

Sweeney programme - end of life care collaborative

Frequently Asked Questions

1. 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
- 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.

2. 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.

3. What the client will do and how the Foundation will help

To participate in this programme, we ask you to identify a core team of up to 6 individuals. We also ask you to secure active sponsorship through a named executive sponsor who will chair a fortnightly 30-minute steering group for the programme. The sponsor will also represent the work at the Board. We also ask for clinical sponsorship through a named clinical champion. Responsibilities are similar to the executive sponsor, but the clinical champion will also represent the work with clinical colleagues.

In addition, we ask you for a 'key contact' to act as a bridge between The Point of Care Foundation team and your organisation. Typically this person is a senior member of staff with expertise in improvement, who is well connected in the organisation.

The roles of each of these individuals is described more fully below.

4. Who should form the core team?

The core team will typically comprise 6 individuals, and include a senior nurse, doctor and manager. It is vital that staff who work directly with patients are involved in the programme, but others who work in "back office" functions can also make a valuable contribution, alongside their clinical colleagues. This group provides leadership for the work at team level. We ask that as far as possible the same core team participate in the programme throughout.

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.

5. 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 Sweeney programme's work and it is celebrated in the organisation
- Chair the Sweeney programme steering group 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 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

6. *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 Steering group, and provide support to the Core Group.

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

- being a member of the Steering group, 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 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.

7. *What is the role of the key contact?*

The key contact is the main point of contact between the Point of Care Foundation team, and the participating organisation. 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 and the participating 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.

8. How will patients and families be involved?

Patients' and families experiences are at the centre of this work. We will be asking how you intend to incorporate involvement into your work, building on the approaches to PPI that are already used in your organisation. This will mean inviting service users onto the steering group for your project, as well as actively engaging patients or family members to share their experiences and contribute to co-design groups.

9. Programme assignments

We ask teams to undertake a small number of assignments during the course of the programme. We understand the service on NHS staff, and these are designed to be short and focused, and directly related to securing the outcomes you seek.

These are:

Assignment 1 – patient shadowing (September 2018 and ongoing)

Assignment 2 – Team collectively writes the narrative of the “ideal patient experience” (October 2018)

Assignment 3 – With guidance we ask teams to derive a driver diagram for their project and accompanying measurement plan (November 2018)

Assignment 4 – We ask teams to prepare an elevator pitch for their project for the second learning event (February 2019)

Assignment 5 – We ask teams to prepare to present their work at the final celebration showcase event – these presentations can take the form of verbal presentation, workshop, poster or creative depiction of their project (Summer 2019)

Assignment 6 – We ask teams to submit a short project report using a template based on the Squire guidelines for evaluation of quality improvement projects (Summer 2019).

10. Cost

The programme cost is £4,800 excl VAT per NHS organisation. Participating organisations' contribution also 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 three learning events.

11. Time

In addition to attending the three learning events, ensuring that the core team has the time to carry out the improvement work is the main time requirement. Typically this represents a half day per week for each team member plus attending regional and local events.

Ensuring that additional frontline staff are available to implement small projects within this programme. This requires some backfilling to enable the staff to devote time to this work. The extent will be determined by the scale and complexity of the work, decided locally.

12. Evaluation

We believe it is vital that we evaluate the programme, and contribute to the evidence of what works in quality improvement. We will evaluate the learning events, and undertake a follow up survey 6 months after the completion of the programme, to evaluate impact.

How to apply and key dates

Applications for this programme will open on 1st July 2018 and remain open for 4 weeks from the date of the receipt of an application pack. Work will begin in October 2018. Applicants will be told the result of their application within 2 weeks of us receiving it.

13. Key dates:

Learning event 1 (October 2018)

Learning event 2 (March 2019)

Celebration and showcasing event (Summer 2019)

14. 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.