

Living well to the very end - Patient and family-centred care (PFCC) programme

Information for applicants

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1. 'Living well to the very end' patient and family centred care programme:

'Living well to the very end' is a patient and family centred care programme, developed as a partnership between the Point of Care Foundation and NHS England. It is supported by the Health Foundation.

This programme focuses on the care of people at the end of life, within generalist, rather than palliative settings. Using an evidence-based and radical approach, 'Living well to the very end' uses a collaborative methodology based on the IHI's Breakthrough Series collaborative. It is truly unique in the extent to which it draws on patient shadowing to help teams understand the experience of patients and families, and to create the urgency for change. This programme builds on the successful programme run by The King's Fund and The Health Foundation from 2010 to 2013.

Following the success of the 2016 'Living well to the very end' cohort, we are looking for 20 multi-disciplinary clinical teams from health and care provider organisations across the UK,

to participate in the next phase of the programme. We welcome applications from NHS providers of acute, community and primary care, as well as non-NHS providers of health and social care. We are looking for teams which have already demonstrated commitment to transforming patients' experience of care, and invite them to work with us to transform end of life care. This work will complement existing improvement work, appeal to the values of staff, and help sustain and spread the improvements already made. Participating teams will also receive mentorship from those who have led this work in participating teams in previous cohorts.

There has never been a greater focus on patients' experience as a key component of quality, nor greater acknowledgement of the value to staff of delivering excellent care. But the NHS still has some way to go before it achieves the vision of reliably providing excellent patient experience. Through this programme we are working to support organisations and frontline staff to achieve demonstrable improvements in care for patients and in the experience of staff delivering care across the UK.

The quality of care at the end of life care has come under particular scrutiny, with significant variation in patients' and families' experience. With the publication of [Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015-2020](#), there is now a framework to do just this for care at the end of life. This programme will target the practical challenges that are a priority for you. It will provide you with the opportunity to take the lead in this area, and to be an exemplar.

2. Programme aims:

The programme supports participating organisations and teams within them to:

- develop capacity to deliver high-quality patients' (and families') experience of care
- develop capacity to improve the experience of staff
- promote patients' experience as a high priority on the quality agenda alongside safety and clinical effectiveness
- build on the synergies that exist between work in patients' safety and patients' experience, to enhance the effectiveness of both areas of work
- spread learning and build capacity across their organisation.

3. Who is the programme for?

The programme is for multi-disciplinary teams who work in end of life care in generalist, rather than palliative care settings. Whilst the work can be supported and/or guided by palliative care specialists within the multi-disciplinary team, it must take place in a generalist setting. It is also critical to success that teams are supported in this work by leaders within their organisations, and so we ask that the application form demonstrates explicit support

from an executive sponsor and a clinical champion, the definitions of which are set out in the team roles section below.

We are seeking applications which demonstrate:

- A real commitment to learning
- clearly stated aims and objectives of the proposed improvement work and consideration of how the anticipated outcomes could be measured
- commitment to considering care from patients' perspectives, and involving service users and families in your improvement work
- consideration of what you want to get out of the programme and what you hope to achieve for your service
- meaningful executive and senior clinical sponsorship for the work
- commitment to improving staff experience as well as patients' experience

4. Benefits of the programme/key features:

The programme is jointly led by clinicians and quality improvement experts from NHS England (South), the National Clinical Director for End of Life Care and the Point of Care Foundation. Those on the programme will also receive coaching and mentorship from those who have led projects in participating teams of previous cohorts. Together our faculty will deliver learning events and rapid improvement days followed by two 100 day action periods, during which you will be supported by expert coaching and mentoring to undertake rapid improvements. We will also work with you to disseminate your work.

The programme is designed based on the well-tested methods for improvement:

- the Institute for Healthcare Improvement's work to identify the key drivers of patients' experience
- the Model for Improvement
- the Patient and Family-centred Care methodology devised by the University of Pittsburgh medical centre

The programme offers:

- two days of learning events where we bring teams together, followed by 100 day action periods during which you will be supported to undertake rapid improvements
- practical support for your teams from our faculty experts
- mentorship and coaching from those who have led projects as part of previous participating teams
- assignments and learning materials
- webinars to aid communication and sharing between events
- the opportunity to showcase your work
- support with disseminating your work

The curriculum includes:

- Patient and Family-centred Care methodology and practice
- techniques to understand your patients' experience
- devising high-quality measures for improvement
- using data for improvement
- understanding and improving staff experience
- engaging frontline staff in improvement
- building staff resilience
- evaluating your work and demonstrating impact

5. Team roles and commitment:

Each team should be comprised of a Guiding council, and a Working or Core group. The Guiding Council should be made up of your Executive Sponsor, who provides organisational leadership for the work, your Clinical Champion who provides clinical leadership, your Key Contact who acts as the bridge between your team and the Point of Care Foundation Faculty, a Scribe who can coordinate meetings and ideally a patient or carer. Further description of these roles are set out in the FAQs below and we ask that individuals are identified for these roles as part of your application.

