Greater Manchester
Cancer Alliance

Defining Accountabilities for Personalised Care Interventions:

End of Treatment Summaries & Personalised Stratified Follow-Up in Prostate

Purpose and background

The importance of support for people affected by cancer is widely recognised, but there are known gaps in service provision across the country. Personalised Care interventions can support the psychosocial needs of these patients, and provide opportunities to improve quality of life and experiences of care if this is delivered to a high standard.

The document was created based on discussions with Greater Manchester Trusts' Personalised Care Leads, Lead Cancer Nurses and clinicians, where concerns were raised over the implementation of Personalised Stratified Follow-Up (PSFU) pathways. These concerns broadly covered: a) the confusion between PSFU and Patient Initiated Follow-Up (PIFU) pathways, b) which Trusts are accountable for the delivery of End of Treatment Summaries (EOTS) and PSFU when patients received are receiving care from more than one organisation, and c) the variation in EOTS terminology.

This document aims to address these three areas.

Clarification of differences between PIFU and PSFU pathways

PSFU is the approach to follow-up used in cancer care, and focuses on offering the patient Personalised Care interventions focused on:

*'**PSFU** means patients know that when they complete primary treatment they will be offered:*

- *Information about signs and symptoms to look out for which could suggest their cancer has recurred or progressed*
- *Rapid access back to their cancer team, including telephone advice and support, if they are worried about any symptoms, including possible side effects of treatment*
- *Regular surveillance scans or tests (depending on cancer type), with quicker and easier access to results so that any anxiety is kept to a minimum*
- *Personalised care and support planning and support for self-management, to help them to improve their health and wellbeing in the long term'*

(NHS England & NHS Improvement, 2020)

It is important PSFU is not confused with Patient Initiated Follow-Up (PIFU).

*‘**PIFU** is when a patient initiates an appointment when they need one, based on their symptoms and individual circumstances. PIFU gives patients or their carers control over their follow-up care.’*

(NHS England and NHS Improvement, 2022)

Whilst both pathways give the patient ownership of their follow-up care, PIFU requires **all follow-up to be initiated by the patient** and a clear shared decision-making process followed and documented before putting a patient on a PIFU pathway.

Alternatively, PSFU allows the patient to initiate contact (as per PIFU) if they have worrying symptoms or concerns, **but additionally, they will also receive scheduled surveillance scans, tests and/or holistic needs assessments as required and defined by a clinical protocol**. These tests will allow continued monitoring by their clinical teams, without the need to attend face-to-face appointments. PSFU pathways are also complemented by an End of Treatment Summary discussion and document, where key information (as outlined above) is provided, to prepare the patient for self-management.

Benefits of PSFU

For the patient, the benefits of PSFU include: personalisation in the care provided, consideration of their needs and preferences, access to surveillance that enables the detection and management of cancer-related psychosocial conditions, encouraging self-management, increasing people’s knowledge, confidence and understanding of their condition, encouraging lifestyle changes to reduce the risk/impact of cancer recurrence, reducing travel to hospitals and reducing anxiety through more timely access to results.

From a systems and staff perspective, PSFU can: enhance care continuity, improve communication and links with primary care teams, improve knowledge of pathways for referral/ signposting to services and third sector support, improves productivity and use of staff time, free up outpatient capacity, reduce duplication of surveillance tests, and reduce demand for unplanned care (NHS England & NHS Improvement, 2020).

The implementation of PSFU is an essential aspect of the NHS Long Term Plan (NHS England, 2021), highlighting that ‘After treatment, patients will move to a follow-up pathway that suits their needs, and ensures they can get rapid access to clinical support where they are worried that their cancer may have recurred.’

In line with this, the Cancer Alliance Planning Pack highlights a need to ensure End of Treatment Summaries (EOTS) are available for all cancer patients, with data submitted to COSD. Furthermore, this guidance specifies that fully operational and sustainable PSFU should be in place in Trusts for breast, prostate, colorectal and endometrial cancers by March 2024 (NHS Cancer Programme, 2023)

Clarification of differences between Treatment Summaries and End of Treatment Summaries

For the purposes of this document and the implementation of Personalised Care within Greater Manchester, the terms below apply:

Treatment Summary: To include any treatment summary that focuses on a single treatment modality, such as the summary provided upon completion of radiotherapy, chemotherapy or surgery. This phrase will also incorporate the terms ‘mid-treatment summary’ and ‘single-modality treatment summary’ used by some teams.

