

Public Involvement consultation.

Enabling safer bathing for people living with epilepsy.

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- 1 Photograph of Naomi in intensive care
- 2 The online feedback meeting held 20/7/21

Dedication.

Mr Gordon Collier (14/5/32-1/9/20) who sat by Naomi's bedside every day for the seven weeks she was in intensive care. Also, to Naomi & family, and all the intensive care teams at Salford Royal Hospital and Wythenshawe Hospital in Greater Manchester.



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Abstract

This public involvement consultation (PIC) was set up to explore the opinions and ideas of people living with epilepsy for developing a full research project on the topic of prevention of drowning in the bath. The general advice available for people living with epilepsy (PLE) is to have showers instead of baths, or to have a chaperone and not to bath if alone (Epilepsy Action 2019). However, we know that people with epilepsy do have baths and have them alone, and that there are fatal and non-fatal accidents. Twelve people (7 men and 5 women) took part in the PIC via online meetings and written feedback. Principles of thematic content analysis were applied to detailed notes that were taken, and these were examined independently by the two authors to identify similarities and key issues. Seven categories were identified: Research issues and methods, encouraging language, advice and information, options available, consequences, influencing factors and perceptions of risk. The PIC confirmed that people do bathe alone and that the reasoning behind this is complex and warrants investigation. This includes consideration of language, emotions, personal biography and context, and the role of specialists.

Accessible summary

Epilepsy Action advise people who have epilepsy to have a shower instead of a bath, or to have someone with them when they bathe. However, people who have epilepsy do sometimes have baths on their own because they want to and there is no one around to help, or because they do not have a shower. People just want to be able to choose like anyone else.

Having a bath without someone around though is a risk, because if a person with epilepsy has a seizure when they are in the bath, then there is a risk of drowning. There are statistics available that confirm that some individuals with epilepsy have drowned in the bath, but there is no equipment available that might help prevent this for people with epilepsy. We wanted to understand the issue much better and develop some research. So to start this process, we got in touch with twelve people who lived with epilepsy to tell us what they thought about the idea. Ten of the people were diagnosed with epilepsy, one was a mother, and one was a sister of a person with epilepsy.

We had some online meetings and one-to-one conversations online. Some people sent us written feedback based on initial questions we asked, such as, 'do you think this is an important issue to research'? and 'what do you think we should focus on'? We collected all the information together and identified what the similarities and differences were. The main categories we identified were, research issues and methods, encouraging language, advice and information, options available, consequences, influencing factors and perceptions of risk. We need to consider language, emotions, personal biography and context and the role of specialists. Even though there were only 12 people involved in the public involvement consultation, we can conclude that this is an important topic and that a research project is needed so that we can understand much more about the issue and work towards improved safety.

Introduction and background

This document reports on a public involvement consultation (PIC) with people living with epilepsy (PLE). The purpose of the project was to consult with PLE on their opinions and ideas for developing a full research project on the topic of prevention of drowning in the bath. The initial idea for the research came about from a family experience where my (first author) niece, Naomi, was resuscitated by her mother Ruth, (my sister) after having a seizure whilst bathing. She spent seven weeks in intensive care (see figure 1) and fully recovered. However, it prompted some questions about equipment to prevent serious accidents such as this. Initial exploration found that there is no equipment to help prevent drowning in the bath, and that the issue is largely neglected in the literature. No mention is made of preventative equipment in the independent review of the death of Connor Sparrowhawk who drowned in the bath in a care home in 2013 (Verita, 2015). Discussing the issue with an engineering lecturer, Dan Garner, led us to the decision to first establish what the issues might be, and this PIC is part of that process.

Anecdotally we know that people with epilepsy do have baths and have them alone, and that there are accidents. This is despite the fact that advice for PLE appears to be, as one of the contributors put it, 'the same now as it has always been', that is, to have showers instead of baths, or

to have a chaperone and not to bathe if alone (Epilepsy Action 2019).