The Core or Working Group provides the functional management of the project and will be supported by the Guiding Council. The team members of this group will depend on the care experience you are working on, but will typically comprise of 6 individuals, including a senior nurse, doctor and manager. The core team must have the time, resource and support from within their organisation to carry out this work effectively, and we advise that the Working group meets weekly for half an hour.

We are asking participant organisations to commit to the programme for ten months from April/May 2017. We also ask you to secure active sponsorship from the Board through an identified Executive Sponsor and Clinical Champion, as well as identify a Key Contact to act as a bridge between your team and the Point of Care Foundation. Three members of your team will be expected to attend the learning events, and as learning is cumulative we ask that where possible the same three team members attend both events. Members of your team will also be expected to attend the learning webinars between the events, and to complete set assignments throughout the programme, which are designed to help facilitate your project.

6. Patient and family involvement:

Patients' and families experiences are at the centre of this work. We will be asking in your application how you intend to incorporate involvement into your work, building on the approaches to patient and public involvement that are already used in your organisation. As part of the programme will also provide training to help your team really see the care

experience through the patient's eyes, and practical tools to involve patients and families in your work, and your team will be expected to use these throughout the programme.

7. Cost:

There is no cost to participating in this programme. Your organisation's contribution includes enabling staff time to participate in the programme and carry out the improvement work.

You will also cover costs of travel (and accommodation if needed) to two learning events plus a potential peer-review visit to another organisation.

8. Key dates:

Please note the follow dates below for the application timeline.

<u>Date</u>	<u>Activity</u>
24th February 2017	Applications open
31st March 2017	Applications close

Please note the below dates of activity that your team will be expected to attend if accepted on to the programme. **All applicants will be notified of the outcome of their application before 28th April 2017.**

<u>Date</u>	<u>Activity</u>	<u>Location</u>
April – May 2017	The Point of Care Foundation Faculty will be in touch to organise an introductory site visit to meet your team in April or May.	Local
7th June 2017	Learning webinar – introduction to the programme	
13th July 2017	Learning event 1	London

14th July – 18th October 2017	100 day action period for rapid improvement	Local
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6th September 2017	Learning webinar	Local
18th October 2017	Learning event 2	London

18th October 2017 – 25th January 2017	100 day action period for rapid improvement	Local
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9. Evaluation:

We believe it is vital that we evaluate the programme, and contribute to the evidence of what works in quality improvement. We have appointed independent researchers to help us with this. We will ask participating teams to take part in the evaluation, for example by being interviewed about the programme by researchers, but where possible this will be done by telephone.

Each team will also be expected to undertake a short internal project report to document their work. This will be based on the Squire guidelines¹ and this will be provided at the beginning of the programme to successful applicants.

10. How to apply

The application form will be live on the Point of Care Foundation's website on the 24th of February 2017. For some guidance in what the application form will be asking, please see the 2016 form [here](#). Please note that this application form will be subject to revision before being launched formally on the 24th February.

If you would like an informal discussion about the programme, please get in touch with Sophie Lansdowne, Senior Programmes Officer: Quality Improvement, at the Point of Care Foundation:

T: 0203 841 5581

E: sophielansdowne@pointofcarefoundation.org.uk

Please note that the deadline for applications is 31st March 2017. For further information, please see the FAQs below.

11. Frequently Asked Questions:

What do we mean by patients' experience?

Patients' experience includes all aspects of the quality of care, as experienced by patients. The Institute of Medicine's (IoM 2001) definition of quality provides a useful definition of quality namely care that is:

- patient-centred
- safe

¹ Davidoff F et al. (2008) Publication guidelines for quality improvement in health care: evolution of the SQUIRE project. *Quality and Safety in Healthcare* 17 (Suppl.1)

- effective (therefore encapsulating clinical quality)
- timely
- efficient
- equitable

The IoM further goes on to define the dimensions of patient-centred care as demonstrating all of the following attributes:

- compassion, empathy and responsiveness to needs, values and expressed preferences
- co-ordination and integration
- high-quality information, communication and education
- delivering physical comfort
- providing emotional support, relieving fear and anxiety
- involving family and friends

This definition goes beyond single aspects of patient-centred care, such as dignity. It is distinct from concepts, such as patient involvement, in planning and delivery of services more broadly.

What do we mean by a care experience?

This programme focuses on improving the end of life 'care experience' for patients. By care experience we mean an aspect of care that is defined from the patients' perspective. You will decide where to focus your work – for example on particular wards or teams, and when the experience begins and ends. For example, the experience might begin when patients are admitted to a particular setting. It might continue as patients move between settings; and might end with the follow-up and bereavement care of families after the death of a loved one.

What is the role of the executive sponsor?

There are two aspects to the role of the executive sponsor – first to demonstrate organisational leadership for work on patients' experience, and second to hold project teams to account.

