In the best interests of the baby?
The ethics of newborn hearing screening
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Workshop Goal

1. To raise awareness of ethical aspects of newborn hearing screening

2. Two tools
   • Analyse
   • Provide practical guidance
Who is here?

- Audiologists
- Hearing Screeners
- Parents
- Hearing screening management
- Others
Ethics Refresher 101

- Respect
- Benefit
- Avoid harms
- Fairness
What does a Hearing Screening Pathway involve?
Hearing Screening Pathway
Hearing screening pathway

Screen  ---  1 month

Diagnosis  ---  3 months

Early Intervention  ---  6 months
Ethical
- Respect
- Benefit
- Harm
- Equitable

Clinical
- 1
- 3
- 6
Best interests of the baby

• Early detection gives babies with hearing loss the best possible start in life
• The best way to establish this is for the baby to complete the hearing screening pathway
• Therefore it follows that the baby should only exit the pathway if he/she passes their hearing screening or is enrolled in early intervention
Hearing Screening Pathway
Pathway Exits

- Parent decline no screening
- Parent decline incomplete screening
- Parent decline audiology referral
- Lost contact with family
- Family moved out of state
- Palliation
- Deceased
- Never be eligible

Never be eligible
Target Condition

1/1000
Pre Screening

1/100
AABR1 Refer

1/10
AABR2 Refer
What to do when you lose contact with a baby within the screening pathway?

- Should you *always* follow up parents who exit the pathway?
- What would influence you to follow up a family?
  - How would you do that?
  - What would you say?
  - Who would you contact?
- Do parents have to stay within the treatment pathway?
- Who is able to decide what is in the child’s best interests (in relation to their hearing screening—the parents? Or other hearing health practitioner? as an RCH employee?
Zone of Parental Discretion

**Best interests of child**
Decision will produce *maximum* benefits

“good enough” interests

**Zone of parental discretion**
Accept parent’s decisions

**No parental discretion**
Override parent’s decisions where decision is contrary to child’s interest (ie harmful)

Lynn Gillam, Childrens Bioethics Centre, RCH
Red Zone – what do you do?

• Voluntary versus mandatory
• Scope of VIHSP staff roles
• RCH Policy and Procedure
Red Zone- what should you do?

Consultation

- It is important to consult with other colleagues and fully utilise internal resources if you have concerns for a child - you may not have enough information to assess that the children are experiencing harm

Referral

- The referral to the paediatrician and the social work department will enable further relevant information to be obtained to assess the safety and wellbeing of children
Red Zone
Vulnerable Children

8. Flowchart of Steps for Responding to Suspected Child Abuse

Concerns for child's safety or wellbeing

CONTACT

- Own manager, supervisor or person in charge
- AND
- If concerns persist, refer to professionals with expertise in the management of suspected child abuse. Early telephone consultation with VPMS is strongly encouraged.

Suspect Physical Abuse
- Refer to VPMS & RCH Social Work

Suspect Sexual Abuse
- Refer to VPMS & RCH Social Work

Suspect Neglect
- Refer to VPMS & RCH Social Work

ASSESS

- Assess whether the child requires hospital admission (if not already an inpatient) through consultation with the General Medicine Consultant or relevant subspecialist e.g. neurosurgery, orthopaedics, burns.
- Consult with VPMS to determine the best time, place and person to conduct forensic medical examination.
- Full assessment to be completed and documented by the most relevant professional(s):
  - Medical assessment
  - Psychological and risk assessment
  - Specialist forensic medical assessment

IF child is assessed as being at risk or vulnerable THEN

PLAN

A RCH multi-disciplinary discussion should occur with all relevant professionals to determine:
- Who will report to Child Protection (if not done already) or Child FIRST or Police
- SCAN Meeting (for inpatients)
- Who will make appropriate service referrals
- Plans for ongoing care and treatment, admission or discharge
- Allocation of responsibility for follow up

ACTION

- Implement the agreed plan
- Ensure person(s) responsible for follow up review the plan to ensure actions have occurred

*VPMS is available 24/7 state-wide for telephone forensic medical consultation and advice.

Concerns for child’s safety or wellbeing

CONSULT
Own manager, supervisor or person in charge*
AND
If concerns persist, refer to professionals with expertise in the management of suspected child abuse. Early telephone consultation with VFPMS is strongly encouraged.

- Suspect Physical Abuse
  Refer to VFPMS & RCH Social Work
- Suspect Sexual Abuse
  Refer to VFPMS & RCH Gatehouse
- Suspect Neglect
  Refer to VFPMS & RCH Social Work
Types of pressures used to influence patients in health care

1. Persuasion
   ‘appeal to reason’
   Based on information

2. Inducements

3. “Interpersonal Leverage”
   Relying on trust within therapeutic relationship

4. Threats

5. Physical force

Generally Ethically acceptable

Ethically problematic

Clare Delany, Childrens Bioethics Centre, RCH
You overhear a screener saying to a parent who wants to decline "nobody else has ever declined – you would be the first"
Types of pressures used to influence patients in health care

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   ‘appeal to reason’
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Generally Ethically acceptable

Ethically problematic

Clare Delany, Childrens Bioethics Centre, RCH
You are a resident of Luxembourg entitled to a parenting allowance

Your hearing screener informs you the parenting allowance will be reduced if you don’t have your baby’s hearing screened
Types of pressures used to influence patients in health care

1. Persuasion
   ‘appeal to reason’
   Based on information

2. Inducements

3. “Interpersonal Leverage”
   Relying on trust within therapeutic relationship

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5. Physical force

Ethically problematic

Generally Ethically acceptable

Clare Delany, Childrens Bioethics Centre, RCH
A parent is not responding to your phone calls. Should you use another phone number to call from so that they won’t recognize the number?
Types of pressures used to influence patients in health care

1. **Persuasion**
   - ‘appeal to reason’
   - Based on information

2. **Inducements**

3. **“Interpersonal Leverage”**
   - Relying on trust within therapeutic relationship

4. **Threats**

5. **Physical force**

Generally Ethically acceptable

Ethically problematic

Clare Delany, Childrens Bioethics Centre, RCH
Case Study Analysis – How to
Parents Decision
• Benefits (baby, parents, families)
• Risks/harms (baby, parents, families)
• Where does this decision fit in the Parental Zone of Discretion?
Case Study Analysis – How to

• What course of action will you undertake?
• Do you want to influence the parent?
• What are the risks and benefits of your proposed action?
• Does it respect parental decision making?
• How will you communicate this action to the parent?
Case Study One

Parents chose to withdraw their baby from hearing screening without being screened

* They will not be going to audiology either
Case Study Two

The baby has completed one AABR screen with a Refer response

Parents chose to exit from the hearing screening process

* no bypass to audiology
Case Study Three

The baby has had an unclear responses on both AABR1 and AABR2

Parents indicate that they are not interested in attending audiology
Development of Ethical Guidelines:

- Identify the practical options
- What is possible given resources are finite?
- Consider the harms/benefits
- How can staff respect parents as decision makers whilst keeping in mind the best interests of the baby?