Dates:

12th, 19th and 26th of November 2026

9.30 – 12.30

Patient and Carer Experience:

Delivering safe, equitable, quality care.

Handbook

brighton and sussex medical school

Welcome

Welcome to Delivering Patient and Carer Experience: Safe, Equitable, Quality Care.

For any enquiries, queries or questions please contact cpd@bsms.ac.uk
You can also find more information on [add web pages]

"The course sparked new thoughts even on areas I already had a lot of knowledge of" – *Estelle Phillips, Qualitative Senior Analyst, NHS England and course participant.*

"I was able to implement some of the learning within a week of the first session. It sparked lots of thought and I have taken some of the ideas back to my teams to see how we can influence change towards a more patient-centred feedback direction" – *Michelle Offen, Head of Occupational Therapy (Trust-wide) University Hospitals Sussex NHS Foundation Trust and course participant.*

Introduction

The Mid Staffordshire disaster was meant to be a watershed moment for the NHS. Widespread harm was caused because, according to the Francis Inquiry, the Trust “did not listen sufficiently to its patients”.

Subsequent harms in maternity services – Morecambe Bay, Shrewsbury & Telford, East Kent, Nottingham and the Amos Review - have also revealed a failure to listen and learn from patients and carers.

Baroness Cumberlege’s review of medicines and medical devices showed that a contributory factor to harms was a failure to take women’s concerns seriously.

Lord Darzi, in his 2024 Independent Investigation of the NHS in England, said that “the patient voice is simply not loud enough”, and that listening to patients and carers about what’s important to them would help the NHS deliver tangible improvements to people’s experience of the NHS.

It is clear that there is a need for change in the NHS to a service where the voices, experiences and suggestions of those who use healthcare services, and their carers, are sought, heard, and acted upon, in order to ensure that services are high quality, safe and deliver the best possible outcomes. The importance of this is amplified for those who experience inequalities.

Not only are repeated harms expensive with compensation claims for maternity care alone being over double the amount the NHS spends on maternity services each year, but there is a risk of damaging the confidence of those who need to use healthcare services and the morale of staff who do their best daily to deliver the best care in often challenging circumstances.

Our Approach

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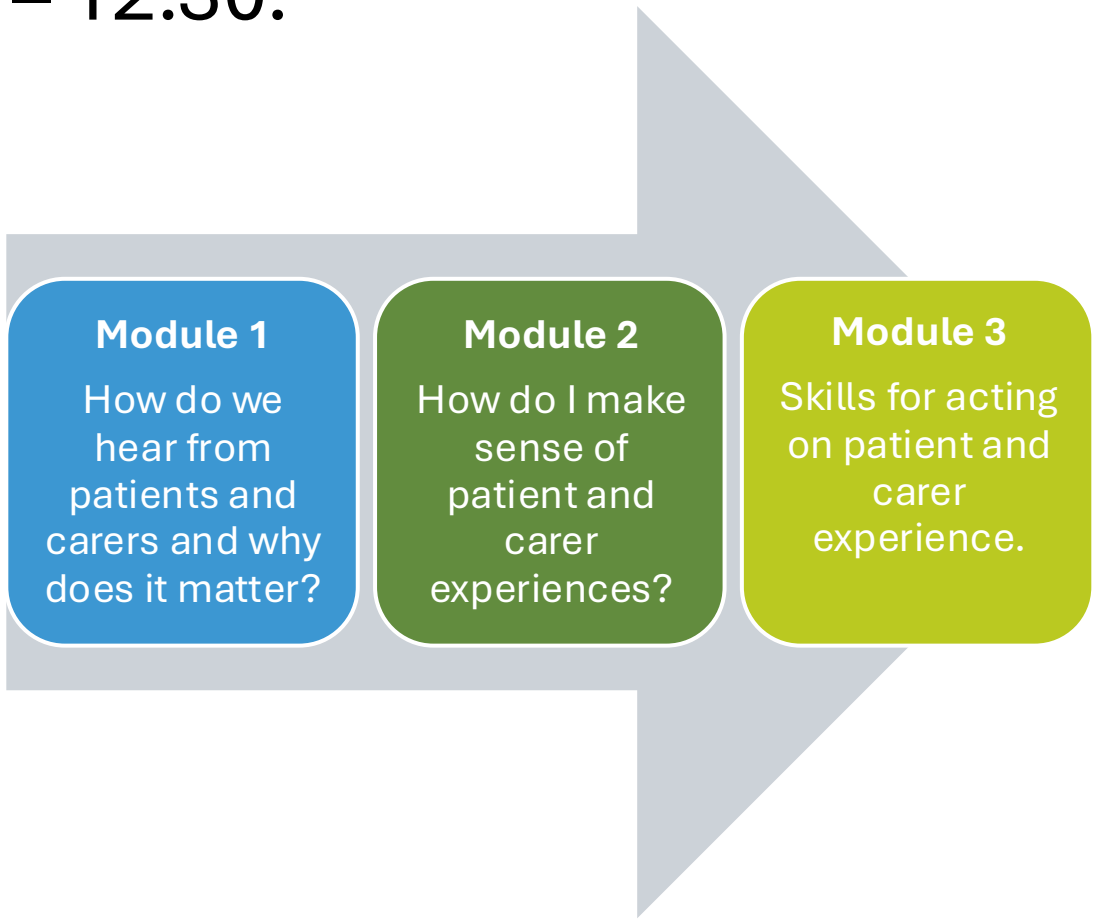
Three half-day modules 9.30 – 12.30.

