

# The impact of INQUEST's service on families' experiences: an analysis 2010 – 2013

December 2013

### Introduction

In April 2013 INQUEST undertook a detailed analysis of the impact of its service delivery over the previous three years. The aim was to see whether INQUEST had achieved its objectives of improving bereaved family members' understanding of their rights, where to access quality advice and support and increased ability to participate in the inquest and investigation system. We also aimed to help reduce isolation, increase families' understanding of complex legal procedures and how to find out how their relative has died and potentially to move on at the conclusion of the inquest. Originally we estimated that 2,250 bereaved family members would have been assisted over this time. However our estimate was exceeded and in fact, 3,336 family members had been assisted.

### **Background**

It is widely recognised that whilst any sudden and unnatural death is traumatic, the death of someone in custody or other circumstances requiring an inquest carries with it additional trauma. Many families will talk to us about their fears, uncertainties and feelings in the way that they are unable to do with anyone else, including their lawyers. Because we have a detailed knowledge and understanding of both the legal processes involved and the practical and emotional needs of families and that we offer a non-judgmental, confidential and free service, we are able to support families in a way that they can be fully involved in the preparation for an inquest.

They also know that we will be offering this service to others who are facing similar situations and therefore we can reassure them that they are not alone and that however appalling their individual experience we can set it in a broader context. This enables families to cope better with the stress, anxiety and stigma generated by these deaths that if left unaddressed become a more serious physical and health issue with the consequent impact on the NHS and wider society.

### Family survey

INQUEST conducted a one-off survey of families who had received our service between 2010 and 2013 to ask them a number of specific questions about the impact of that assistance on their physical and mental health.

The results from the returned questionnaires suggest a positive impact on both mental and physical health. We think this is, in part, due to the close relationships the staff develop with service users, and the way in which these relationships are experienced as extremely supportive.

The impact on bereaved families' mental health following a death is clearly significant. As would be expected every respondent described their enjoyment of life in the days after they were told about the death as poor, and the majority of respondents described their state of mind in the days after they were told of the death as poor. A high proportion of respondents described poor physical health at this time, and a significant proportion described their relationships with family, friends and partners as 'poor'.

### Q4: In the days after you were told about the death how would you describe your:

Physical health:

Poor (58%) Same as normal (42%)

• State of mind:

Poor (92%) Same as normal (8%)

Family relationships:

Poor (48%) Same as normal (26%) Better than normal (26%)

The service offered by INQUEST had a clear beneficial effect on families during a difficult time. Not only did many families report that the service helped maintain their physical health or mental well-being (in that there was no deterioration as a result of receiving our service), half stated that INQUEST's service helped their physical health and a significant majority (88%) of respondents said that INQUEST's service helped their state of mind. Taken together, this translates to all those families responding to the survey reporting that our service had a positive impact in helping to maintain their physical and mental health and well-being. The individual figures and percentages are outlined below.

### Q20: How do you think INQUEST's service impacted on your:

Physical health:

Helped (50%) No change (50%)

• State of mind:

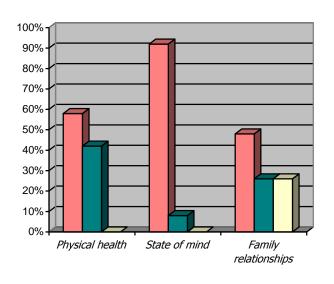
Helped (88%) No change (12%)

Family relationships:

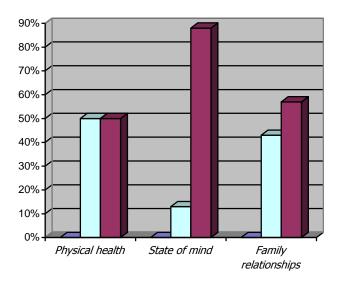
Helped (57%) No change (43%)

Q4: In the days after you were told about the death how would you describe your:

Q20: How do you think INQUEST's service impacted on your:



■ Poor ■ Same as normal ■ Better than normal



### **Further feedback**

Following an analysis of INQUEST's feedback mechanisms in March 2011, we also gather data via a short questionnaire sent to families at the conclusion of each case. This aims to gauge the impact of our service and to collate suggestions for improvement or expansion. Quantitative analysis of all **end of case questionnaires** received between March 2011-April 2013 showed the following:

### Q2: How would you assess the overall quality and level of the casework service provided by INQUEST

100% of respondents said that INQUEST's service was "very good" (the highest rating) with 3 adding there should be an "excellent" category.

