



FINDINGS FROM THE CONSULTATIONS WITH
YOUNG PEOPLE REGARDING THE
CONFIDENTIAL ENQUIRY INTO MATERNAL AND
CHILD HEALTH (CEMACH)'S CHILD DEATH
REVIEW

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Executive summary

Two consultation sessions with young people took place in February to gather their views on the Confidential Enquiry into Maternal & Child Health (CEMACH) Child Death Review. It is clear from the report that follows that these young people value the work of CEMACH and they see it is an important project, as its results can have an educational and preventative impact on children's lives.

As one participant summed up, "The benefits will always outweigh the sensitivities of it, as it will prevent other similar situations occurring again."

With this praise they gave their views on how cases could be managed and what type of questioning they would ask to get a truer picture of the events that took place. The participants were able to cite areas of development such as publicising their findings and ensuring that their findings do make a difference to minimising child death through more effective public education and training.

They gave some interesting feedback on possible areas that CEMACH could work on in terms of child health and how young people like themselves could be involved in the work of CEMACH.

Acknowledgements

I would like to thank the young people and staff from St. Marylebone School and Barnet FE College who gave up their time to share their views on the work of CEMACH. I would also like to thank CEMACH's staff for their input into both planning and delivery of the sessions.

Background

CEMACH recognised the importance of children's participation in its work. CEMACH had previously consulted with parent bodies and organisations representing children but not actively involved children in their activities.

The National Advisory Committee For Enquiries Into Child Health (NACECH) had been encouraged to include a children's participation component in the Child Death Review. Furthermore, the Patient Information Advisory Group have indicated that CEMACH must consult with children regarding the ethical issues and sensitivities surrounding the collection of information on child death, specifically deaths of young people aged between 14 – 18 years.

As CEMACH does not have in-house expertise in children's participation, it commissioned the National Children's Bureau (NCB) to carry out two consultation exercises with young people regarding the Child Death Review. This was undertaken alongside two members of CEMACH's staff team.

The National Children's Bureau (NCB), www.ncb.org.uk, is a registered charity that undertakes research, policy and practice development and dissemination. It works to identify and promote the voices, well-being and interests of all children and young people across every aspect of their lives. It advocates the participation of all children and

young people in all matters affecting them (in relation to children and young people aged 0-18). It challenges disadvantage in childhood.

NCB has adopted and works within the UN Convention on the Rights of the Child, and according to NCB's stated values and principles and in consultation with CEMACH planned some consultation session to look at the Child Death Review.

Aims

The primary aim of this consultation exercise was to obtain the views of young people on the CEMACH's Child Death Review, specifically the handling and sharing of sensitive information regarding deaths of adolescents, for example teenage suicides and from substance misuse.

Objectives included;

- To explain the work of CEMACH on child death and the objectives of the pilot in a format which young people will be able to understand and relate to.
- To create consultation tools that will engage young people.
- To facilitate up to two sessions with young people who have an interest in health and social care in the London area.
- To enable young people to have a voice and influence the developments of the Child Health Enquiry.
- To let the National Advisory Committee For Enquiries Into Child Health (NACECH) hear the views of young people who would not normally have a chance to give their opinions in this area.
- To set up systems that will measure the effectiveness of the methods used to engage and involve young people in the consultations.

Outcomes

- Young people have an understanding of CEMACH's child health enquiry.
- Young people have an understanding of the mechanisms for influencing and informing the work of CEMACH.
- Young people have developed key skills in areas relevant to influencing the project.
- Young people have evidence of influencing and informing adult led organisations.
- Young people from a wide range of backgrounds have an opportunity to participate in developments of the project.
- Young people are meaningfully involved in the developments of the CEMACH's work.
- CEMACH has improved awareness of, and engagement with, young people.

Methodology

Janine Shaw from NCB, together with Jana Kovar and Rosie Houston from CEMACH undertook two consultations with 24 young people aged between 14-20 years of age. The original plan was to work with under 18's, but later chose the second group with older students to gain the views of young men as well as young women. Only 25% of this group were over 18 and there was a gender mix of 18 females and 6 of them were male.

