



**Healthy London  
Partnership**

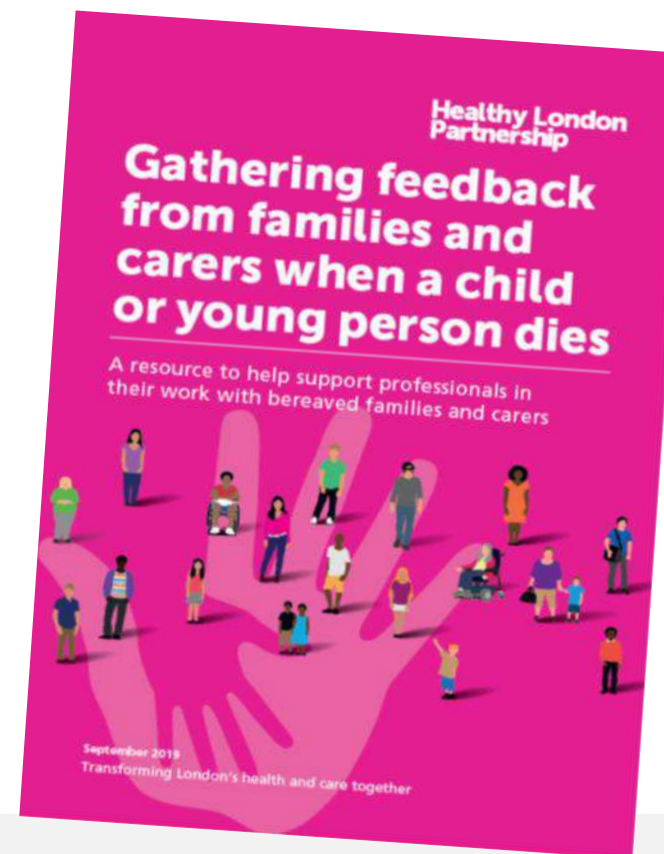
# PEN Awards

**Wednesday 16<sup>th</sup> September 2020**

**Category: Using Insight for Improvement**

**David McKinlay  
Programme Manager**

 **@HealthyLDN  
@SandsUK**



Supported by and delivering for:



**Public Health  
England**



**SUPPORTED BY  
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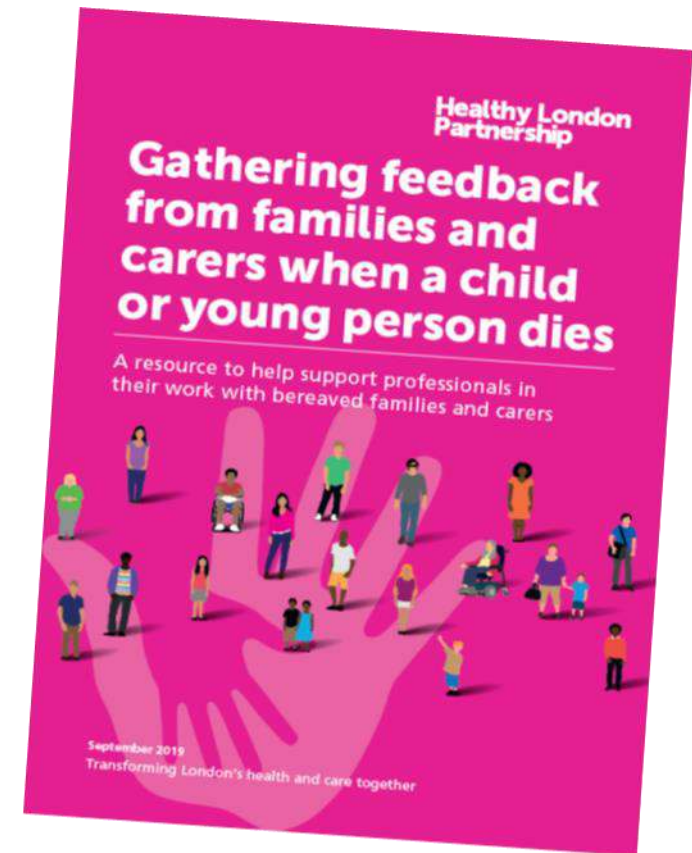
**London's NHS organisations include all of London's CCGs, NHS England and Health Education England**

# What is Gathering feedback from families?

- Online resource launched September 2019
- Evidence based
- Highlights key principles of **ideal bereavement care**
- Provides **guidance** on the considerations that should be taken into account before seeking to collect information from bereaved families
- Provides an **adaptable tool** to support the **collection of feedback** from parents and carers – the *Childhood Bereavement Experience Measure*
- Consolidates existing literature & information

For:

- Bereavement support staff
- Key workers
- Commissioners
- Bereaved families
- All professionals involved in the care of bereaved families