End of Treatment Summary: The term used for a summary of all treatment undergone by the patient, with the added components required within a PSFU pathway (such as red flag symptoms, side effects and late effects, health and wellbeing information). The EOTS should incorporate details of all treatments undertaken, and act as a summary that prepares patients to enter onto a self-management pathway.

Pathways Mapping

Exceptions

Figures 1-6 (below) highlight the **general approach** to the allocation of accountabilities for specific patient pathways, in relation to their nurse-led follow-up once they have been placed on a PSFU pathway by the consultant. This does not replace or alter the accountability or location of any existing consultant appointments occurring at six weeks after treatment, nor does it account for variations in follow-up location due to factors such as consultant preferences, patient preferences or unique, complex cases. Where Figures 1-6 are deviated from, the treating trust should discuss with the relevant clinical team, and an agreement reached for which Trust is overseeing the patient’s EOTS and PSFU pathway.

How this document should be used

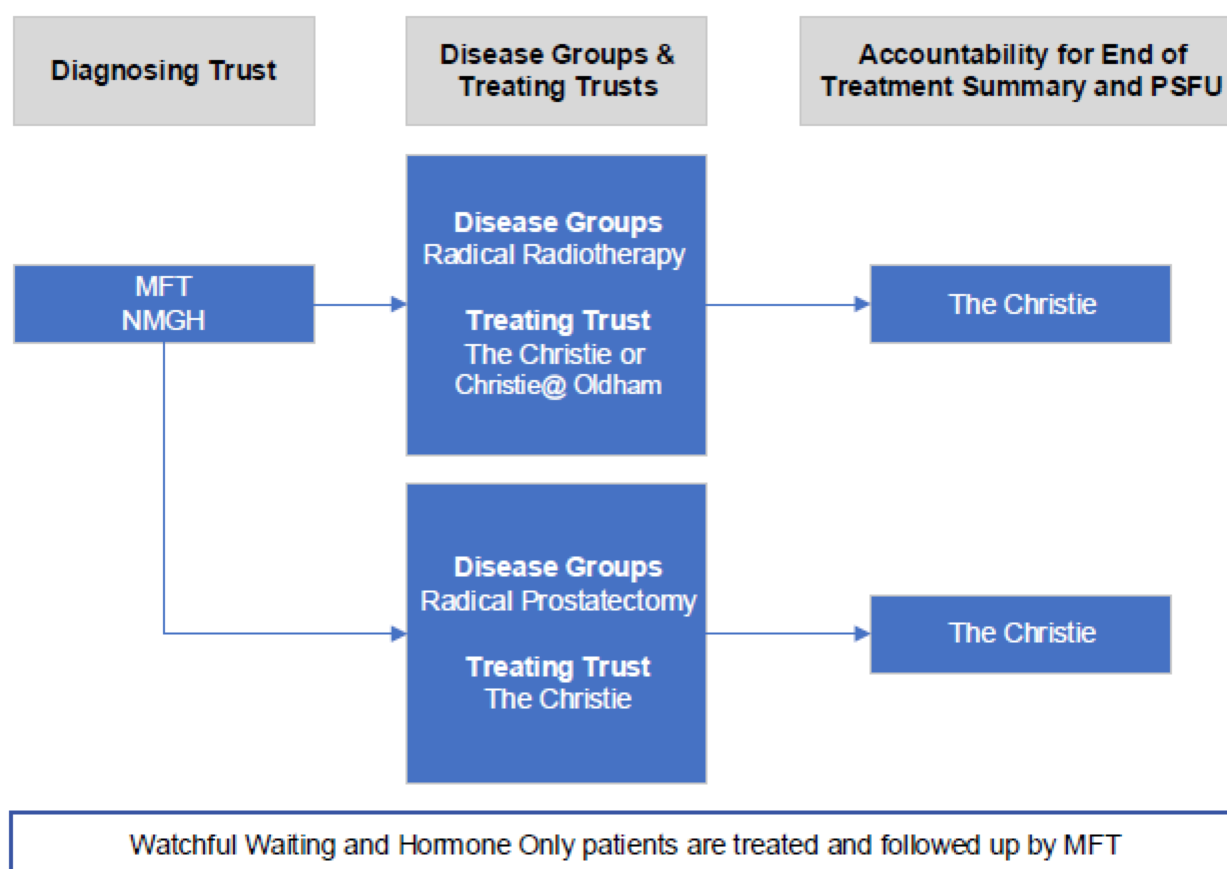
- After using this document to identify which pathways your organisation is responsible for overseeing, local agreement should be reached about who is responsible for doing the EOTS consultation and document (whether consultant or clinical nurse specialist), and when in the pathways this will be completed. The method of tracking the patient for PSFU should also be ascertained and organised within the Trust.
- For Trusts completing patient treatment and **not** overseeing their follow-up, a treatment summary (and any completed Holistic Needs Assessments/Personalised Care and Support Plans) should be shared with the accountable Trust for each phase of completed treatment,