### Q4: How would you rate our INQUEST Handbook for families?

69% of respondents to this question said it was "Very helpful" while the remaining 31% said it was "helpful"

A selection of the comments made by families about the impact of INQUEST's service can be found in Appendix 1. These clearly demonstrate the positive impact that the casework service had on families' physical and mental health and well being.

A number of families also offered **unsolicited feedback** in the form of cards, letters and comments via social media such as Facebook. This type of feedback is now routinely saved and analysed (in a similar way to the formal feedback gathered through end of case questionnaires) to form an evidence base about the impact of INQUEST's work and to inform our ongoing evaluation of the service and planning for the future. Representative comments from this feedback include:

"I couldn't have coped without you"

"Thank you for all the support you provided XX [friend of widow]. She seemed like a different woman when she walked out of the meeting with the Trust. She felt like a huge weight was lifted from her shoulders."

"I know you're not counsellors but I feel really comfortable talking to you and feel you help and understand more than any counsellor."

"Thank you very much for all the help and support you have given me at this time of distress. It has given me and my family a big relief. The stress has been reduced."

A further mechanism through which INQUEST receives feedback on its work is when **families write or speak publicly about the impact of our service as part of policy and campaigning work**. We regularly speak to families about their experiences to compile evidence and case studies for responses to parliamentary inquiries, consultations and research reports. We also work to ensure that families are supported and empowered to raise their views and concerns directly with policy and decision makers – for example by giving oral evidence to parliamentary committees, talking at public events or writing articles for magazines, newspapers and other publications. As part of this work families regularly comment on the impact of the service they received.

For example, Yvonne Bailey, mother of 16 year old Joseph Scholes who took his own life in custody both inspired and wrote an introduction for INQUEST's Skills and Support Toolkit (the resource for families and friends dealing with the aftermath of a sudden bereavement produced as one of the milestones for outcome 5). Yvonne Bailey said that:



"The guidance we were gifted from INQUEST helped my family and me to survive the unimaginable loss of Joseph....During my darkest days INQUEST gave me the information, education and encouragement which inspired me to achieve more than I ever thought possible. My family and I remain forever indebted to them"

She also spoke about the impact INQUEST's service had on her physical and mental well-being at the October 2012 parliamentary launch of our research report on the death of children and young people in prison (*Fatally Flawed*) and in a report compiled by the Diana, Princess of Wales Memorial Fund to celebrate their work (*15 years*, *15 stories*):

"One of the main things we got from INQUEST apart from the life-saving support — and I do not say that lightly, I truly don't think I would be here without them — was information. They gave exactly the right amount of information, as well as emotional and practical support. We knew virtually nothing about the legal system. INQUEST took away all that worry. Any information we needed was a phone call away."

The sisters of Sean Rigg spoke about the importance of INQUEST's service when they gave a speech at a fundraising dinner in March 2013. Samantha Rigg-David said:

"Whenever we needed [INQUEST] they were always on the end of the phone - advising us, comforting us, making calls on our behalf and imparting their vast knowledge of what would happen, and what we needed to do - and all the things to watch out for - INQUEST simply never left our side, so to speak. I sincerely believe we would have never had gotten this far without them."

Her sister Marcia Rigg went on:

"INQUEST was without any doubt a lifeline to my family within hours of police liaison officers coming to tell us that Sean had died in police custody, as you have just heard from my sister Samantha, and continues to be a lifeline to many other families who find themselves in the same predicament as my family."