Nevertheless, we know that:

- In the UK there are around 600,000 people with epilepsy (around 1 in 100 people), with around 87 diagnosed daily and 21 epilepsy related deaths each week (Epilepsy Research UK, nd).
- Life expectancy is reduced for people with epilepsy (PwE) (Gaitatzis et al 2004)
- Death rates in people with epilepsy have risen by 70% between 2001 and 2014 (Public Health England 2018)
- Seizure related death in the bath is not an uncommon occurrence (Cihan et al 2018).
- There is a ten times greater incidence of drowning in the bath than the general population (Bain et al 2018).
- The UK water incident database (WAID) indicate that 24 people died with seizures in the bath 2016-2020, with at least 91 other awaiting classification (though this appears to include jacuzzis and hot tubs) (National Water Safety Forum, 2020).

Figure 1. Naomi on an extracorporeal membrane oxygenation machine in Wythenshawe Hospital intensive care unit. October 2014 (thanks to Naomi and Ruth for permission to use this image).



Therefore, we set up this PIC as a collaboration to gain the perspective of PLE in identifying how important this topic might be and what the key issues are (NB the concept of 'safer bathing', rather than 'prevention of drowning' was in fact introduced based on the outcomes of this PIC).

Public involvement consultation methods

Method

Emails were sent in the first instance to a local Epilepsy Action group in Sheffield. We then met with Angie Pullen (CEO of Epilepsy Action) who confirmed permission for our continuing contact with three individuals accessing the organisation who were interested in taking part. This was achieved via the local branch putting us in touch with others. Similarly, Jane Hanna (CEO of SUDEP) put us in touch with three people. The other contributors either came forward on hearing about the project in presentations and conversations or were personal contacts of the authors.

We also contacted the research design service (RDS) at the National Institute for Health Research (NIHR) for advice and support, which was available throughout the duration of the consultation period and beyond. We successfully applied for £300 from their public involvement fund and

were therefore able to offer each contributor £25 Amazon vouchers as a token of thanks and compensation for their time. Contributors were regularly kept up to date with progress via email throughout the duration of the consultation.

Twelve people in total contributed to the project, seven women and five men. One was a mother, one a sister and ten people were diagnosed with epilepsy. Contributors were asked to self-describe gender, ethnicity, and age (as shown below) and they were asked to confirm that they agreed for the meetings to be recorded. They were also asked to confirm that they were happy for their names to appear on any publications or presentations to acknowledge their contribution. They were also advised that they would need to feel able to discuss difficult issues.

Age

Age range 24-64

Ethnicity

Black African = 1

English = 1

White/British (one Welsh born) = 9

Four online meetings were held. An explanatory document (written in plain English – see appendix 1) with a series of initial questions to prompt discussion were sent to contributors via email a week before.

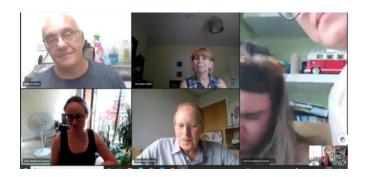
The online meetings (Microsoft Teams) were conducted with clusters of not more than four people. These took place on 15th, 16th, 21st and 23rd June 2021. Three additional contributors offered email feedback based on the questions outlined in appendix 1. Online meetings were guided by the questions shown in appendix 1, but were conversational in style, facilitated by the first author. These were recorded only for an aide memoir. The two authors kept detailed notes of the conversations.

Principles of a thematic content analysis were used to inform organisation of the notes. The initial questions (appendix 1) were used to organise a summary of the key issues noted from both the emailed feedback and the group conversations, and these were placed in table form to enable comparison across the responses. The notes for each were compared to identify similarities. This was done independently by the two authors, then the descriptions of each cluster of points was discussed and agreed.

A final meeting was also held on July 20th, 2021, where all contributors were invited to hear feedback on what was found and to have the opportunity to discuss it further. Five people attended. An evaluation meeting was also held with NIHR RDS, after which the vouchers were distributed. In addition, the final draft of this PIC report was sent to the

contributors to provide opportunity to remove details, suggest changes and generally review the document.

Figure 2. Online feedback meeting 20/7/21



Ethics

As this was a public involvement consultation, ethics committee permissions were not required (Pandya-Wood et al 2017). However, ethical principles were adhered to in the conduct of the consultation. Contributors were asked for permissions, confirmed by email, for being identified by name in any published documents. Agreement for recording the meetings as an aide memoir and for making photographic images public was also given.