shortly after treatment completion. This document should be shared with the relevant Prostate clinical teams in each pathway.

The below diagrams highlight the various patient pathways across Greater Manchester, based on where patients receive their diagnosis, treatment and follow-up care. At the end of each diagram, a column entitled 'Accountability for End of Treatment Summary and PSFU' is included, to show which organisation is responsible for this elements.

'Accountability for End of Treatment Summary and PSFU' is defined as overseeing completion of the End of Treatment Summary consultation and accompanying document, initiating the patient onto PSFU tracking and ongoing surveillance tests as required as part of their pathway. Whilst this is primarily applicable to patients on Supported Self-Management pathways, this accountability also applies for completing the EOTS with patients on Professionally-Led pathways, as part of their ongoing support and monitoring.

Figure 1. Manchester Foundation Trust (MFT) Pathways



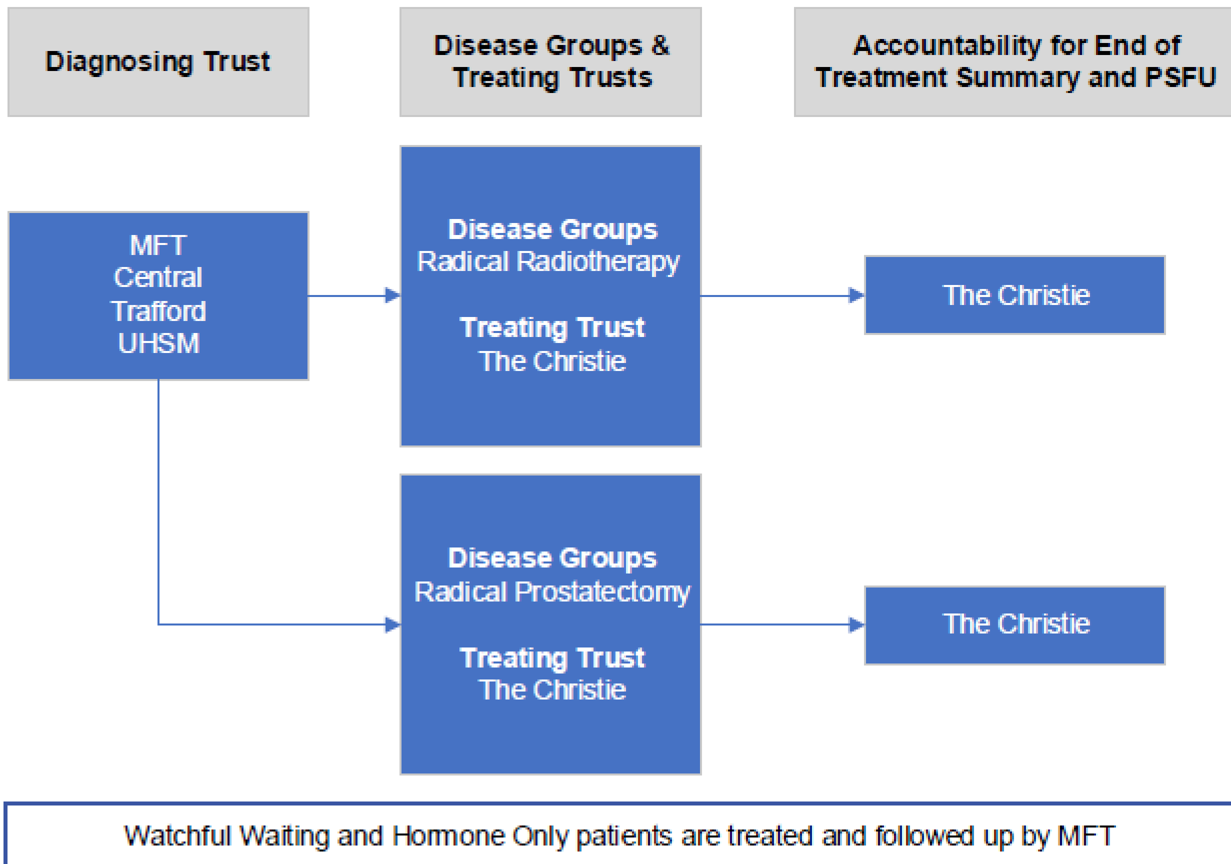

Diagnosing Trust
Disease Groups & Treating Trusts
Accountability for End of Treatment Summary and PSFU
MFT
Central
Trafford
UHSM
Disease Groups
Radical Radiotherapy
Treating Trust
The Christie
The Christie
Disease Groups
Radical Prostatectomy
Treating Trust
The Christie
The Christie
Watchful Waiting and Hormone Only patients are treated and followed up by MFT