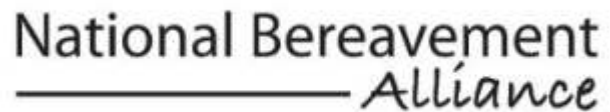
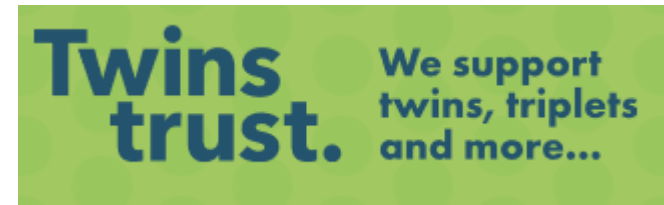
# Why develop it?

- **Approximately 5000 children across the UK die each year**
- Each death has a profound effect on the child's family and wider network
- Parent feedback can inform improvements in bereavement services and care
- Until June 2017, no nationally validated measures to capture the experience of women, families and carers following the death of a baby or child
- *Gathering feedback from families following the death of their baby* published for **maternity care**

**Why is there no similar suite of agreed sensitively tested questions to use following the death of a child?**



# Do parents want to feed back on their own care?

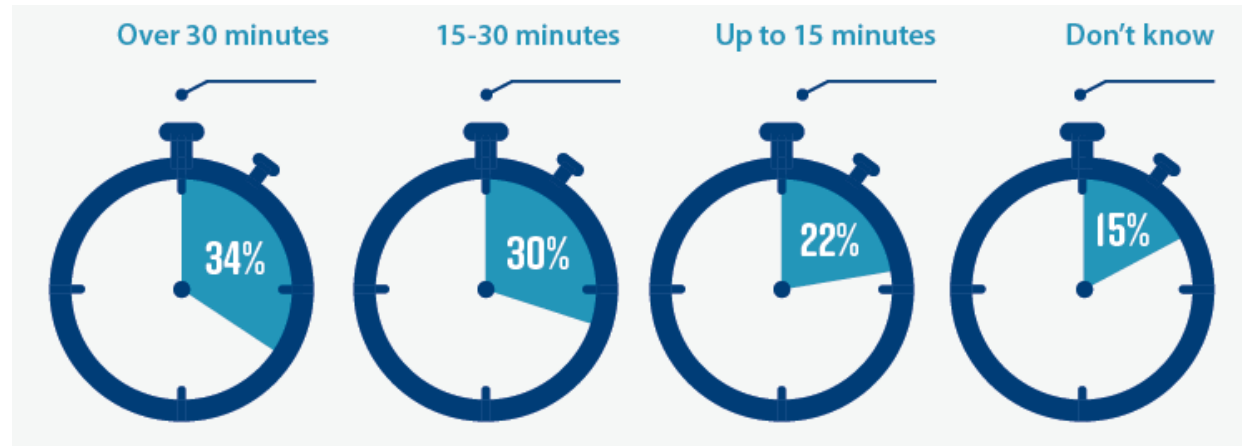




# Sands survey results – input from 382 families

# 98%

of bereaved parents felt that they should be offered the opportunity to provide feedback.



“I feel people deal with grief differently and there is no specific time to be asked this. It would probably be good to ask people to complete a form when the time is right for them than applying any kind of pressure.”