This three-part course aims to support attendees to understand why patient and carer experience should be at the centre of delivering healthcare services, and how it can be used to influence change and improvement.

We aim to build on the experience and knowledge of attendees, stimulating thought, questioning and exploration.

The modules draw on the expertise of module leads, bringing local and national lenses to the content and encouraging consideration through questions and group deliberation of key issues during the session.



Learning and certificate of completion

The style is highly participatory, with attendees working in groups to discuss key concepts and topics. We expect attendees to be fully present, using an enquiring mindset and respectful questioning to challenge others' views.

While there is no formal assessment of learning, we ask for feedback on key learning points.

Attendees will receive a formal Certificate of Completion from BSMS at the end of the three modules stating hours of learning received.

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Learning outcomes

Module 1 – How do we hear from patients and carers and why does it matter?

Learners will have:

- Discussed barriers to getting patient and carer experience acted on.
- Explored context and concepts in patient and carer experience.
- Considered sources of evidence, including strengths and weaknesses.

Module 2 – How do I make sense of patient and carer experiences?

Learners will have:

- Explored different ways of understanding patient and carer experiences as key to delivering inclusive, high quality, safe care.
- Looked at different ways of knowing to understand and build a detailed picture.
- Considered how to deepen understanding.

Module 3 – Skills for acting on patient and carer experience.

Learners will have:

- Understood some of the opportunities and barriers to learning from patient and carer experience.
- Considered levers to influence change and improvement.
- Considered how the value of patient-centred improvement can be demonstrated through role models and visible good practice.

Model of delivery

This course will take place online, through MS Teams. Attendees are expected to be fully present throughout delivery, ensuring that both microphones and cameras are working optimally to support participation.

An interactive platform is used as a tool to support introductions within the group, capture live learning and provide a record of each module for students to revisit.

It is expected that attendees will attend 100% of the course. If you are unable to attend for all or part of a module please contact the course administrator as soon as possible.

If you need to cancel your place on this module, please contact the course administrator as soon as you can so that the place can be given to someone else.

Course contact details are cpd@bsms.ac.uk

Modules in detail

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Module 1 – How do we hear from patients and carers and why does it matter?

Pre module question:
What are the barriers to getting patient feedback heard and acted on?

Welcome		
1	About the course and introductions	
2	Barriers to acting on patient experience.	Group work, plenary discussion and taught content.
Break		
3	Context and concepts.	Action learning, taught content and group discussion.
4	Sources of evidence including strengths and weaknesses.	Group work and plenary discussion.
Key take-aways and looking forward to the next session		

Module 1 – How do we hear from patients and carers and why does it matter?

Learners will have:

Discussed barriers to getting patient and carer experience acted on.

Explored context and concepts in patient and carer experience.

Considered sources of evidence, including strengths and weaknesses.

Personal Journal Notes

Module 2 – How do we make sense of patient and carer experiences?

Pre module question:
What do you think are the challenges in making sense of what patients and carers tell us about their experiences of care?