The ethnic background of the participants were as follows;

White British = 5	Iraqi = 1
African = 2	Irish = 1
Black Caribbean = 3	Any other white background = 2
Greek Cypriot = 1	Any other Asian = 1
Greek Syrian = 1	Half Turkish/Half Greek = 1
Indian = 1	Portuguese and African = 1
Turkish Cypriot = 1	White and black African = 1
Turkish = 2	

Young people were selected from those who have an interest in health and social care, with one group of school students studying GNVQs in Health and Social Care and another group studying for their 'A' levels in Social Sciences. CEMACH wanted to get a cross section of views so went to two separate London boroughs, Barnet and Camden. The young people came from around inner and outer London.

The consultations took place in February and were created in consultation with CEMACH staff. In pre consultation discussions we agreed to gather evidence on what young people thought of the project in general, any practical ideas and priorities for young people to enhance its success and to establish what young people approved of and didn't approve of; what their concerns were and identification of avoidable factors.

The emphasis of the sessions were on gaining ideas and feedback through the participation of all participants using creative means of receiving feedback. NCB strives to adopt good practice standards in children's participation, so that all such activity is meaningful to young people. The consultations were planned with a mixture of information sharing through presentations, games, thought showers and small group discussion on areas which young people would be able to relate to.

It was important to establish ground rules at the start of each session so that all the participants felt comfortable discussing and sharing information within the group. Explaining confidentiality was a key aspect of the ground rules as some of the issues around death might have triggered some emotional or past experiences of death by the participants.

Four of the young people who took part considered themselves as having disabilities, mainly learning difficulties, so the lay out of the sessions ensured that they would be able to participate throughout with as little individual writing as possible.

Outline of sessions

A full outline of the session can be found in appendix 1 but the main areas are set out below

- Setting the scene – It was felt it was important to set the context of the sessions by giving an explanation of CEMACH, confidential enquiries and what the Child Health Enquiry and Child Death Review entails. To set this within the context of confidentiality within the enquiry's methodology ensured the participants were able to respond to the case studies.
- Case studies - We gave 3 case examples of young people who died through either suicide, substance misuse or a road traffic accident. Within these we asked the participants to focus on:
 - Apart from the information gathered what else would you want to know about the case?
 - What can be learnt from the case?
 - What are the benefits with this approach of monitoring child death in this way?
 - What are the sensitivities associated with collecting this sort of information .
 - Gathering an opinion on the ethical issues associated with collecting this information.
- Feedback on CEMACH 's Child Death Review in general.
- Advising for the future. We wanted to elicit from the group any areas of child health that the participants felt would be useful to focus on in the future.

Response to CEMACH's work on the child death review

What young people thought of CEMACH's Child Death Review in general?

When we first explained about the work of CEMACH in the introduction, the young people's response was a natural one of being both quite curious and squeamish. After the more detailed explanation from CEMACH staff and working on some of the case studies it became apparent that the young people thought it was a worthwhile project. They fed back to us that the benefits were that it was educational and lessons could be learnt from it so that other deaths could be prevented. They didn't feel that too much information needed to be given away for trends to be collated. They also understood that the collection of information was for a purpose and therefore it out weighed the sensitivities of what this might involve.

They were able to identify the sensitive parts of the programme maintaining anonymity and being tactful then collecting information. If CEMACH were to share case studies on a wider scale to promote safer outcomes for children and young people then they should not share too much information, so that the individuals could be identified. They also thought that families should be asked permission if the case is going to be used to publicise possible problems with the wider public.

They understood that the families left behind would be grieving, so revealing certain information (if it was due to substance misuse or suicide) may add to the pain. They were quite vocal at stating that if each case is treated individually, and not just as 'another case', those investigating will be sensitive and this will aid the process and outcomes.

The case studies

Three case studies were chosen by CEMACH to stimulate discussions about the gathering of information from CEMAH.

- Case study A looked at a young woman who had been raped and then committed suicide,
- Case study B was around a death associated with substance misuse and
- Case study C was a report on a young person who had been killed in a car accident.

Appendix 2 gives a full account of all of the feedback from the young people on the questions asked. In summary participants were able to give many practical questions and pointers that would need to be further investigated to give a clearer idea of how the young person had died. Some of these questions related looking in more depth into their recent health history but also asking people who had seen the young person before their death and questions about their emotional and physical state.

In case study A they asked;

"Was there an opportunity for her to talk to someone?"

"How was her behaviour after the event – had it been monitored formally or informally?"

"What support did her family get for themselves to deal with it and then to be able to offer her?"

In Case study B they asked;

"Did the bus driver notice anything strange?"

"Why was she served alcohol in the first place?" (she was under age)

"Why did she leave on her own?"