Figure 2. Tameside NHS Trust Pathways

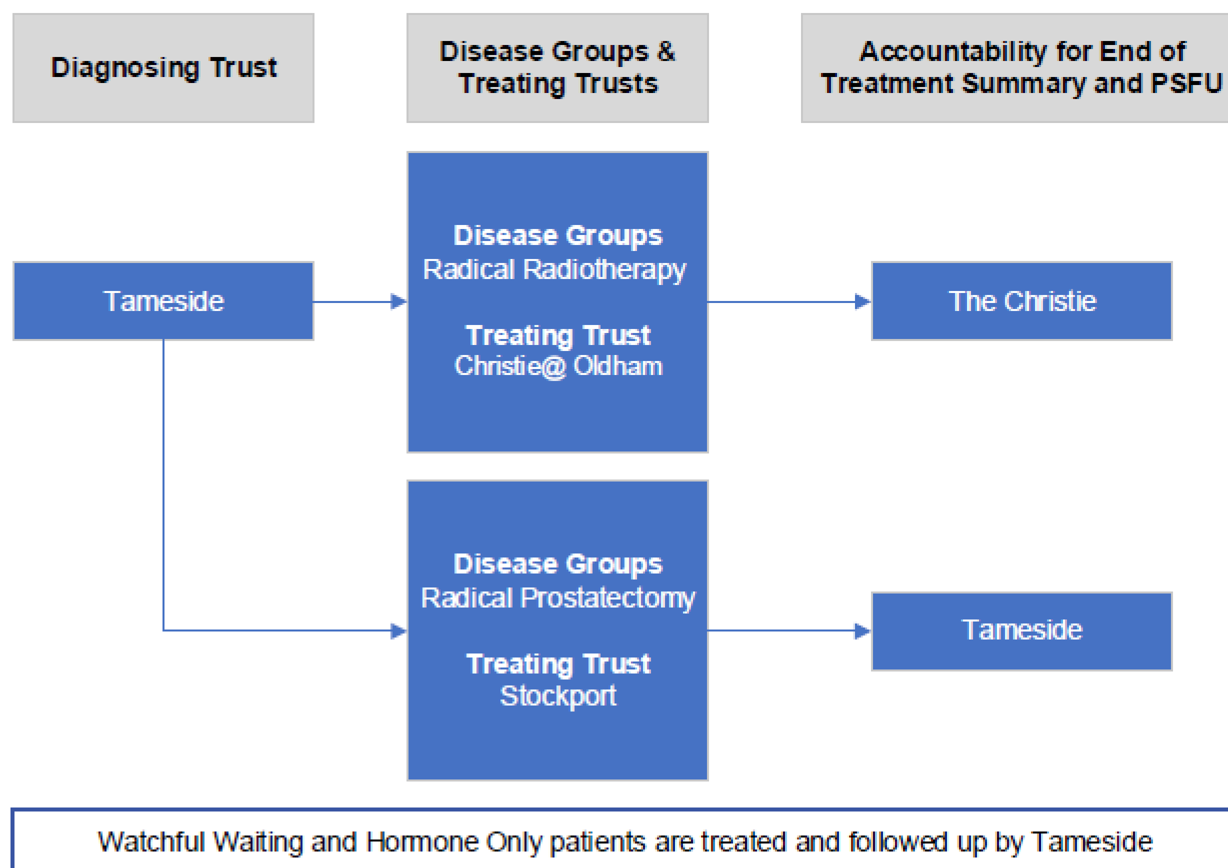