Bereaved parent



Email / Online

# 74%



Paper

# 72%



Face to face

# 53%



Phone

# 25%



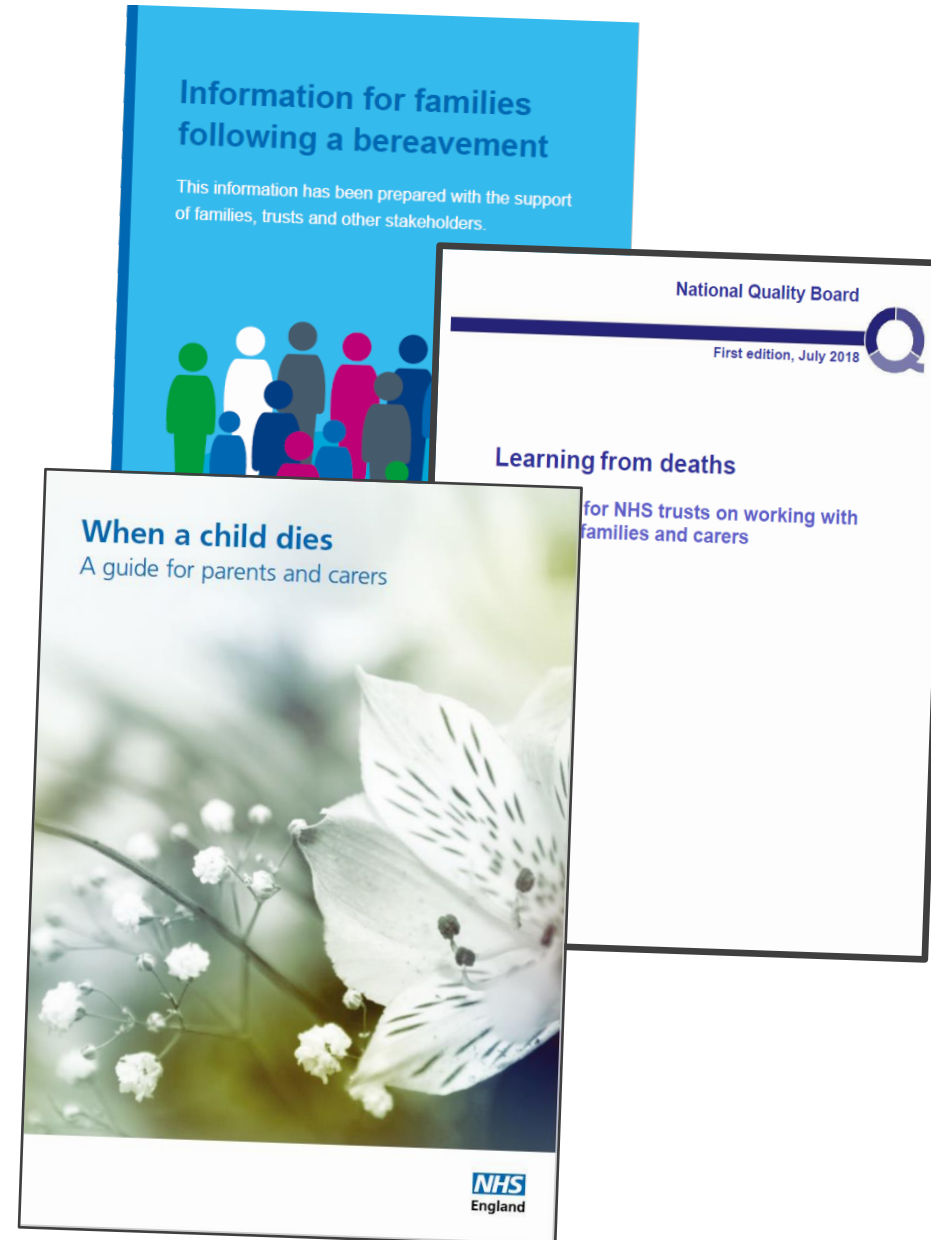
The medical professionals collecting feedback may contact lots of families, but for each family this is a major part of their life and it shouldn't be treated as a standard process.

**Bereaved parent**



# What is high quality bereavement care?

- Reviewed published literature
- Established a working group:
  - ✓ Parent Advisors
  - ✓ National Children's Hospital Bereavement Network Group
  - ✓ Bereavement Nurse Specialists
  - ✓ Child Bereavement Facilitator
  - ✓ Trust Bereavement Lead
  - ✓ Bereavement Service Manager
  - ✓ Bereavement Counsellor
  - ✓ Child Death Review professionals
  - ✓ Paediatric Consultants
  - ✓ Consultant in Public Health
  - ✓ Family liaison nurse specialist in paediatrics
  - ✓ Nursing Directorate - NHS England and NHS Improvement
  - ✓ Commissioner of Children's Services
  - ✓ Charity
  - ✓ Healthy London Partnership networks



# Ideal bereavement care would include:

## 1. END OF LIFE / PALLIATIVE CARE

- Respect the family's privacy and wishes at the time of their child's death
- Provide opportunities for the family to view, have contact, and make memories with their child (where appropriate)
- Inform families about the post mortem process
- Provide support around any decisions requiring consent
- Provide practical information in relation to the registration of a death, the collection of a death certificate, personal belongings, medical and other records

## 2. COMPASSIONATE CARE

- Treat bereaved families with compassion, dignity, respect, kindness, and sympathy
- Ensure that information collected is treated confidentially
- Look out for signs of isolation and encourage families to invite friends to attend meetings and seek support

## 3. SUPPORTIVE ENVIRONMENT

- Consider appropriate venues and forums for proposed meetings and interactions and give families a choice
- Provide support to families when decisions are required to be made within short timeframes
- Provide families with time and space to process information and do not pressurise them to make decisions or engage with services

## 4. COMPASSIONATE COMMUNICATIONS

- Staff should properly introduce themselves
- Ensure communications are:
  - in plain, understandable language (free of jargon) with clarification of any technical terms, phrases, acronyms, processes, procedures, and organisations
  - Clear, concise and provided in an easily digestible format
  - Person centred, sensitive, sincere and appropriate in tone with sensitive headings
  - Transparent, open and honest
  - Accessible in the language of choice