In Case study C they asked:

"Why was he out so late?"

"How did his friend not manage to get knocked over?" (Had he heard the vehicle when the other boy couldn't due to hearing problems?)

"What head injury had he gained?"

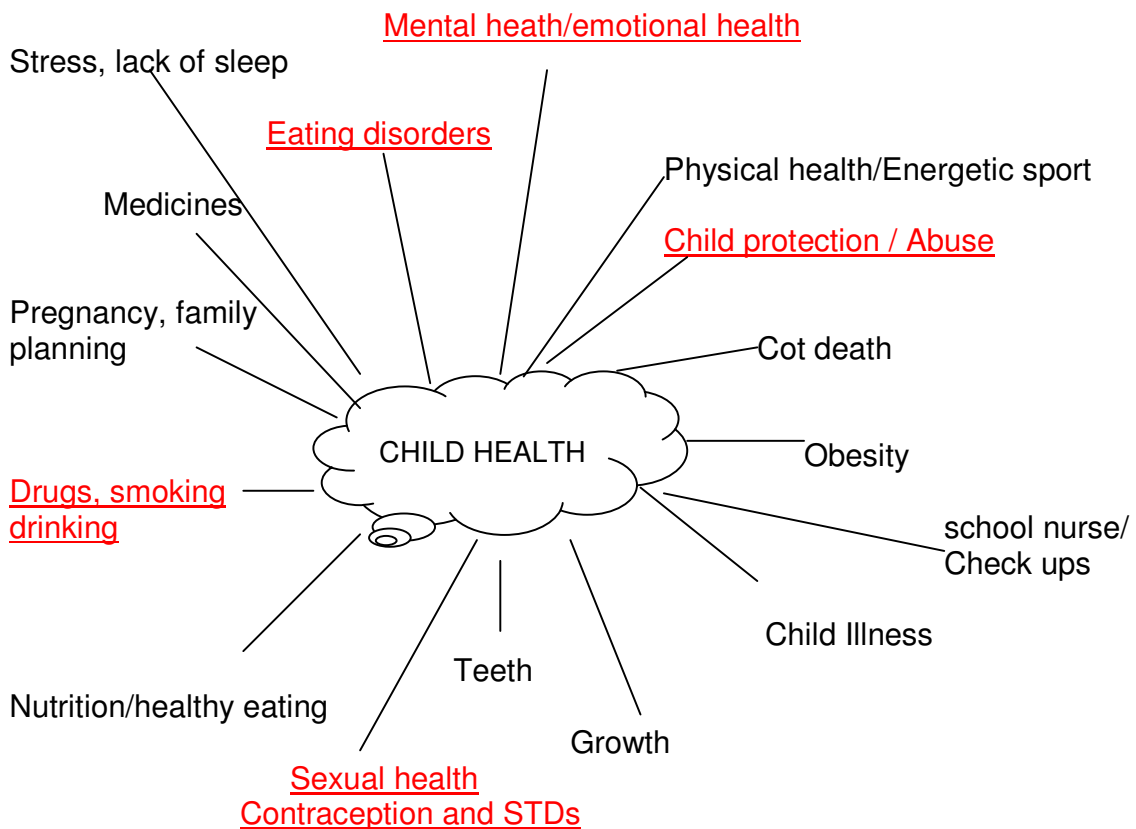
Both groups were able to identify many learning points from each of the cases. The older group asked why CEMACH's work was not publicised more widely to the public as just reading the cases would educate the general public from possible harmful events that do occur. The young people said that there needs to be greater awareness of dangers and education could help this with regards to substance misuse and traffic accidents.

They gave practical tips that could get shared from reading the case studies. These included always travelling home with a friend or work late at night with someone else. Carrying mobile phones, learning self defence, making sure other people know where you are however late at night were some other ideas. The young people fed back that from the case studies it was evident that more training is needed to be given on young people's emotional health, looking out for the signs and symptoms, so they can be supported better to prevent suicide and possible drug misuse. Awareness of different people's views and response because of their ethnicity, religion and backgrounds would allow flexibility in support offered to young people who having emotional problems. CEMACH had a role to play in passing on these conclusions to relevant bodies to follow through.

Other practical tips such as how to walk safely on unlit roads, lighting up more roads, giving drivers more warnings of pedestrians walking in un lit streets, everyone learning first aid and being aware of your physical environment were given.