Information and updates on the progress of the PIC were provided regularly throughout and the feedback meeting ensured contributors had the opportunity to consolidate the experience and verify the findings as presented.

Findings

The findings are presented here within seven main categories:

- Research issues and methods
- Encouraging language
- Advice and information
- Options available
- Consequences
- Influencing factors
- Perceptions of risk

There is a lot of overlap between the categories identified, but we have tried to capture the main focus of the points within each subheading.

Research issues and methods

The questions about research methods led to identifying a range of ideas. Generally, there was a sense that as 'no one has asked us about this before', and as people felt marginalised, they wanted us to collect as much information as possible. The relevant issues we identified from the feedback that need to be considered for investigative purposes were:

- 1. It can be difficult to talk about
- 2. Onboarding process to epilepsy identity (when diagnosed)
- Collect as much information as possible e.g., personal management, mental wellbeing, safety security, physical implications,
- 4. Include lots of different perspectives, people with epilepsy, parents, carers, nurses
- 5. Include young people
- 6. Include people with learning disability
- 7. Face to face

- 8. Emails
- 9. Interview
- 10. Survey
- 11. Questionnaires
- 12. Phenomenology
- 13. Different methods so there is choice
- 14. Use Epilepsy Action, Epilepsy Society, Epilepsy Sparks, specialist nursing teams

Encouraging Language

This was something we implemented immediately, as mentioned in the introduction. We had framed all our initial work around the idea of 'preventing drowning' but this changed to 'enabling safer bathing' because of the strength of feeling about a constructive rather than negative focus. This was also informed by the point made in the PIC that our aim should clearly acknowledge that this was not about encouraging PLE to use baths, but to understand that where people did decide to bath, this could be made safer.

Advice and information

There were many facets to this because there was such a diversity of experience, even within this small group. This included the fact that some people, for example the older contributors, were diagnosed as children many years ago, and had had little or no information that they could remember at the time. This history was felt to be very important,

and that it was also important to understand individual biographies when studying epilepsy.

There was a general belief that PLE (and/or their parents) were given very little information and that they had been left to figure things out for themselves. Part of the discussion concerned whether, if information and advice is given about safety, it may not be remembered due to cognitive difficulties, not uncommon for PLE. Relatives were sometimes relied on to compensate for memory problems.

This discussion led to questions being raised about the timing of information. For example, if information was given at the time of diagnosis, would it be remembered, was it revisited later? There was a sense of an absence of information overall, with gaps being filled by self-directed research and trial and error in everyday life. The type of information, whether it was heard, and whether it was understood, were all thought to be significant in relation to whether information was internalised or not. The issues of whether advice given was followed was therefore not felt to be a straightforward issue of 'choice'. In some cases, it was clear that choices were made by others, and that it might be important to consider the transition from childhood to adulthood in whether information was revisited once a cared for child became an

adult (if that adult child required ongoing support and supervision), for example, if a person had learning disabilities.

Options Available

It was discussed that many people may not have a shower or be able to afford to have one installed. Therefore, bathing may be their only option, contrary to advice available. In addition, many people live alone and do not have access to someone to chaperone, so personal context had to be considered.

Another rather different issue about options concerned one person who had wanted to give birth in a birthing pool, but was categorically refused this option, an issue of regret and disappointment. This had long lasting effects and lifechanging consequences.

Consequences

Fear and worry for both PLE and family were discussed as was the potential consequences of PLE bathing alone. Fear of injury and sustaining of injuries was a major concern to some people. Others had not considered the possible risks, or the risks just had not occurred to them. Some people were consciously aware of the potential risks but evaded the issue. Some, despite having full understanding, made an

active choice to take a bath, expressing the desire to be the same as everyone else. It was discussed that for people with learning disabilities, the issues of choice may be removed, with decisions about bathing being made for them.

There was also a suggestion that decisions were sometimes highly influenced by the (feeling of) dominant medical oversight of a person's epilepsy, where autonomy was compromised by the feeling of needing permission to undertake certain activities.

Influencing factors

Factors influencing the decision to take baths were considered. The priority for some people was relaxation, pampering and enjoyment, factors which promoted positive mental health. However, for others, taking a bath was purely for hygiene purposes. Some people simply preferred taking baths to showers.