Welcome		
1	Review of learning and introduction to the module	
2	Quantitative data – what does it tell us about how people experience their health and care?	Group work, plenary discussion and taught content.
Break		
3	Qualitative data and other ways of knowing: how does this help us to understand more?	Group work, taught content.
4	Dialogue: when dialogue and equalising power can take us to a new level of understanding with people shaping improvements based on their experiences.	Plenary discussion, taught content.
Key take-aways and looking forward to the next session		

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Looked at different ways of knowing to understand and build a detailed picture.

Considered how to deepen understanding.

Personal Journal Notes

Module 3 – Skills for acting on patient and carer experience

Pre module question:
What examples do you have of when patient and carer experience has been used for learning?

Welcome		
1	Review of learning and introduction to the module	
2	Learning for improvement	Group work, plenary discussion and taught content.
Break		
3	Support for improvement	Case study and facilitated group discussion.
4	Demonstrating improvement	Case study and facilitated group discussion / plenary and taught content.
5	Course review and key learning points.	Plenary.
Key take-aways , thanks and close.		

Module 3 – Skills for acting on patient and carer experience.

Learners will have:

Understood some of the opportunities and barriers to learning from patient and carer experience.

Considered levers to influence change and improvement.

Considered how the value of patient-centred improvement can be demonstrated through role models and visible good practice.

Personal Journal Notes

About the team

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Brighton and Sussex Medical School provides high quality education and learning experiences and consistently features in the top three medical schools in the National Student Survey. The School is an important source of expertise for study design and course accreditation.

Jessie Cunnett is Assistant Professor in Healthcare Leadership, Commissioning and Change Management at Brighton and Sussex Medical School. She is an advocate for patient voice and public involvement with over 25 years experience having worked directly with families impacted by some of the most high-profile and politically complex care failures, including Mid Staffordshire NHS Foundation Trust, the Morecambe Bay Hospital Maternity Unit, and as Co-Chair of the First Do No Harm Patient Reference Group reporting to parliament.

Jane Lodge is Assistant Professor in Healthcare Leadership, Commissioning and Change Management at Brighton and Sussex Medical School. She draws on 25 years' experience of working in NHS leadership and management roles focussed on patient, carer and public involvement, and has worked across Sussex, regionally and nationally, and is a Board member for three Sussex based charities.

Miles Sibley is a founder of the Patient Experience Library and the author of Inadmissible Evidence and Responding to Challenge. He ran a local Healthwatch for some years and now serves on the Board of Care Opinion and contributes to Expert Collaborative Groups at the THIS Institute.

Reading lists and key resources

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Core Background Reading

Patient Experience: Who Is Listening? | The King's Fund (2023)

What Are Health Inequalities? | The King's Fund (2025)

Patient experience: do patients feel involved in decisions about their care? | Nuffield Trust (2024)

Module 1 – Recommended reading

Why is patient and carer experience important?

These reports show the importance of hearing the patient voice in the context of patient safety and avoidable harm.

Inadmissible Evidence. Patient Experience Library 2020.

Patient experience: who is listening? King's Fund 2023.

Where do you find sources of patient and carer experience evidence?

A round-up of the main ways in which patient experience evidence is gathered can be found in Appendix 1, page 37 in this report.

Patient Experience in England – 2025 edition. Patient Experience Library.

What are the strengths and limitations of different sources?

This paper finds that while patient complaints could offer insights for quality improvement, their potential is undermined by factors including muddled routes and adverse incentives.

Do national policies for complaint handling in English hospitals support quality improvement? Lessons from a case study. The Royal Society of Medicine 2022.

This paper finds that while there are standardised procedures for complaints and survey work, there are no common methods for analysing compliment letters. This speaks to a tendency in healthcare to focus on what goes wrong rather than what goes right.

Identifying and encouraging high-quality healthcare, an analysis of the content and aims of patient letters of compliment. BMJ 2020.

This article highlights that healthcare professionals can rationalise patients' motives for complaining in ways that marginalise their concerns.

"It's sometimes hard to know what patients are playing at": How healthcare professionals make sense of why patients and families complain about care. BMJ 2017

Module 2 – Recommended reading

Quantitative –Starting with the data - what does this tell us about how the system fails some people more than others?

