



Organisation Description

The **East Midlands Cancer Alliance Centre for Psychosocial Health** (EMCA-CPH) and the **Mid-Notts Cancer Psychology Service** are two regional services providing:

- Specialist mental health support for cancer patients
- Psychological skills training for cancer care staff
- Impactful research output

We work across the East Midlands Region with patients from 5 integrated care boards, 8 NHS Trusts, and over 20 primary care networks.



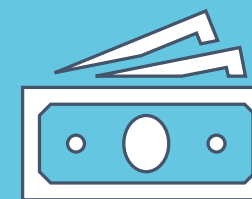
The Patient Involvement Collaboration (PIC) – Rationale and Context



We wanted to put the patient voice at the centre of service decision-making, particularly as significant evidence suggests clinicians routinely overestimate their own clinical effectiveness.



Therefore, we established a patient involvement group made up of cancer patients who had sought psychological support.



Financial reimbursement reflects the value we place on PIC members, plus helping engagement and accessibility.

Development of the PIC



Established September 2024



At the end of therapy, patients were routinely invited to contribute to service development. This led to 14 founding group members



The group decided on their own name (PIC) and Terms of Reference, championing their perspective, and the co-development giving joint ownership to the group



Holding explicit discussions about what people feel safe to share and how things will be shared, has made it easier for people to engage and to respect each others' views

PIC Group Format



The group meets at least quarterly, meaning it's fully embedded into the service with continued dialogue between PIC members and service.



Meetings take place online to increase accessibility. Key stakeholders attend the group to present their issue and hear feedback directly from PIC members.



Meetings are recorded to ensure all views are captured, and to enable ongoing evaluation and continued improvement of the PIC.



Opportunities for ad hoc involvement at other times of the year, allowing for a timely and rapid response to service decisions.

Key Outputs of the PIC so far

- **Impact** across the whole East Midlands
- **Co-designing patient pathway processes** contributing to patient recovery outcomes in the top 1% nationwide
- **Research** funding co-applicants and advisors of research and innovation projects, including:
 - Preventing cancer
 - Evaluating psychological skills training for cancer care staff
 - Staying well after therapy
- **Contributions** to staff training developments and clinical work



Key Outputs of the PIC so far

- **Advising on health-tech improvements** e.g. the innovative Florence text message service to help people manage their own mental health before, during and after therapy
- **Input into commissioning and funding decisions**
- **Sharing** about the service via media communications
- **Feedback:** PIC members continuously updated on how their ideas have been put into practice/influenced change – to maintain engagement and highlight value





Example of PIC Group in Action

Task: Advice and guidance from PIC group on amendments to demographic form patients are asked to complete when referred to the service

PIC Group in Action – Discussing ‘next of kin’

The screenshot shows a Microsoft Word document titled "Cancer Psychology Personal Details Form 2025.doc" in Compatibility Mode. The document is a form with several sections:

- Gender Identity:** "If you describe your gender with another term, please provide this here:" followed by a dotted line for input. Below it, "Is your gender identity the same as the sex you were assigned at birth? (please circle)" with options: Yes, No, Prefer not to say.
- Pregnancy Status:** "Are you currently pregnant or on maternity leave? (please circle)" with options: Yes, No, Prefer not to say.
- Next of Kin:** "Next of kin:", "Relationship of next of kin:", "Next of kin phone number and address:".
- Sexual Orientation:** "(please circle one or more that applies to you)" with options: Heterosexual, Lesbian /Gay Woman /Gay Man, Bisexual, Unsure, Prefer not to say.
- Marital Status:** "(please circle)" with options: Married/Civil partnership, Single, Widowed, Divorced/Civil partnership dissolved, Separated, Prefer not to say.

The video conference interface on the right shows a grid of participants: Adam Hill, John Hallam, Erin Baker, Zahra Khan, Janet Park..., Neil Perrons, Louise B., and mark bai... (with a +4 icon indicating more participants).

Putting Feedback into Action

Before:

Next of kin:

Relationship of next of kin:

Next of kin phone number and address:

After:

Emergency contact:

Relationship to emergency contact:

Emergency contact phone number and address:

PIC Group in Action – Discussing ‘Pregnancy’

AutoSave Off Cancer Psychology Personal Details Form 2025.doc - Compatibility Mode • Saved

File Home Insert Design Layout References Mailings Review View Help Table Design Table Layout

Clipboard Font Paragraph Styles Editing Voice Sensitivity Editor Add-ins

Gender: (please circle)

Male Female

Non-binary Prefer not to say

If you describe your gender with another term, please provide this here:

Is your gender identity the same as the sex you were assigned at birth? (please circle)

Yes No Prefer not to say

Date of birth:

Religion:

Are you currently pregnant or on maternity leave? (please circle)

Yes No Prefer not to say

Next of kin:

Relationship of next of kin:

Next of kin phone number and address:

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Adam Hill

John Hallam

Erin Baker

Zahra Khan Neil Perrons

mark baines Sophie Kaur

Karen M... +4

Putting Feedback into Action

Before:

Are you currently pregnant or on maternity leave? <i>(please circle)</i>		
Yes	No	Prefer not to say

After:

Are you currently pregnant or on maternity leave? (please circle)	
(This is important as pregnancy can affect your emotional wellbeing, treatment decisions, and support needs)	
YES	NO
Prefer not to say	

Testimonials – Views of PIC Members



Karen Munford-Gibbs

The PIC group has given me a way to turn my own cancer journey into something that can help others. I've had support when I needed it most and using the amazing Florence text service.

Now I can share my knowledge, experience and views to make a difference.

Louise Beevers

As a founding member of this group, I cannot even begin to express how the work we have achieved so far has positively impacted my own life living with terminal cancer. The work we do goes a long way to future proofing services for generations to come too.

In my journey so far I have had contact with many different care providers but EMCA is the first and only service provision in cancer care that has invested time, expertise and consideration in actually listening and actioning the patient voice. Not only this but the PIC group has also opened avenues for its members to become actively engaged in current, relevant and helpful research. The work that EMCA and consequently, the PIC group do has personally given my life constructive purpose and I believe this to be a big contributing factor to my living longer, beyond my own expectations. The ability to contribute from our own lived experience can only improve, strengthen and solidify cancer care services.

PIC is not just a group, it is a lifeline. EMCA-CPH initiating its existence, has made life for those of us living with cancer and beyond as that of a recognised and valued one and our unique input can only really positively influence care and services for those patients yet to come.

Annette Massey

One of the most satisfying aspects for me is seeing how our thoughts and discussions from consultations are acted upon and put into practice. We are always kept fully informed about any outcomes from the meetings and it never feels like a 'tick box' exercise.

I see the online meetings as a safe space for everyone, where we are treated with respect and encouraged to contribute in the manner we feel most comfortable with - some members are confident to speak freely at the time - others prefer to think about things and make their contribution in other ways, which makes for a really comfortable and productive environment.

I always come away from the group feeling valued, and I am grateful to be given the opportunity to do something meaningful and worthwhile while I negotiate my own ongoing cancer journey and everything that goes with that.

Neil Perrons

As a cancer patient who required help from the psychotherapy service, I was delighted to be invited to take part in the Patient Involvement Collaboration. For me, this engagement provides an opportunity for me to 'give something back' and help shape the service for future cancer patients. It is immensely rewarding and I am thankful that the EMCA-CPH have taken the initiative to champion patient involvement.

Next steps



Group development and inviting others who complete therapy to take part. Aim of increasing diversity in group membership



Formalised service evaluation of PIC group, including experiences of group members and outputs



Co-publishing papers



Co-presenting at conferences

Any Questions?

