

Our Reference

North East and North Cumbria ICB\ FOI ICB 24–273 NECS – John Snow House Durham University Science Park Durham DH1 3YG

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By Email 16 October 2024

Dear Applicant

# <u>Freedom of Information Act 2000 – Request for Information – NHS North East and North Cumbria Integrated Care Board (NENC ICB)</u>

Thank you for your request received by North of England Commissioning Support (NECS) on 2 October 2024 for information held by NHS North East and North Cumbria Integrated Care Board (the ICB) under the provisions of the Freedom of Information Act 2000.

The ICB covers the areas of County Durham, Gateshead, Newcastle, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley (which covers the five local authorities of Darlington, Hartlepool, Middlesbrough, Redcar and Cleveland and Stockton-on-Tees).

Please find the information you requested on behalf of the ICB as follows.

#### **Your Request**

I am keen to understand more about how Personalised Stratified Follow Up (PSFU), for patients who have completed their hospital-based treatment for primary breast cancer, is being delivered in practice and the role Cancer Alliances have in this.

At the end of their hospital-based treatment, all primary breast cancer patients used to be offered-in addition to yearly mammograms for suitable patients – an annual clinical appointment for a period of five years, known as Routine Follow Up. In recent years, there has been a move away from Routine Follow Up and towards Personalised Stratified Follow Up (PSFU) at the end of hospital-based treatment. PSFU would give the option of Patient Initiated follow-up (PIFU) or Routine Follow Up – with both pathways continuing to offer annual mammograms for suitable patients. While the terms PSFU and PIFU are sometimes used interchangeably, for the questions below PSFU is being used to mean the overarching approach which encompasses the specific options of Routine Follow Up and PIFU. Note that sometimes other terms are used instead of PSFU or PIFU, e.g. supported self-managed follow up, stratified follow up or open access follow up.

www.northeastnorthcumbria.nhs.uk







In accordance with the Freedom of Information Act 2000, I would appreciate it if you could respond to the following questions. Please use an X in the boxes to indicate your answer when required or provide numerical data where requested. Note that some questions are open questions, and some ask for copies of documents.

When in questions we refer to Trusts that 'form part of a Cancer Alliance' we mean Trusts providing breast cancer services in your Cancer Alliance area.

The questions in this request all relate to the PSFU pathway for primary breast cancer patients.

## The relationship between the Cancer Alliance and Trusts

- 1. Which Trusts form part of your Cancer Alliance?
- 2. Is there a Cancer Alliance written document that covers the PSFU pathway for when patients with primary breast cancer finish their hospital-based treatment? This might be referred to as a Standard Operating Procedure, a PSFU Protocol, guideline or another name.

Yes	
No	
Don't Know	

If yes, please provide your current, or most recent, version of this document.

**If yes**, please confirm what year the document was last updated and whether the document is still in use.

**If no**, please provide any cancer alliance wide guidelines that cover the PSFU pathway for breast cancer that you may have.

3. If the answer the question 2 was 'Yes', have all Trusts that form part of the Cancer Alliance agreed to follow this document?

Yes, all Trusts have agreed	
Some Trusts have agreed	
None of the Trusts have agreed	
Don't Know	

**If 'Some Trusts have agreed'**, please provide the names of Trusts that have agreed and the names of Trusts in the process of agreeing.

**If 'None of the Trusts have agreed'**, please provide the names of Trusts in the process of agreeing, if there are any.

- 4. If there are written agreements between the Cancer Alliance and any of the Trusts that form part of the Cancer Alliance in relation to the protocol, please provide these.
- 5. If the answer to question 2 was 'Yes', were all Trusts that form part of the Cancer Alliance actively involved in developing it?

All Trusts that form part of the alliance were	
involved	
Some but not all Trusts	
No Trusts were involved	

6. Have you worked with Trusts that form part of the Cancer Alliance to develop their own Standard Operating Procedure or a PSFU Protocol for breast cancer?