Young people's ideas on future areas for CEMACH to focus on

We undertook a thought shower on what young people see as child health to stimulate ideas for possible future projects that CEMACH could undertake. This was done at the start of the session and they related back to after the case studies.



The underlined areas were the areas that the young people thought could be possible projects of interest to them for National Advisory Committee For Enquiries Into Child Health (NACECH) to pursue. An interesting observation was that for both groups chose mental health, eating disorders, drugs, smoking and drinking and sexual health as their preferences. Additionally, the younger group chose child protection.

How could CEMACH and NACECH possibly involve young people in future projects?

Young people in the school session suggested a number of ways that they and other young people could get involved in CEMACH's project work:

- a) Undertaking surveys/ questionnaires, although they explained that this was not a means of engaging all young people.
- b) Getting other teenagers to speak to them/young people like them about the work and to gather ideas.
- c) CEMACH to attend group meetings like this session.
- d) Face to face discussions on a individual basis.
- e) Getting young people involved in planning of the projects.

Recommendations

The young people who took part in the consultation sessions praised the work of CEMACH. They had requested CEMACH's work to be made more public so that other children, young people and adults could benefit from their learning.

(Through CEMACH's Child Death Review) "People can be more aware of how accidents happen" and "it can prevent it from happening again"

They wanted CEMACH to ensure that professional bodies and government organisations were aware of CEMACH's findings too, so they could take action to make children's lives safer through a safer physical environment, and for more affective education and training to be offered to enhance skills and awareness of both children, young people and the adults who work with them to increase their chances of living beyond childhood and into adulthood.

The benefits of learning from this project are "we could learn how to handle the situation if it happened again."

They wanted other young people to have an opportunity to shape the work of CEMACH and recommended how this could be done in the responses section above.

Evaluation of the sessions

As part of NCB participation practice we undertake evaluations with participants to gauge how they have experienced working alongside us. We only had time to undertake an evaluation with the school group by means of a visual target. Young people posted notes on it in two different rings to say what they liked and didn't like about the session. A selection of positive points included;

- Talking in the group and the questionnaire (case study).
- Good case studies.
- I liked you (the staff).
- I like the fact that we talked about real life cases.
- I like the fact that we were tackling real life issues.
- We got to see each other's points of view and had a good understanding of child health and death.

Some areas that didn't receive such positive feedback in the outer circle included:

- The discussion.
- The powerpoint presentation.
- I found the Powerpoint quite complex but still had a good understanding,
- The introduction.
- Talking openly.
- The need to talk about death it hurts.

Appendix 1



CONSULTATION WITH YOUNG PEOPLE REGARDING CEMACH CHILD HEALTH PROJECT AND CHILD DEATH REVIEW PROJECT

Facilitator's plan

Facilitators

Janine Shaw, Head of Children and Young People's Participation,
Jana Kovar, National projects manager, CEMACH
Rosie Houston, CEMACH

School; St. Marylebone school,

Aims of the session

The primary aim of this consultation exercise is to obtain the views of young people on the CEMACH child death review project approach, specifically the handling and sharing of sensitive information regarding deaths of adolescents, for example teenage suicides and from substance misuse.

Objectives;

- To explain the work of CEMACH on child health and the pilot's objectives in a format which young people will be able to understand and relate to.
- To create consultation tools that will engage young people
- To facilitate up to two sessions with young people who have an interest in health and social care in the London area
- To enable young people to have a voice and influence the developments of the child health project.
- To let CEMACH advisory group hear the views of young people who would not normally have a chance to give their opinions in this area
- To set up systems that will measure the effectiveness of the methods used to engage and involve young people in the consultations

Outcomes

- Young people have an understanding of CEMACH's child health project.
- Young people have an understanding of the mechanisms for influencing and informing the work of CEMACH.
- Young people have developed key skills in areas relevant to influencing the project
- Young people have evidence of influencing and informing adult led organisations.

- Young people from a wide range of backgrounds have an opportunity to participate in developments of the project.
- Young people are meaningfully involved in the developments of the CEMACH's work
- CEMACH has improved awareness of, and engagement with, young people.

Schedule of day

11.45 – 12.05pm Welcome and introductions

Introduction

- Workers introduce who they are
Brief introduction to session, how their answers will be recorded and what will happen with the results.
- Programme and timetable of the day stuck on wall
- We are here to listen to what you have to say. Explain that there are no right or wrong answers and that views and opinions may be different.
- We are basically here to have fun and get your views. But if you need to take a break you can but let us know first. Point out a place they can go.
- Explain the importance of ground rules: to give everyone a chance to have their say. These will be set by the group but include confidentiality, participation, respect each others points of view, ask questions if you don't understand, have fun, language.