The leadership role comprises:

- demonstrating that the organisation values patient-centred care, and that patients' experience is core business
- advocating organisational values that place patients' experience at the core
- supporting practical steps to reward patient-centred care
- modelling the priority and importance of the work, through regularly attending steering groups, noticing and taking an interest in the data emerging from the work, etc.

- showing energy and enthusiasm – challenging cynicism
- identifying the resources necessary to conduct the work, negotiating across the organisation where changes/improvements have repercussions that go beyond the clinical area that is under detailed review (e.g., identifying blockages that are preventing improvements from happening or being sustained)
- ensuring that there is time allocated for participants to do this work
- ensuring the programme is reinforced as a learning programme as well as an improvement programme.

The accountability role comprises:

- holding the core team and project teams to account
- ensuring there is administrative support/a scribe to keep track of the work
- ensuring that the work is reported regularly to the board, and that there is commitment to action in response to these reports.

In practical terms this will mean that the executive sponsor will:

- link the work of the programme into the organisation's broader vision, values and objectives – and will not allow it to be conducted in isolation
- ensure that the work draws in corporate services, such as HR or facilities, where this is needed to advance the work of the programme
- engage Board colleagues in the work, to ensure the Board pays attention to the PFCC work and it is celebrated in the organisation
- chair the Guiding Council for the PFCC programme and attend the meetings regularly. This role is described as 'a committed, enthusiastic, and organised professional to serve as a champion to guide and expand the PFCC work and to serve as the linchpin for communications'. This group should aim to meet every fortnight for 30 minutes – same place, same time.
- ensure that invitations for sub-groups are sent from the sponsor's own office, giving a clear message that this work is valued at a senior level in the organisation, and that active participation is strongly encouraged
- lead by example, participating in aspects of the programme

What is the role of the clinical champion?

The clinical champion is similar to the executive sponsor: they provide clinical leadership to this work and are an active member of the Guiding Council, and provide support to the Core or Working Group.

The clinical champion will inspire colleagues to make and sustain required changes. Key aspects of the role include:

- being a member of the Guiding Council for the PFCC programme, and attending the meetings reliably. Like the executive sponsor, 'a committed, enthusiastic, and organised professional to serve as a champion to guide and expand the PFCC

work.’ This group should aim to meet every fortnight for 30 minutes – same place, same time

- modelling the priority and importance of the work, through regularly attending steering groups, noticing and taking an interest in the data emerging from the work, etc.
- showing energy and enthusiasm, and challenging cynicism
- negotiating across the organisation where changes/improvements have repercussions that go beyond the clinical area that is under detailed review
- lead by example – including participating in project groups and patient shadowing.

What is the role of the key contact?

The key contact is the main point of contact between the Point of Care Foundation team, the faculty and the trust. Typically this person is a senior member of staff with expertise in improvement, who is well connected in the organisation. The key contact:

- acts as a conduit for communications between The Point of Care Foundation team, faculty and the teams
- is a source of support and expertise regarding the programme for the participating teams
- cascades information sent by the Point of Care foundation team to relevant team members and ensure that teams have committed to action when needed
- will be the point of co-ordination for feedback to the Point of Care Foundation team in relation to:
 - providing routine reports and feedback to The Point of Care Foundation and senior management within the trust
 - having regular catch-up calls with team and faculty
 - ensuring that teams collect data on agreed measures
 - ensuring that the teams keep to their agreed project plans
 - maintaining momentum – ensuring that teams hold relevant local events etc
 - co-ordination of requests for help and support from teams to The Point of Care Foundation team and faculty.

Key contacts:

- are not a substitute for the teams themselves
- will not necessarily know the details of the work, and will rely on the core team to provide this information.

Who should form the core team?

The core team will typically comprise 6 individuals, and include a senior nurse, doctor and manager. (For smaller organisations, such as those within primary care, we will discuss the

team composition with you). It is vital that staff who work directly with patients are involved in the programme.

The core team must have the time, resource and support from within their organisation to carry out this work effectively. Typically, this might represent a half day per week, but it will depend on the scale of the work undertaken, the complexity of the pathway, and the extent to which you broaden the work out to include more frontline staff.

You yourselves will know who it is in your organisation that is likely to make change happen. This is far more important than the specific professional background of the individuals.

Additional frontline staff will participate in local learning events as well as small, time-limited projects, identified by the core team. The extent of this will depend on the complexity of the work undertaken by the teams.

About the Point of Care Foundation:

We are an independent charity working to radically improve the way people are cared for and to support the staff who deliver care. The Patient and Family Centred Care programme was previously run by the Point of Care team at the King's Fund, supported by the Health Foundation.

About The Health Foundation

Patient and family centred care is part of The Health Foundation's spreading improvement programme. The Health Foundation is an independent charity working to continuously improve the quality of health care in the UK.

Additional resources about the programme methods

- [The Patient and Family Centred Care 'Go Guide'](#)
- [The Patient and Family Centred Care toolkit](#)