Anger, resentment, and the desire to 'be normal' were influencing factors. A need was also expressed about being in control of personal decision making, rather than have 'rules' imposed. The recommendation to take showers served as an unwanted reminder about their epilepsy diagnosis and they resented having to even

consider that they needed to make a choice between bathing and showering.

Perceptions of Risk

The PIC prompted specific consideration around perception of personal risk taking. For some PLE, the risks associated with taking baths were felt to be low. This may have been determined by long periods of seizure freedom, as if no submersion accidents had been experienced, there was a sense that 'it has never happened' so people were more likely to feel secure. Naomi, whose accident prompted the PIC (referred to in the introduction), had never had an accident in the bath before, from age 18 months to age 17 years, despite taking regular supervised baths. This point raised another issue in that young children are presumed to automatically be supervised by adults whilst bathing, but when children with epilepsy transition to adulthood (with ongoing care needs), the risk may or may not be revisited, as needs change.

A fatalistic attitude was also evident towards the risks of bathing because of the awareness that death can occur suddenly and unexpectedly for people diagnosed with epilepsy. This led to adopting a viewpoint of resignation towards events over which PLE had no control.

Discussion

The findings of this PIC confirmed the anecdotal knowledge that PLE are having baths alone. Although only twelve people were involved in this PIC, their contributions along with the limited literature available, does suggest that this is an area of experience that warrants attention.

The variety and range of suggestions outlined in the research method category suggests unlimited possibilities to take this research forward and the potential research project focus has been significantly shaped by what was found in this consultation. In particular, the shift from 'prevention of drowning' to 'enabling safer bathing' was a key adjustment. It was important that the focus should be on promoting enablement, rather than making negative associations. However, there will be times when reference to the idea of 'preventing drowning' is necessary in order to communicate academic issues clearly.

The PIC revealed some ambiguity in relation to information given, received, or heard. Epilepsy Specialist Nurses (ESN) are reported to give safety information (Hopkins & Irvine, 2010), but there was little evidence of awareness of this in their own experience, that they recalled. The role of the ESN was experienced differently, including the absence of an ESN provision, and variations in the content and timing of

information where ESN services existed. Certainly, absence of any information about bathing risks was highlighted by some contributors. However, where information had been provided, it may have been overlooked, unrecognised or not remembered. This may be the case if bathing risks are discussed amidst complex and distressing information about epilepsy diagnosis. This might happen at 'onboarding' (becoming part of the clinical world and medical system) clinic appointments where information overload can result in little being remembered and create a feeling of being overwhelmed (Cunningham et al. 2002).

The PIC triggered thinking in a more sophisticated way about the meaning of 'choice'. For some people, there was concern that the idea of 'choosing' to bath implied wilful neglect of their own safety or other people's anxiety about it, whereas in fact it was more complex. For people with learning disabilities, it may be imposed with 'carers' imposing their own judgement and selecting what they believe to be the safest option, on behalf of the learning-disabled person (which might be more risk averse).

PLE can commonly experience cognitive limitations that affect memory (Baxendale & Healey 2020) so may overlook consideration of the potential consequences. In addition, it seemed that choosing to bath

was not necessarily seen as a risky choice, even by chaperones, maybe due to a false sense of security because accidents had not previously happened (until they did, as described in the introduction).

The PIC also prompted greater consideration of emotional aspects of living with epilepsy. Contributors shared personal experiences related to living with epilepsy, including alarming accounts of traumatic accidents in the bathroom. Contributors spoke in general about the wider experience of living with epilepsy, which can lead to feeling different and excluded, and being fearful. Coping with seizures and the physical consequences of injury was highlighted as a significant difficulty, which caused loss of confidence, a feeling of being different to others, and generated significant emotional toll, an issue that cannot be divorced from research considerations.

A common theme that recurred through the conversations was how important the personal biography and context was to understanding PLE. This may be of relevance for people who live alone or who cannot afford to have a shower installed. Also relevant here is the issue of personal preference and motivation for taking a bath, and a resistance to 'special rules' for PLE that there may be resentment about in everyday life (Keddie et al. 2016).