Who we are, why we are here?

Aim; to obtain the views of young people on the CEMACH child death review project approach, specifically the handling and sharing of sensitive information regarding deaths of adolescents, for example teenage suicides and from substance misuse.

Introductions from group

Icebreaker - famous couples

12.05 – 12.10

Thought shower; what do you think of when we use the term *child health*? Child health written in the centre of the page and write around it. (return to later)

12.10pm – 12.15

Scene setting: What is CEMACH and what is this project?
Brief description - Jana

- Explanation of CEMACH, confidential enquiries and what the child health review/child death review project entails
- Explanation so the rationale for child death review and confidential enquiry methodology is understood – though not too much of a focus on this
How we might do this; pictorially create a diagram of what CEMACH is all about – work CEMACH in the middle with arrows pointing outwards as to who they work with, projects involved, enquiries process (who they speak to; parents/GPs?), methods used and outcomes aspired to.....

12.15 – 12.40

Case example of young person who died including suicide and substance misuse. Break the group into 4 and work through two case studies each answering the following questions;

- What types of questions would you ask with regards to this?
- Can be learnt from the case?
- What are the benefits of monitoring child death in this way?
- What are likely to be the problems with collecting information on child death?
- How can these problems be overcome?
- What are the benefits of monitoring child death as opposed to the sensitivities around information sharing?

12.40-12.50 Break

12.50-1.20 Thought shower; what do you think of when we use the term *child health*? Child health written in the centre of the page and write around it **how?** In the next area outside of the written words find out how they might be involved in a project looking at these areas of interest

Advising for the future; in groups of 6 undertake an exercise where the young people are put in charge of the project of child health (chosen from their thought shower) to see what they focus on and how they would develop it. E.g. as young advisors, facilitators of discussions with other young people, sitting in forums, websites, questionnaires, consultations set up to use in H&SC groups.

Feedback; to group ideas

1.20 – 1.25 Final thought shower

- a) What do you think of the project in general
- b) What do you see as the practical ideas and priorities for young people in this project to enhance its success
- c) What they approve of and don't approve of; what their concerns are and identification of avoidable factors

1.25 – 1.35

Thank all the participants for their involvement and let them know that what they told you will go into a report and will be sent to CEMACH. A summary report will be sent to their teacher to share out.

Feedback from group - target exercise

Give out vouchers

Items needed for consultations:

Pens, flipchart paper

bluetack

Groundrules poster

Target poster

Monitoring Forms

Young NCB leaflets

Loudspeakers

Cemach leaflets

Appendix 2

Case study A

Apart from the information gathered what else would you want to know about this case?

- When she went home was there anyone there to support her?
- Who raped her – was it someone she knew?
- Where did she live?
- Where was she walking the dog?
- Details of the care (physical and psychological) she received at the sanctuary?
- Was the rapist charged?
- Who from the staff was on call at the weekend?
- Did she have past history of psychological problems?
- How sensitively did the police/family deal with the incident?
- What religion / ethnicity was she – was she from minority group. Would her community look down on the rape?
- How was her behavior after the event – had it been monitored?
- How did she get home after the rape?
- What support did family get themselves and give to her?
- Who was the male friend to her?
- Question the male friend
- Did she think it was her fault?
- Did she take drugs?
- Why was she forced to kill herself?
- Why was she so upset?
- Did she know the person who raped her?
- Was she pregnant or did she get an STI?
- Was there an opportunity to talk to somebody?
- Was she in a relationship – or had she split up?
- Did she have enemies – was she warned?
- College investigators – how did she get on?
- Results from examination?

What are the sensitivities associated with collecting this sort of information

- Sensitive
- Tack required for family members
- People may know the person it happened to and not keep it confidential
- Health information is okay, but personal information shouldn't, for example that she was a champion swimmer may mean that someone may be able to identify them.
- Rapists might retaliate
- Not capable of answering questions
- Might not feel safe to say whole story
- Personal – hard to share info
- Doctors might not know answer

What can be learnt from the case?