	Yes, all			
	Yes, some			
	No			
	Don't Know			
	If 'Yes, some', which Trusts did you work with?			
7.	Please provide assurance reports undertaken by the Cancer Alliance in the last three years about progress towards achieving NHS planning requirements on PSFU that include breast cancer. If the assurance reports over the past three years do not include breast cancer, could you provide the most recent one that did?			
3.	Has the Cancer Alliance undertaken a local audit/s of adherence to PSFU protocols relating to breast cancer?			
	Yes			
	No			
	Don't Know			
9.	<ul><li>If yes, please provide the most recent version?</li><li>Does the Cancer Alliance have a current estimate of the number of outpatient slots being redeployed through the implementation of the PSFU for breast cancer?</li></ul>			
	Yes			
	No			
	Don't Know			
	If yes, please provide this estimate and explai	n the time period it relates to.		
10	Does the Cancer Alliance have an active peer network that champions PSFU (including for primary breast cancer) within clinical teams?			
	Yes			
	No			
	Don't Know			
11. Has the Cancer Alliance undertaken a review of the Breast Cancer PSFU pathway to ensure it helps tackle health inequalities?				
	Yes			
	No			
	Don't Know			
	=			

12. Has the Cancer Alliance completed a PSFU audit tool covering the pathways for primary breast cancer patients that have completed their hospital-based treatment?

If yes, please share the details and results of the most recent review?

Yes	

No	
Don't Know	

**If yes**, is the audit tool still up to date?

Yes	
No	
Don't know	

Please provide the most recent version of the audit tool, if one was developed at any point.

### **Our Response**

We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB holds some of the information you have requested.

1. The Foundation Trusts FTs) listed below form part of the Cancer Alliance:

County Durham and Darlington NHS FT

Gateshead Health NHS FT

Newcastle upon Tyne Hospitals NHS FT

North Cumbria Integrated Care NHS FT

North Tees and Hartlepool NHS FT

Northumbria Healthcare NHS FT

South Tees Hospitals NHS FT

South Tyneside and Sunderland NHS FT (does not have a primary breast service, but does have a metastatic pathway)

- 2. There is a Cancer Alliance written document that covers the PSFU pathway for when patients with primary breast cancer finish their hospital-based treatment. This document was updated September 2024 (attached) and is still in use.
- 3. All trusts that form part of the Cancer Alliance have agreed to follow this document.
- 4. All trusts have adopted the PSFU guidelines, there are no individual written agreements as the guidelines are adopted through the Breast Managed Clinical Network (MCN).
- 5. All trusts that form part of the Cancer Alliance were actively involved in developing it through the Breast MCN.
- 6. Yes, we have worked with Trusts that form part of the Cancer Alliance to develop their own Standard Operating Procedure or a PSFU Protocol for breast cancer. We have provided support via the managed clinical network and as required via the NCA's monthly Personalised Care Working Group.
- 7. The NCA has not produced assurance reports in relation to planning requirements on PSFU that include breast cancer. Our most recent quarterly assurance return for Q1 25/26 stated: PSFU was operational for breast, prostate, colorectal and endometrial cancers except in two units (North Cumbria Integrated Care, who needed to make progress on colorectal and prostate, as well as Newcastle upon Tyne Hospitals, who need to make progress with urology), delays were for operational issues.
- 8. No formal audits have been undertaken however PSFU is monitored via the Breast MCN, regular engagement with providers and via review of cancer outcomes and services data (COSD) and other Trust level data.
- 9. The Cancer Alliance does not have a current estimate of the number of outpatient slots being redeployed through the implementation of the PSFU for breast cancer. Data is gathered but it has not been analysed as part of the wider system ask around this shift from outpatients.

- 10. The Cancer Alliance has an active peer network that champions PSFU (including for primary breast cancer) within clinical teams. We have an active Lead Cancer Nurse group that reviews PSFU implementation in general as well as the Breast MCN and the NCA's Clinical Leadership Group.
- 11. The Cancer Alliance has not undertaken a review of the Breast Cancer PSFU pathway to ensure it helps tackle health inequalities. However, easy read versions are available/to be adapted locally for each Trust.
- 12. The Cancer Alliance has not completed a PSFU audit tool covering the pathways for primary breast cancer patients that have completed their hospital-based treatment.

In accordance with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS ICB website <a href="https://northeastnorthcumbria.nhs.uk/">https://northeastnorthcumbria.nhs.uk/</a>.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision, you should write to the Senior Governance Manager using the contact details at the top of this letter quoting the appropriate reference number.

If you are not content with the outcome your review, you do have the right of complaint to the Information Commissioner as established by section 50 of the Freedom of Information Act 2000. Generally, the Information Commissioner cannot make a decision unless you have exhausted the complaints procedure provided by the North of England Commissioning Support Unit.

The Information Commissioner can be contacted at:

Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

#### www.ico.org.uk

Any information we provide following your request under the Freedom of Information Act will not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector Information Regulations 2015 <a href="www.legislation.gov.uk">www.legislation.gov.uk</a>. This will not affect your initial information request.

Yours sincerely

S Davies

S Davies Information Governance Officer