Making Families Count

Improving healthcare through family engagement

STRATEGIC PLAN, AUTUMN 2025

1. Vision, Mission, Purpose and Values

Our vision
is that healthcare is improved by working well with families[1], learning from them, and supporting them when things go wrong.

Our purpose
is to work in partnership with health and care agencies to support the development of safer, more compassionate care by improving collaboration with families.

Our mission
is to improve engagement between services and families, learning from families, when things go wrong and using this learning to improve care and reduce harm.

Our underpinning values

- Collaboration: working in partnership with families and with professionals
- Authentic: sharing our lived experiences
- Compassionate: understanding distress, bereavement and subjectivity
- Power dynamics: understanding and acknowledging the power dynamic in coproduction

2. Our history

Making Families Count (MFC) was a project run by NHS England South East Region, established in 2015. A group of family members who had experienced harm and trauma worked with NHS clinicians to develop and provide training to improve the ways families were treated during investigations that followed an unexpected and untoward incident. In 2019 MFC was established as a Community Interest Company. The organisation remained small and focussed, and gained a strong reputation in patient safety work, providing unique training based on our lived experiences.

Our unique approach has always involved traumatised families telling our stories alongside an experienced senior health professional, so that we model working together, and we

[1] Note: We use the term family carers to mean anyone who is significant to the patient, including biological and non biological family and friends who may or may not live in the same household or even the same country.

acknowledge that senior leadership and clinical skills are crucial to effect transformation within organisations.

We have worked in partnership with many NHS Trusts, developed toolkits, learning materials, and developed projects to improve how clinicians work with families in mental health services.

Much has changed and improved in the NHS since we started work, in particular the expectation that families must be properly involved in investigations following incidents, as set out on the Patient Safety Incident Response Framework, (PSIRF).

Our next phase builds on our work to date, envisages some growth, and more emphasis on family engagement in our own work, and through that in service design and delivery by health and care organisations, to learn from when things go wrong, improve care and improve outcomes.

3. Why family engagement matters

Listening and engaging with families in all areas of healthcare improves patient care, supports better patient outcomes and improved safety, and improves learning for individuals and services.

- Families know their unwell family member well and their knowledge is vital to clinicians in assessment and treatment; this is true for all aspects of healthcare, including for example understanding symptoms, pain thresholds and what people can and cannot manage following discharge.
- Listening and engaging with families in all areas of healthcare offers vital opportunities to listen to and learn from families

The Duty of Candour and the new PSIRF structures require healthcare organisations to be open with families, and engage with them compassionately. However, there remain some significant blocks to doing this well, including

- the need for improved communication with families and understanding their experience, expertise and perspectives
- the need to improve understanding and treatment of families as partners in care
- the importance of recognising, supporting, and using families as safety observers

4. Our Ambitions for the next 5 – 10 years

We aim to become **the** organisation that embodies family engagement, offering support, best practice and collaborating with existing local family voices groups and encouraging more to develop.

To achieve this requires us to develop partnership projects that support and disseminate implementation of best practice in family engagement. We need to do this with families who have been traumatically bereaved to support learning from their stories, and with

families who want and need to get involved in supporting the care of a family member to improve care and avoid harm.

We would like to see family engagement being as strong an aspiration with accompanying infrastructures by health and care organisations as is now the case for patients as Experts by Experience.

Currently, to achieve this we will need to work with partners who can provide the necessary infrastructure to support all our work. In the future we hope to grow our organisation and put it on a more stable financial footing.

5. Our work

Making Families Count works in partnership with health and care agencies to support the development of safer, more compassionate care by improving collaboration with families.

Our recent and current projects include

- Autism Oxford. Those who are neurodiverse, with or without a diagnosis of autism, figure significantly amongst people who experience suicidal ideation or end their own lives. We delivered training to professionals working with children and young people, and to family members working to keep their children safe. Our lived experience input supported the input from Autism Oxford who have experience of providing diagnosis and support to those with autism.
- Life Beyond the Cubicle: funded by NHS England (with HEE legacy funds). This project was developed in partnership with Oxford Health NHS Foundation Trust. We co-created, tested, evaluate and published eLearning Resources on the NHS platform. These resources were independently evaluated and shown to help clinicians to work well with families when someone is experiencing an acute mental health crisis, so as to improve care and safety. We have now agreed a partnership with UK Healthcare conferences whereby we provide the facilitators and programme for training to support Trusts to embed this approach across their workforce. UK Healthcare conferences will provide all the admin, marketing and technical support.
- Contributing to work being done by Gateway to develop a Healthcare Family Liaison Officer (FLO) training in collaboration with NHS Trusts and a University to standardise training for FLOs. Our role is to provide and support families for this training and to share best practice in the work of FLOs.