We also gather feedback from families during **Family Forums.** During the course of these day-long sessions, families are invited to leave their feedback (on any aspect of the Family Forum, INQUEST's service, their thoughts on the discussions or anything else) on anonymous, handwritten post-it notes which were added to a large wall poster. Many of the comments recorded families' thanks for the "supportive" service they received (with a typical note being "Thanks so much. Your support is great. Keep up the good work") and a significant number of families explicitly mentioning the impact that this aspect of INQUEST's work has on them. Sample comments from one Family Forum (in November 2012) included:

"Thank you – talking to others helps our grief."

"Lost until I found out about INQUEST. At last someone who listens."

"Thank you INQUEST Family Forum. Helps me so much"

### **Conclusions and next steps**

The different methods, both quantitative and qualitative, of gathering feedback and measuring impact have produced consistent results over a three year period. Overall the feedback suggests that **all** families who used our service during this time reported INQUEST's service helped them to at least maintain their physical and/or mental health **and** 65% of those who used our service during the project lifetime reported a positive impact on their physical and mental health.

Our evaluation of the impact of INQUEST's work has underlined how crucial our role can be in helping those bereaved by a traumatic death to cope with the complex legal processes that follow and, by extension, help ensure that their mental and physical health and well-being are maintained.

The overwhelming, positive feedback from families about INQUEST's service also demonstrates the ongoing need for our work. It was noticeable that when asked how INQUEST's service could be improved, nearly two thirds of the families who took part in our end of project questionnaire in April 2013 specifically identified the need for continued and improved funding (see Appendix 2 of this report). Representative comments included:

Funding is an issue because with more of the right funding, INQUEST would be more accessible and available, it would enable them to offer their services to more people and assist in the difficulties of understanding the judicial system, court hearings, and inquests.

More funding, more services, if I had the time I would volunteer for you

I would like to see you better funded

The feedback also indicates a need to develop the different forums and resources, both human and written, that empower and engage the community of people bereaved by sudden and traumatic death. INQUEST will be taking these lessons forward as we seek funding both to continue to provide our important service to be eaved families and to enable us to develop it even further.

### Appendix 1

# Ongoing feedback mechanisms: sample of family responses to end of case questionnaires (March 2011 to April 2013)

### Q3. How beneficial has the advice and casework service been to you?

"Would have been lost without INQUEST. Period."

"INQUEST ... helps you to understand a very complex circumstance which when a loved one is lost is already difficult. Our caseworker has also provided good advice, kind, supportive, helpful – without our caseworker and INQUEST this would have been an intolerable time for me and my family. Thank you so much."

"[INQUEST's service] helped me understand what was going to take place at A's inquest and I wasn't on my own. Made me feel that someone cared and it was comforting."

"We have never been in a situation like this ever, the help and support from our caseworker at this sad time was a great help. Talking to our caseworker in a distressed state at times helped me so much. We will always be grateful for her help."

"Without the support, care and help given by our caseworker I could not have got through those traumatic months cause by the death of B in prison... I was left scared and floundering when I found I had been named by B as his "next of kin". Our caseworker's gentle, softly spoken words of comfort and guidance brought me through a very difficult period. Without her being there for me, I know I would have gone under."

"We could not thank you enough after M's inquest... We as a family had no idea of how to even start going about preparing for M's inquest and to be honest we were scared, not really understanding what to expect but with the support and comfort from you we felt assured. You were such a solid support to our family throughout M's inquest."

"The advice offered was invaluable at a very difficult time for me and my family."

"Your service was invaluable, not only did you provide information as requested you were proactive in giving help and advice in areas we had never even thought about. On a personal level you offered comfort and support especially when everyone else was making things as difficult as possible – especially HMP Durham and the coroners office."

## Q6. Other comments or suggestions you might have about the casework service provided by INQUEST:

"I only wish all families in my position could have the type and quality of support that I had."