- More awareness about walking out late a night - Don't go out walking late
- Emphasis on self defense/awareness
- Don't let rape victims go home so soon – provide more emotional support and after the rape
- Put more weight on psychological care, e.g. Counselling and comfort
- Educate parents and supporters about what to do
- Be aware of religious/ethnicity sensitivity information
- Offer translator if language issues
- Carry a rape alarm, spray alarm
- Not walking alone at night
- Reassurance from police on her safety particularly at night
- Not to be out too late by yourself, not left on your own
- Support is around
- She was sent home too early, why?
- Light place, more people

What are the benefits with this approach of monitoring child death in this way?

- To stop it happening again
- To be able to handle the situation if it happened again
- Help other children
- Showing caring
- Safer to tell others about rape
- Less kids die
- Find evidence – draw conclusion
- Feel more confident

Case B – substance misuse

Apart from the information gathered what else would you want to know about this case?

- Where had she been the night before?
- Had anyone seen her – what state was she in?
- How do they know she fell asleep?
- How did she get split up from her friends?
- Why did she not have a mobile phone on her?
- More GP information on health?
- Was she under age?
- Why was she served in the first place?
- How much alcohol in the bloodstream?
- What type of alcohol spirits, beer, wine?
- Was she aware the effects of alcohol, e.g. mixing drinks?
- Why did she go home alone?
- What was she wearing?
- Ethnicity – where was she from?
- How many drinks had she had?
- How was her behaviour with her friends?
- How cold was it?

What are the sensitivities associated with collecting this sort of information

- Do not treat as just another case – treat each one individually and sensitively
- Friendly rapport important
- Maybe pub/shop might get into trouble for serving her
- Could point blame at parents
- While parents grieving shouldn't ask questionnaire
- Upset
- Media spotlight not want to be used as a statistic
- Should get permission from parents, parents should want the case to be resolved

What can be learnt from the case?

- Don't drink too much
- Stay with buddy/safety in numbers
- Phone someone
- Tell someone where she is going
- Dress sensibly
- Make sure you let someone know if you are in trouble
- Do not go home alone
- Alcohol education e.g. on binge drinking
- Organize your night at the start – how you will get home?
- Tell people the risks of weather and hypothermia – what might happen i.e. bizarre behaviour

What are the benefits with this approach of monitoring child death in this way?

- The benefits will always outweigh the sensitive of it, as it will prevent and stop other similar situations occurring again.
- Find out how it happened – pass on message to others about problems of drinking
- People want to help other people so on balance it is important to share the information

Case study C

Apart from the information gathered what else would you want to know about this case?

- Was the road lit up?
- Was family called?
- Was the driver drunk?
- What happened between being hit and the ambulance arriving?
- How long it took for the ambulance?
- First aid, shocked, probably too shocked for friends to administer it?
- Why out so late - 14 yrs old out at 11.50pm?
- How was he traveling?
- What did his friend do – speak with him?
- How long to hospital?
- What happened when he got to hospital – treatment he refused?

- What happened before?
- Had he heard van coming?
- Driver – get details e.g. how fast was the driving, drinking, and any other physical details?
- What was the boy doing that night? Drugs/drinking
- What head injury he gained?
- What state was he in?
- Did his friends know 1st aid?
- Did friends get injured?
- Dyslexic – road signs, could he read them?
- Would basic first aid have helped him?
- Road layouts, pavements and lighting
- Were the paramedics appropriately trained for childcare?

What are the sensitivities associated with collecting this sort of information

- Make sure no-one will know who he is
- As long as it is all confidential then there shouldn't be any problems
- Drs notes referring to father although maybe this impacted on his behaviour
- His dyslexia
- No sensitivities in this case – its just simple, tragic though

What can be learnt from the case?

- Don't drink and drive
- People should be more aware when crossing roads
- People, especially young, should have more info/education in first aid
- Stop it happening
- People can be more aware of HOW accidents happen
- Don't walk or be cautious when walking in dark lanes
- Walk with someone older
- Recommendations about lighting in country areas
- Warnings to drivers
- Hearing problem – be more aware at night
- Time of night – especially after hours
- Driver at night in the areas – aware of pedestrians
- Road awareness
- Lighting - Don't walk on road with no lighting
- Are road signs appropriate for those who don't read
- Be with buddies more than 3 people
- Be cautious of your surroundings
- Town planning should have lights

What are the benefits with this approach of monitoring child death in this way?

- Benefits outweigh the sensitivities
- Need to weigh up what's best, preventing it happening again or embarrassing someone
- My group noted how all deaths occurred in rural areas – are there appropriate services in these areas?