

Ref. No: 2621
Date: 15/06/25
Subject: Bone cancer long-term follow-up and late effects services details

REQUEST

Under the Freedom of Information Act 2000, please provide the following information about long-term follow-up and late effects services available to patients within your organisation who have been treated for primary bone cancer (bone sarcoma).

This Freedom of Information (FOI) request is part of a UK-wide service mapping exercise examining national long-term follow-up and late effects services for patients and survivors of primary bone cancer. This study has ethical approval and is led by researchers at the University of Bath and the Bone Cancer Research Trust (BCRT).

We are seeking information that is already recorded and held by your organisation. If the requested information is not held, please indicate this in your response.

To support an accurate and comprehensive response, we kindly ask that this request is reviewed by, or forwarded to, the most appropriate services within your organisation. This may include sarcoma services, as well as paediatric, teenage and young adult (TYA), and adult teams involved in the care of patients with primary bone cancer (for example, oncology, orthopaedic surgery, radiotherapy, bone tumour or surveillance clinics, allied health professionals, endocrinologists etc and any dedicated late effects services).

Responses to this FOI will contribute to a detailed and comprehensive overview of current service provision. This will support our aim to better inform patients and families about the support available to them, as well as to identify any gaps or disparities in access and provision.

Please find below definitions of long-term follow-up and late effects services for the purposes of this FOI. We recognise that the terms “long-term follow-up” and “late effects service” are sometimes used interchangeably, and their application may vary between organisations.

- Long-term follow-up: Long-term follow-up describes the ongoing clinical reviews required after completion of cancer treatment. Initially, these reviews may include surveillance investigations (e.g. imaging). Over time, once a

period of clinical stability is reached, routine imaging may cease; however, follow-up continues. Long-term follow-up includes monitoring for potential late effects of treatment and the management of any issues that arise as a result.

- Late effects service: A late effects service focuses on the assessment and management of health problems that occur months or years after treatment, including those related to surgery, chemotherapy, or radiotherapy. This may be delivered as a distinct service, or as part of a broader long-term follow-up service.
- Late effects monitoring service: A late effects monitoring service provides structured, ongoing surveillance for potential late effects following cancer treatment. This typically involves regular, scheduled reviews and may include investigations (e.g. imaging, blood tests, or functional assessments) to identify late effects early, even in the absence of symptoms.

1. Please provide details of the region your NHS Trust/Health Board represent:

2. Does your Trust/Health Board currently provide, host, or commission any service(s) that deliver long-term follow-up and/or late effects care for patients previously treated for primary bone cancer?

- a. Yes
- b. No

3. If yes, please provide details of the service:

- a. Service name:
- b. Service location:
- c. Website (if available):
- d. This service is best described as a (please indicate):
 - i. Long-term follow-up service
 - ii. Late effects service
 - iii. Late effects monitoring service
 - iv. Combined long-term and late effects service
 - v. No service provided
 - vi. Other (please specify)
 - vii. Don't know

4. Please fill in further details of the service:

- a. Referral pathway(s) into service:
- b. Age eligibility:
 - i. Upper age limit:
 - ii. Lower age limit:
 - iii. Or no age restrictions apply
 - iv. Don't know
- c. Geographical radius/catchment area where patients can access service:

5. Please specify which patient groups are eligible to access this service (please indicate all that apply):

- a. Paediatric
- b. Teenage and Young Adult (TYA)
- c. Adults

d. Don't know

6. Which treatment intent does this service support?

a. Radical or curative treatment only

b. Palliative treatment only

c. Both radical and palliative treatment d. Don't know

7. Does your Trust/Health Board permit follow up contact from the research team solely for the purpose of clarifying information provided in this Freedom of Information response?

a. Yes

b. No

8. If yes, please provide preferred follow-up contact details:

9. Does your Trust/Health Board permit the information provided in this request to be used to inform patients about the availability of your long term follow up and/or late effects service for bone cancer survivors? (Information may be shared publicly for patient signposting and awareness purposes via the Bone Cancer Research Trust website).

a. Yes

b. No

RESPONSE

We do not treat bone sarcoma at MWL