"No other organisation assisted – only INQUEST seem to provide this service. Thank you so much – your charity and those who work for you, especially our caseworker, have been a tremendous support throughout what was an almost four year ordeal, from the news of the death, to the end of the inquest.... Words are not enough – thank you all."



"When R died me and my husband felt no one cared. We had no one at all. INQUEST helped us with our loneliness. If it wasn't for caring people like our caseworker and others from INQUEST our loneliness would have been unbearable. Their support and help was what we needed."

"We did not know where to turn when this nightmare happened to my mother and myself. After looking for some help seems [there is] not much anywhere! You are the only company I could find and you have been a godsend!"

"I think you do a first class job and I hope that you continue campaigning and helping other families in difficult situations."

"Our caseworker was unbelievable and I cannot imagine how I would have come through some dark days without her. Another caseworker came in at the end but took over seamlessly and should be commended for picking up the reins so easily and making us feel that our support was uninterrupted. I think that other organisations should look to yourselves and aim to treat people in our circumstances as well as you do."

### **Appendix 2**

### April 2013 Survey: sample of open question responses

### Q10. How do you feel the inquest process impacted on you and your family?

"Generally positive. It was a difficult process to sit through as it stirred old feelings. However, seeing matters go through in details allowed reflection and brought matters to the fore to be faced and come to terms with."

#### "Traumatic"

"The process is difficult because we think we are making progress when we get dates for the inquest hearing, only for them to be cancelled time and time again we have had four cancelled dates so far. The feelings and emotions are difficult to control it is like being on a roller coaster. We are being given false hope and then cruelly let down by this process."

"It brought a long battle to an end. I felt that there was little else I could do. The hospital had already given an unreserved apology, the Coroner raised Rule 43 and wrote to the Department of Health."

"Very traumatic and distressing. I am divorced but had support of my older son. My ex husband and younger son opposed us getting legal representation and felt we should leave well alone. It has been hard to stay positive but my older son and I now feel vindicated that we made the right choice."

"The impact of this process, which takes a long time from opening and adjourning an inquest, almost four years in the case of my youngest brother, was the most depressing period of my life and this impacted deeply upon me and my husband and sons, and my brother's daughter. It is impossible to express how very stressful the period is before, and building up to the inquest. The hearing itself is also unbelievably stressful with a kind of relief at the end when you know for sure what happened (but in my case I fight on for the arrest and charging of the corrupt officer)."

"Some of my family have disowned me"

"Very stressful as we lead up to it. Not knowing where or how to get help and advice before and during inquest. Worries on how any help or representation would be funded which leads to thoughts of not even going to the inquest and to let it take its course without any involvement. Thanks to INQUEST my determination to see it through to the end was reignited with the help they offered and to path they led me down. Thank you!!"

"29 months after my brother's death we are still waiting for an inquest – we had a pre-inquest review last month. The waiting is extremely hard on us."

"It has played a very large part in my life and I see it as taking too long but nevertheless showing due respect to the life of my son, which was cut short."

"It has brought the family closer but for all the wrong reasons."

### Q18. How would you describe the attitude of INQUEST staff?

"I feel that the expertise is second to none. Always treated with kindness and honesty, I also feel that the support is human and personal."

"My case worker was in regular contact offering support and invaluable advice. Very closely involved both before and during the inquest. This was absolutely invaluable to me."

"brilliant thank you-you threw us a lifeline."

"Our caseworker was simply brilliant – with advice and moral and emotional support. Phone calls to her kept me going throughout what can only be described as an ordeal."

"Our caseworker in particular has been tremendously supportive and helpful"

"I would never have been able to find representation without INQUEST the support, advice & guidance I received & still do was exceptional. I am truly grateful & thank God I found INQUEST when I was desperate & feeling I would never get anywhere after frustrating & fruitless attempts to find help."

