information through a			
	during their transition to adult services.		range of media including email and web based technologies.	2.	Information given to families reflects a partnership approach to	
		2.	Information is developed in partnership with children, young		its development.	
			people and their families to ensure it is appropriate.	3.		
		3.	All children with permanent hearing impairment to have			
			access to support from an appropriately skilled workforce 52			

we	eks of the year:	a)	Children's Services (usually education) are notified within one
a)	Informing education/support services	-,	working day of confirmation of PCHI.
",	morning education/support services		Families are offered a visit within two working days of contact
			(year round).
		ь)	All families of babies and children with confirmed PCHI are
b)	Availability of early support	-,	provided with an explanation of the full range of support
		۱-۱	All families of babies and children with PCHI are given the
-	Consist anticodes	c)	_
c)	Support networks		opportunity to meet other families of deaf children and also contact with older deaf children and adults.
		d)	All families of babies and children with confirmed PCHI are
d)	Ongoing coordinated support		offered a main professional contact to provide ongoing regular
			support and ensure a co-ordinated and coherent service.
			Integrated support and audiology care plans are shared with
			children, young people and their families; education and social
			care plans are shared across all partners.
		e)	The social care needs of all families with a deaf child should be
			reviewed as part of an initial assessment by the lead professional.
e)	Access to social care support		In all areas there should be available a member of Social Care
			staff, with appropriate expertise in working with deaf children and their families to respond to the identified needs.
		4.	All families are supported through a structured transition to adult
			services and independent self-care where appropriate.
		5.	All families of babies with PCHI to be given information about the
4. Tra	ansition to adult services.		full range of communication approaches and supported in their
			choices, in accordance with the principles of Informed Choice.
5. De	veloping early communication.		, , , , , , , , , , , , , , , , , , , ,

Objective		Criteria		Levels of performance for quality standards	
7.	To enable each child to develop	1.	Information about the ways in which children's	1.	All parents and carers accompanying the child are given
	effective communication skills.		communication skills are developed and the relationship		information which will contribute to the integrated support and
1			between hearing and communication is given at the		audiology care plan and which addresses the child's
1			audiological assessment.		communication skills and requirements.
1		2.	Information is given to the parents on accessing resources	2.	
			and facilities which are available to support and develop the	a)	All children with a PCHI must have their integrated support and
1			child's communication.		audiology care plan reviewed regularly and at least annually.
				ь)	All children with a PCHI should have their language and
					communication progress continually monitored and outcomes
1					measured at regular and prescribed intervals.
				c)	The results of the language and communication assessments
					must be available to the parents and the multi-agency team
					with ongoing assessments available to monitor the child's

		3.	Communication and language development of children with PCHI should be equivalent to their normally-hearing peers.	3.	progress. Children with PCHI should have language and communication skills at the key developmental stages comparable to their hearing peers.
with chi	elop the skills of all staff involved ildren and young people with impairment.	1.	Staff can produce documented evidence of appropriate and ongoing professional development.	1.	All staff to participate in appropriate CPD and educational programmes.
9. To mitig	gate inequity.	1.	Action across the multidisciplinary teams to support hard to reach and engage families, children and young people with hearing loss.	1.	All services
		2.	Appropriately trained interpreters available when required.	2.	All services
		3.	Minimum training standards for care professionals supporting hard to reach and engage families, coordinated across professional groups.	3.	All services
		4.	Routine collection of data on service use in areas of deprivation.	4.	All services
10. To make	e the best use of resources.	1. 2.	With the agreement of the parent or carer, information is properly shared across clinical staff and agencies.	1. 2.	DNA rate <5%. Compliance with the sharing of information on children assessed in the audiology department is regularly audited.
		3.	There is a system of joint procurement and rationalisation of hearing aids, listening systems and other devices to minimise purchase and maintenance costs.	3.	The use of hearing aids, listening systems and other devices that have been purchased through a joint procurement system is regularly audited.

Objective	Criteria	Levels of performance for quality standards	
11. To promote and support research and	Establish networks for sharing research expertise and for	1. All services	
the adoption of innovation.	joint data collection.		
	Participate in locally and nationally led research projects.	2. All services	
	 Understand the national and international evidence to promote early adoption of innovation. 	3. All services	
	Links with Academic Health Science Networks for support and help.	4. All services	
	Establish protected time for research and the promotion of innovation adoption.	5. All services	
12. To provide an annual report to the	Data on meeting the standards outlined in this template to	1. All services	
population served by the system.	be published by networks.		

6. Resources	
(Identify all the	
resources in the	
system, to create a	
system budget)	
7. Partners	
(All the partners to	
be engaged in a	
clinical network)	
8. System	
specification	
Specification	
9. Define a plan to	
build the system	
build the system	

What next?

6. Resources

- Identify all the resources in the system, to create a system budget
- 7. Partners
- All the partners to be engaged in a clinical network
- 8. System specification
- 9. Define a plan to build the system

An annual report for each network with some examples

- Screening (coverage, referral, PPV, cost??)
- Audiology (assessments, peer review, hearing aid fitting, RECD)
- Medical and other clinical input (ENT, CI)
- Early support and intervention (language devp, peer support)
- Communication (eg turn taking)
- Education

Building skills and <u>systems</u> for the future

- Training
- Education
- CPD

• Systems

Getting the best hearing and communication for all children

- How many childrens hearing services do we need?
- How many community audiology services do we need?
- How many implantable device services do we need?
- How do they relate to services for children with permanent impairment and to those with transient or mild problems?
- How do we know which networks give the best outcomes and learn from them?
- What are the top ten items to go into a networks annual report?
- Articulate Research strategy
- A discussion on how we get agreement on key elements will be facilitated and the outcomes disseminated as an action plan for developing paediatric audiology services in the coming year

Need for systematic collation of data on population hearing loss and services

- Can we capture the real impact of hearing problems on people in USA the extent to which services give worthwhile outcomes for USA
- This conference should mark the determination to collect big national and state data systematically on incidence, prevalence and outcomes for the population with hearing loss and other auditory dysfunction
- Start by clinical audit
- Publishing data annually by services?
- And go onto look at that by implant centres?
- Annually

You are the future!

- Experience in USA ...
- For USA ...
- Don't let it happen
- Be part of it
- Get involved
- Help co-produce your paediatric early detection and intervention system so that children can have the best start in life
- And then bring added happy years to life

Gareth and colleagues (BAA),

What can we do from audiology Profession to take this forward

Making multidisciplinary work Good examples





Adrian Dighe

How can we move this on for paediatrics



Suki,

What are the next practical steps I
Can take in my area



How can we bring this across sector What are the implications of The new act?

Needs your input to make the detail work