Conclusion and next steps

We can conclude from this PIC that we need to explore as much as we can to understand how drowning can be prevented in the bath by knowing more about how such decisions are made. In particular we need to:

- Understand more about the extent of the issue (people having baths alone)
- Be mindful of using constructive language
- Be as inclusive as possible
- Include different perspectives
- Understand more about who provides information and when it is given
- Understand more about how information is received, understood and processed.
- Consider how awareness of sudden unexpected death (and other relevant issues) affects decision making.
- Consider biography and personal context

These conclusions may seem overstated from such a small PIC with limited diversity of perspective. However, given how informative it has been and the depth of feeling around the issues, it provides an excellent reference point for shaping subsequent research. The next step is to write a proposal and work towards implementing a research project on this important, but overlooked, issue of enabling safer bathing for people living with epilepsy.

The introduction made reference to the origins of the PIC, and its relationship to equipment to prevent drowning in the bath. Although the direction of our inquiries took us to this PIC as a first activity in understanding the issues, parallel to this was a third-year engineering student dissertation project (Hayes 2020) on designing preventative equipment. We hope to also develop this work in the future.

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Appendix 1

Proposed project plan.

The project is a public consultation project.

In the project we are defining 'public' as people living with epilepsy. The purpose of the project is to consult with people living with epilepsy on their opinions about our ideas for developing a full research project. The planned research project will focus on why some people living with epilepsy choose to have a bath when there is a risk of serious accident if someone has a seizure.

Below we have written out our ideas so far and a list of questions that we would like to discuss with you when we meet (the plan for meetings is shown at the end of the document).

Background

How we have got to where we are;

- o We know that some people have drowned in the bath (with epilepsy) and that others have had serious accidents when having a seizure in the bath, but there is very little published information on this that can help health and social care staff or researchers to develop understanding of this issue.
- o We first wondered why there isn't a piece of equipment to stop accidents from happening when bathing.
- o However, because no research has been done on this topic, we need to establish the extent of the 'problem' and whether it is an important topic to research.
- o Therefore we are conducting this consultation project to get the views of the people affected the most.

The possible aim of the research project we would like to design To find out why some people living with epilepsy choose to have a bath when there is a risk of serious accident if they have a seizure.

Objective

- to understand the factors that influence people's (with epilepsy) decisions to take baths on their own.
- to explore how much individual's understand of the risks and their attitude to it
- Should we have more objectives?

Important note

We are not asking you to tell us why <u>you</u> might decide to take such risks.

We are asking you for your opinions on what we could be asking participants in a research project and how we should go about it.

Questions for discussion

- 1 -Is this an important research idea to investigate?
- 2 -What do you think we should focus on?
- 3 -Do you think a national survey would be a suitable way to research this issue?
 - -What other ways could it be researched? (this doesn't need to be research jargon, just any ideas on how we could best find out what we want to know).
 - -How else could data be gathered, what methods should we use?
- 4 Below we have listed some questions that we have come up with so far that might be asked in the research. What do you think? Are there other questions we should be asking?
 - a. Have you been given any advice by a health professional about having baths?
 - a. if so, what advice have you been given?
 - b. What are your reasons for choosing to bath instead of shower, or a shower instead of a bath?
 - c. Are you conscious of any risks when bathing alone?
 - d. Why do you take the risk?
 - e. Have you received information about bathing and safety
 - a. at what point did you receive this information?
 - f. What do you do now to manage risk and protect your safety when having a bath?
 - g. Are you aware of any bathing safety products to prevent accidents?
 - h. Do you think people would be interested in using a bathing safety product if there was one?
- **5** We also want to know your opinion on;
- whether we should aim to include parents of young people with epilepsy, and/or include people under the age of 18 in the research.
- -How we might best involve the public (people living with epilepsy) in the research project or writing the research bid? Please consider whether you would be interested in this.
- -is there anything else we should consider?

The table below shows the project plan and timings of the meetings

Table 1 Project plan and timings of the meetings

Steps in project	Tasks	Preliminary dates
1	Send out draft proposal	May-June
2	Meeting 1**	15 th June 2.30pm tbc
3	Meeting 2*** discussion on final draft. (all contributors to be invited but this can also be done via email)	20 th July 2-4pm tbc
4	Send out amazon vouchers	End of July

^{**}Meeting 1 approx. 1 hour (online using Microsoft teams – an invitation will be sent)