"INQUEST referred me to another organisation which led to discussions with a solicitor"

"I was very impressed with the service – I was treated very kindly and in a professional manner, with a referral to a solicitor"

"If I hadn't contacted INQUEST promptly I would never have found a solicitor to take on my complaint against the police and to represent my family at the inquest."

"Outstanding, when I contacted them, I did not know who else to go to."

"INQUEST have always been there for my family adding extra support in court & IPCC meetings"

### Q19. Was the service provided by INQUEST beneficial to you?

"No-one else could provide this kind of support. It's more than very beneficial, it's exceptional, life saving even, and comes at a time when you don't know where to turn and in circumstances that feel totally overwhelming."

"Without the support and advice from INQUEST I would not have had a case to present at the inquest. I would not have had an experienced legal team to represent me and I'm absolutely sure I would not have achieved what I was aiming for in terms of outcomes from the inquest."

"I was bereaved, in shock, confused not knowing what was happening or what had happened. Coroner, police and hospital were no help. Inquest listened, advised and supported. I needed this service."

"I do not know how we could have coped on our own in this traumatic time. We are immensely grateful to your charity for support and advice."

"I cannot bear to think what those who go through this process do without the help of a charity like INQUEST. All of those who supported me were so helpful and friendly it was more than beneficial. A brilliant combination of practical help over advice, funding, getting the right solicitor and emotional support."

"Without it I would be going to the inquest in a much poorer position. Taken worry off me and family"

"Absolutely crucial"

### Q21. Are there any ways we could improve the service provided by INQUEST?

"It would be wonderful to have a more local provision."

"I feel privileged to have had the support from INQUEST. My only concern is that most families who have suffered the death of a family member in custody do not have support from a caring, supportive organisation such as INQUEST, who importantly also have the necessary legal knowhow and experience to guide the family through the complexities of preparation and participating in an inquest. I only wish resources were available to make sure that the support I had is not the exception but the norm."

"The service that INQUEST provides does not need improving. It needs to be more sustainable as the work they do is so invaluable to be reaved families. What Inquest does need is the financial stability to expand all over the country and be more accessible to people.

"Funding is an issue because with more of the right funding, INQUEST would be more accessible and available, it would enable them to offer their services to more people and assist in the difficulties of understanding the judicial system, court hearings, and inquests. They explain and help you to learn about how and why things need to be done. They attended pre-inquests and IPCC meetings for moral support and professional advice. Their presence gives us confidence and comfort as they are a very caring group of people.

"The Family Forum days are a brilliant way of bringing bereaved families together to share their experiences and to talk about issues, or things they could not have previously talked about. But my understanding is that the family forums can only take a certain number of families per session. I hope that INQUEST can secure more funding to help more families. My family certainly benefited from the family forums, we got the feeling we are not in this alone. With the support and dedication from a wonderful and professional team we are learning to deal with our loss."

"Only if you can attract more funding and expand; your service was crucial to us coming through this awful event feeling we had a positive outcome from the inquest with yourselves and our legal team."

"Just keep up the amazing work that you do."

"To make it clear that you are an independent organisation who assist grieving families at their most vulnerable time offering advice support & guidance."

"More funding, more services, if I had the time I would volunteer for you. I wonder if you could recruit volunteer marketing staff? As a CAB adviser I am aware few people know of INQUEST."

"I feel you are a truly great organisation. I would like to see you better funded."

"It seems to me to be very adequate in the service it provides at the moment. It is quite unusual in Britain today to find a charity that is so consistently supportive when most have severe constraints on what they can do due to lack of funds."

"I'm not sure if you were around in 1998 but I wish I'd been told about you then if you were. I contacted you in 2010 for advice about accessing inquest records and you were very, very helpful. Ironically, your answer and finally finding out what I wanted to know, moved me on a stage. I decided not to pursue a request to read the records and to let my daughter rest in peace and to allow myself to let go a bit. Of course, I will never forget her but nothing is going to bring her back and I needed to let go to some extent. Thank you."