Our training has included webinars and bespoke training for Trusts about

- PSIRF implementation and guidance around good family engagement in investigations
- Duty of Candour – from a family perspective, the implications for policy and practice
- Positive engagement with families – top tips for working with traumatically bereaved families
- Experience of the Family Liaison Role and its importance to families.

However, it is proving increasingly difficult to get sufficient interest and attendance at our training events, for a number of reasons, including our limited marketing reach and the shortage of funds (and time) in the NHS.

6. Our plans

We aim to focus our work to be most effective in helping the NHS to improve. We will do this in two interlinked stands of work:

Family engagement

We will build our own family engagement work, offering peer support (online) to families who have experienced traumatic deaths involving the NHS. This will include families affected by suicide, self harm and homicide. This is a crucial part of our overall strategy as it will offer traumatised families' opportunities for peer support and to effect change in the NHS, which is the aspiration of so many families. It will also ensure that traumatised families can influence all our work, that we remain current and that we ourselves practice the ideals that we are asking the NHS to live up to.

This work will need grant funding.

NHS Trust Transformation through family engagement

Alongside our own family engagement work we plan to work where we can be most effective in enabling change that improves how health and care organisations work with families. This includes:

- Quality Improvement through best practice in family engagement: working with NHS partners to develop, support and disseminate good practice. We will develop and pilot ways to work with family carer groups and NHS leaders to effect change, and to identify how best to demonstrate evidence of change. Currently we are in discussion with an NHS Trust where one of our members has been involved in supporting change.
- This work will provide a model of working that we can propose to other Trusts to build family engagement to drive quality improvements and so provide a foundation for positioning ourselves as **the** organisation for family engagement.
- Roll out of Life Beyond the Cubicle project and the Family Liaison Officer Training described above
- Explore potential future partnerships to offer training in suicide prevention for people with autism, whether or not they have a diagnosis, building on our experience with Autism Oxford described above.

We anticipate that this work will be self- funding and will contribute to our core costs.

7. Governance

To achieve these ambitions, we will recruit new people to our Board so that it reflects the skills and experiences we need to implement our vision and strategy. We will recruit a small

team of associates of families and clinicians. As soon as we raise sufficient income, we will appoint a Chief Executive to drive forward our plans.

8. Our ambitions for the organisation for the next five – ten years

We will become

- A strong not for profit, known as **the** leader of family engagement in health and social care
- With traumatised families at the heart of all our work
- Supporting and supported by networks of leaders in health and social care who we have worked with
- And an efficient infrastructure, a more stable financial footing with regular sources of income

9. How will we evaluate our impact?

We want to see traumatised families having a greater influence on the ways services are developed, delivered and evaluated, where learning from untoward events actually happens.

We will explore different methodologies to measure and evaluate our impact. We will monitor all our direct work with traumatised families, and with family participation groups that work with NHS Trusts, obtaining feedback from families and from senior leaders in health and social care. We will analyse their plans and strategies, measure complaints, their engagement in PSIRF, and collect families' stories and experiences.

10. Next steps

In autumn 2025 we will

- Recruit new Board members and review our legal structures to ensure we are fit for our ambitions.
- Set up online focus group discussions with traumatised families, consulting them about their priorities, and shape our developments of peer support based on their feedback
- Seek grant funding to continue to engage with traumatised families.
- Work with at least one NHS Trust on a transformation programme to embed good family engagement at the heart of their quality improvement development
- Continue to support NHS Trusts to embed the Life Beyond the Cubicle approach in their work with people experiencing a mental health crisis
- Continue to respond to requests for bespoke training and consultancy
- Seek to develop and offer training about suicide prevention for people with autism, whether or not they have a diagnosis
- Offer our expertise to investigators and other bodies seeking to learn from traumatised families.