## 5. PERSONALISED CARE

- Ensure those providing care are trained
- Listen to bereaved families and take their views on board
- Respect the values, culture, faith and beliefs of the family
- Ensure that support is provided to the wider family, including siblings and friends
- Check death certificate for accuracy before providing to a family

## 6. BEREAVEMENT SUPPORT

- Provide bereavement support in the aftermath of a child's death and for as long as is required
- Ensure that suitable and appropriate bereavement support is accessible in a timely fashion and when required
- Signpost bereaved families to sources of high quality advice and support services including: aftercare; chaplaincy; counselling; independent advocacy; legal; local charities, helplines, and family liaison service

## 7. CHILD DEATH REVIEW PROCESS

- Help families understand the child death review process - which organisation will lead, which professionals will input, and the timescales involved
- Ensure that bereaved families have a dedicated and named support officer, a 'key worker'
- Treat bereaved families as equal partners throughout the child death review process
- Ensure timely, responsive contact, information and support from the key worker
- Ensure bereaved families are represented and / or supported at key meetings
- Ensure bereaved families know how to support and contribute towards any investigation(s) into their child's death (where applicable)
- Ensure bereaved families understand how to appeal any decision

## 8. LEARNING CULTURE

- Support bereaved families to provide feedback about the care of their child and their own bereavement care (if they wish to do so)
- Outline ways to raise concerns and welcome challenge positively
- Provide bereaved families opportunities to evaluate any recommendations or action plans developed to improve services following the review of their child's death
- Provide bereaved families opportunities to contribute to, shape and support local guidance, systems, processes, tools or staff training
- Inform bereaved families of any changes to the systems of care resulting from the review of their child's death



# The Childhood Bereavement Experience Measure

## Challenge:

- Scope – breadth of circumstances & time period for the survey
  - How detailed – granular vs high level
  - Completion time / number of questions
  - Themes & sequence
  - Language and tone
  - Quantitative vs qualitative
  - How encourage completion - identifiable vs anonymous
- ✓ Collect feedback from any child death
  - ✗ One-size-fits-all tool
  - ✓ Bank of questions that can be used to tailor an appropriate questionnaire
  - ✗ Be shared in its entirety – 20 questions max
  - ✓ Has both and free text & likert scale
  - ✓ Designed as an anonymous questionnaire
  - ✓ Can complement existing questionnaires

# Childhood Bereavement Experience Measure Cont

## SECTION 1:

### LAST MOMENTS SHARED / PALLIATIVE CARE

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This section covers questions that focus on the period leading up to and immediately  
*[NB Not all of these questions will be appropriate for all families and / or carers].*

To what extent do you feel:	Strongly agree	Agree	Neither agree disagree
1.1. That your child was treated with care and respect?			
1.2. That your privacy was respected at the time of your child's death?			
1.3. That your wishes were respected around the care of your child before and after their death?			

**It is recommended that any questionnaire of the care of bereaved families and carers contains no more than 20 questions and is reviewed by the local legal and complaints teams or Patient Advice and Liaison Service (PALS) before use**

## Feedback – early days

“I am a junior doctor .... have recently started work aiming to explore and ultimately improve palliative care of children and young people in NW London. A significant part of this work would of course involve gathering feedback from bereaved families/carers. The Healthy London Partnership resource is very helpful for me in guiding approach (timing, format etc) of gathering feedback from bereaved families/carers. The CBEM is clearly a fantastic tool to aid evaluation of bereavement services”

*Dr Iona Talintyre, St Mary's Hospital, Imperial College Healthcare NHS Trust*

“Use of the resource has been built into the Barking, Havering and Redbridge (BHR) CDR systems and shared with the bereavement services at BHRUT NHS Hospital Trust. The data that will flow from our questionnaires will be crucial in understanding the effectiveness and the development needs in the services we commission for those faced by the death of a child”

*Daniel Devitt, Interim Children's Commissioner, NHS Redbridge CCG*

“I think it is a brilliant document and very obvious that parents have been part of the framework”

*Chezelle Craig, contributor and bereaved parent*

# Who – the team



**David McKinlay**  
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Partnership



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**Ross Jones**  
Senior Bereavement  
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Coordinator, Sands



# Thank you

This work could not have been completed without:

1. the support of a range of charities in sensitively engaging with their members to promote the Sands survey
2. the open, honest and candid feedback provided by the 382 families who took part in the survey
3. the willingness of a number of families, bereavement professionals and other stakeholders who volunteered their time over a number of months to help shape and refine the work

## Further information

**Email: [hlp.cyp-programme@nhs.net](mailto:hlp.cyp-programme@nhs.net)**

**Website: <https://www.healthylondon.org/our-work/children-young-people/child-death-review-programme/gathering-feedback-from-bereaved-families-and-carers/>**