These articles pull together data on health inequalities, looking at a range of areas including healthy life expectancy, avoidable mortality, mental health and access to and experience of health services .

Health inequalities in a nutshell | The King's Fund

What are health inequalities? The Kings Fund

This analysis looks at data related to health inequalities relating to diagnosed health issues, rather than underlying causes of disease or health; it concludes that health outcomes for disadvantaged groups are worse across a range of measures.

https://www.health.org.uk/reports-and-analysis/analysis/quantifying-health-inequalities-in-england

This summary shows the differences in uptake of the Covid vaccination.

ARC_Vaccination_Uptake_Rates_Infographic.pdf

This report outlines that there are clear differences in A&E attendance between socio economic groups, using census data and emergency care data.

https://www.medrxiv.org/content/10.1101/2023.10.10.23296793v1.full

Qualitative - Looking at what patients and carers have said about their experience to understand more.

These studies show that dialogue with patients and public can reveal genuine barriers to understanding as well as practical barriers to accessing services.

Vaccination in the UK, Access, uptake and equity. Royal College of Paediatrics and Child Health 2025.

Compliant citizens, defiant rebels or neither? Exploring change and complexity in COVID-19 vaccine attitudes and decisions in Bradford, UK: Findings from a follow-up qualitative study. Wiley Health Expectations 2022.

This article outlines insight from people working in health and care services in England.

Understanding the challenges, opportunities, and drivers to addressing health inequalities within local health systems: the UNFAIR case study qualitative project

This report shows how a better focus on the needs of vulnerable minorities could ease A&E pressures.

Module 2 – Recommended reading

Qualitative continued - Looking at what patients and carers have said about their experience to understand more.

Seen and heard - Understanding frequent attendance at A&E, An analysis of linked data in Dorset.

British Red Cross 2024.

This report highlights the issues faced by trans, non-binary and intersex (TNBI) people in accessing primary healthcare.

Train and Treat

This report outlines how language barriers contribute to health inequalities, across a range of healthcare settings.

Lost for Words (Healthwatch)

Dialogue - When dialogue and conversation can take us to a new level of understanding.

This paper suggests that different perspectives of people with type 2 diabetes may increase uptake and adherence.

Identifying Key Moments in Type 2 Diabetes Management, A Qualitative Study of the Experiences of People with Type 2 Diabetes and Diabetes Health Coaches. Wiley - Health Expectations 2024.

This paper describes how an NHS Trust used “compassionate communication” to cut a waiting list from 1109 to 212 and cut waiting times from up to 36 months to a 70-day average.

Recovering staff, recovering services: massive-online support for recovering a paediatric service using Lean and compassionate communication. BMJ Open Quality 2022.

This video with transcript explores the concept of epistemic exclusion, using personal narrative:

The epistemic exclusion of harmed patients in the patient safety field: A call to action from Richard von Abendorff - Patient engagement - Patient Safety Learning - the hub

This paper explores living with long covid through the lens of epistemic injustice:

Exploring invisibility and epistemic injustice in Long Covid—A citizen science qualitative analysis of patient stories from an online Covid community - PMC

Module 3 – Recommended reading

What conditions need to be in place to be able to make improvements based on patient and carer experience feedback?

This article highlights concerns about the proposals in the Dash review to abolish Healthwatch and work of the National Guardians' Office

Hope over experience? Patient and staff voice in the NHS after the Dash review. BMJ 2025

This report highlights issues in relation to "speaking up" in the NHS, including real or perceived barriers to doing so, and the implications of this.

Fear and Futility

The Responding to Challenge report outlines behavioural patterns that are common across healthcare disasters, and what poor cultures look like including examination and change of harmful cultures.

Responding to Challenge and Red Flag Tracker (Patient Experience Library)

Making a case, influencing the decision makers, getting the right people on board.

This teaching resource shows how open access patient feedback can be used as a tool for learning and professional development.

Using Care Opinion in teaching - simple ideas for getting started. Care Opinion 2020.

This article pulls together evidence on how patient feedback has improved quality of care.

Patient feedback to improve quality of patient-centred care in public hospitals: a systematic review of the evidence

This report from the Neurological Alliance outlines recommendations for the conditions where patient insight and involvement influences change and improvement.

Are we listening?

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