Figure 3. Wrightington, Wigan and Leigh (WWL) NHS Trust Pathways

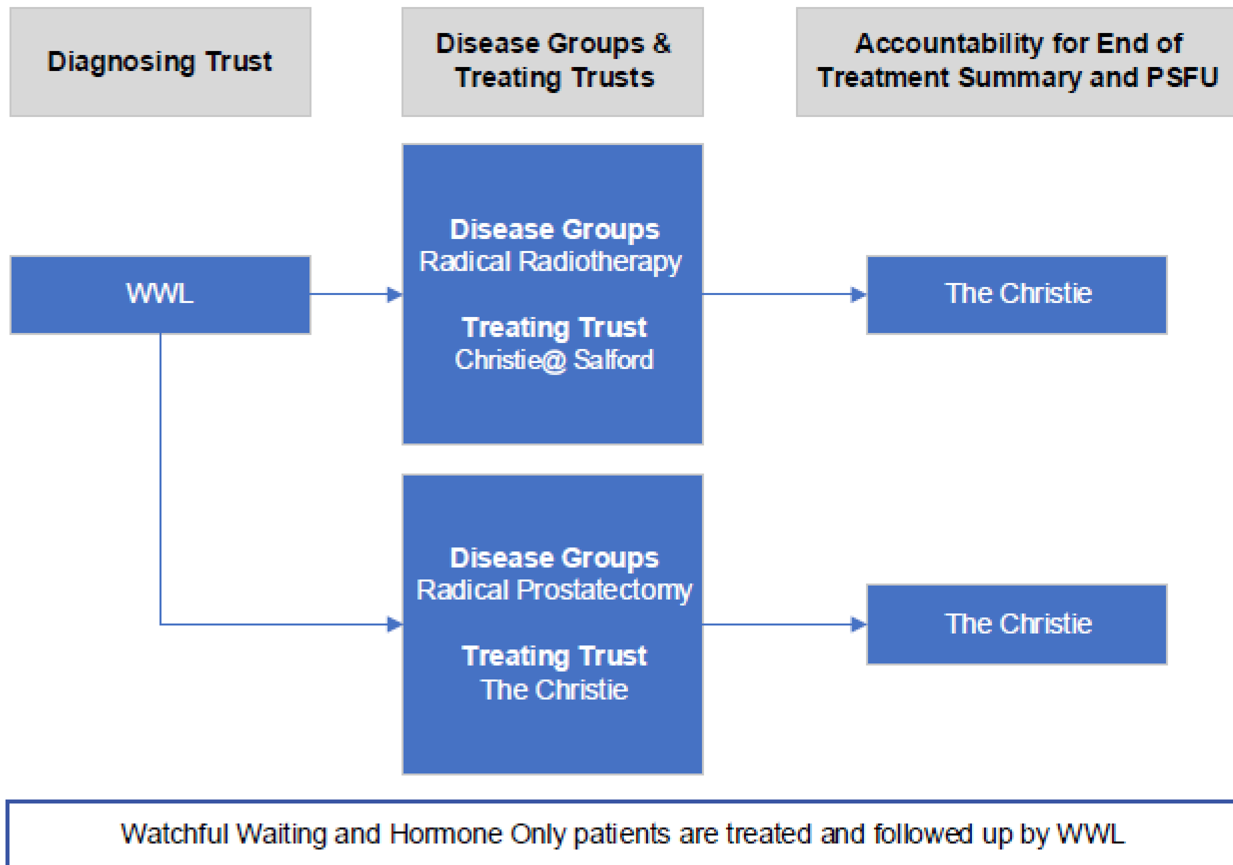
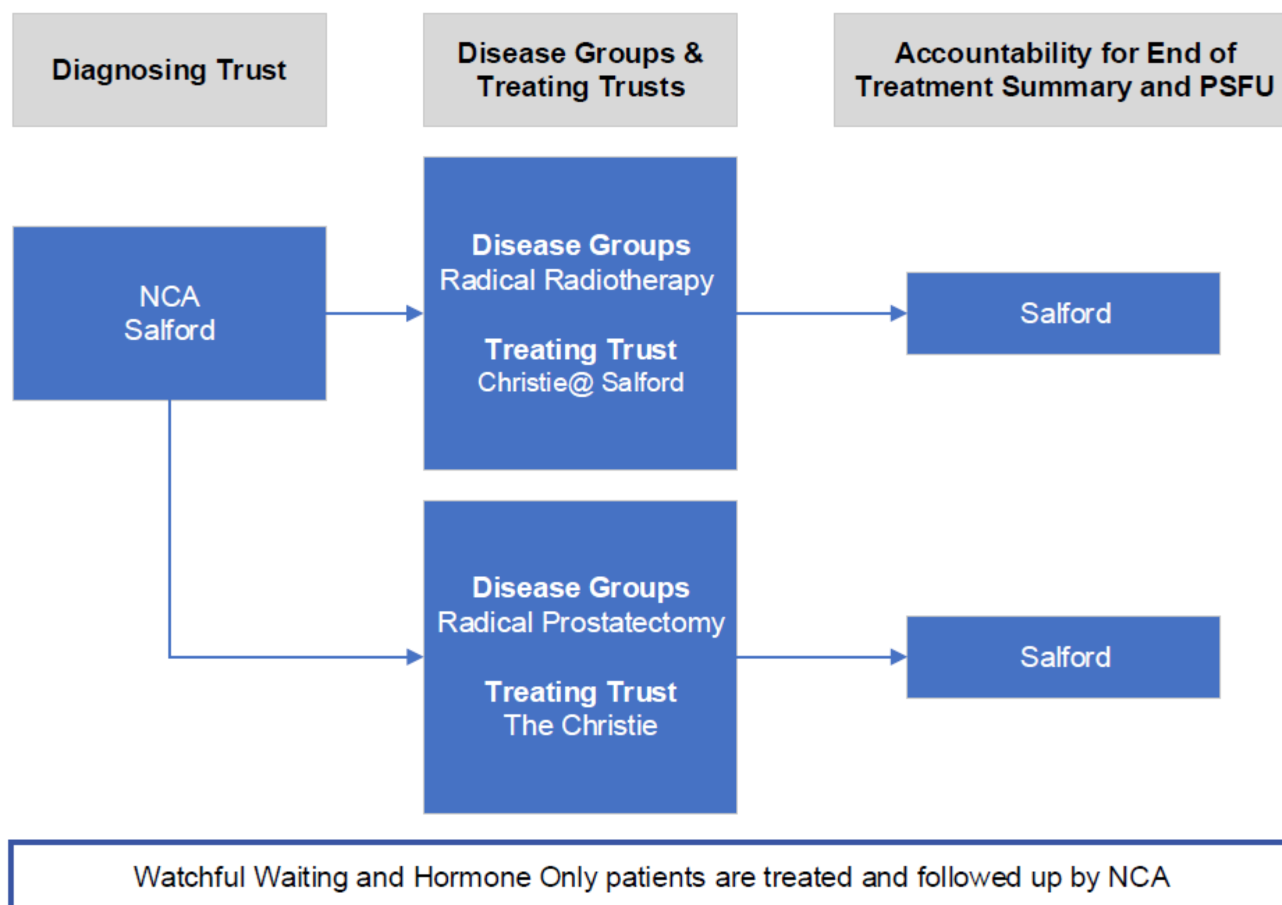
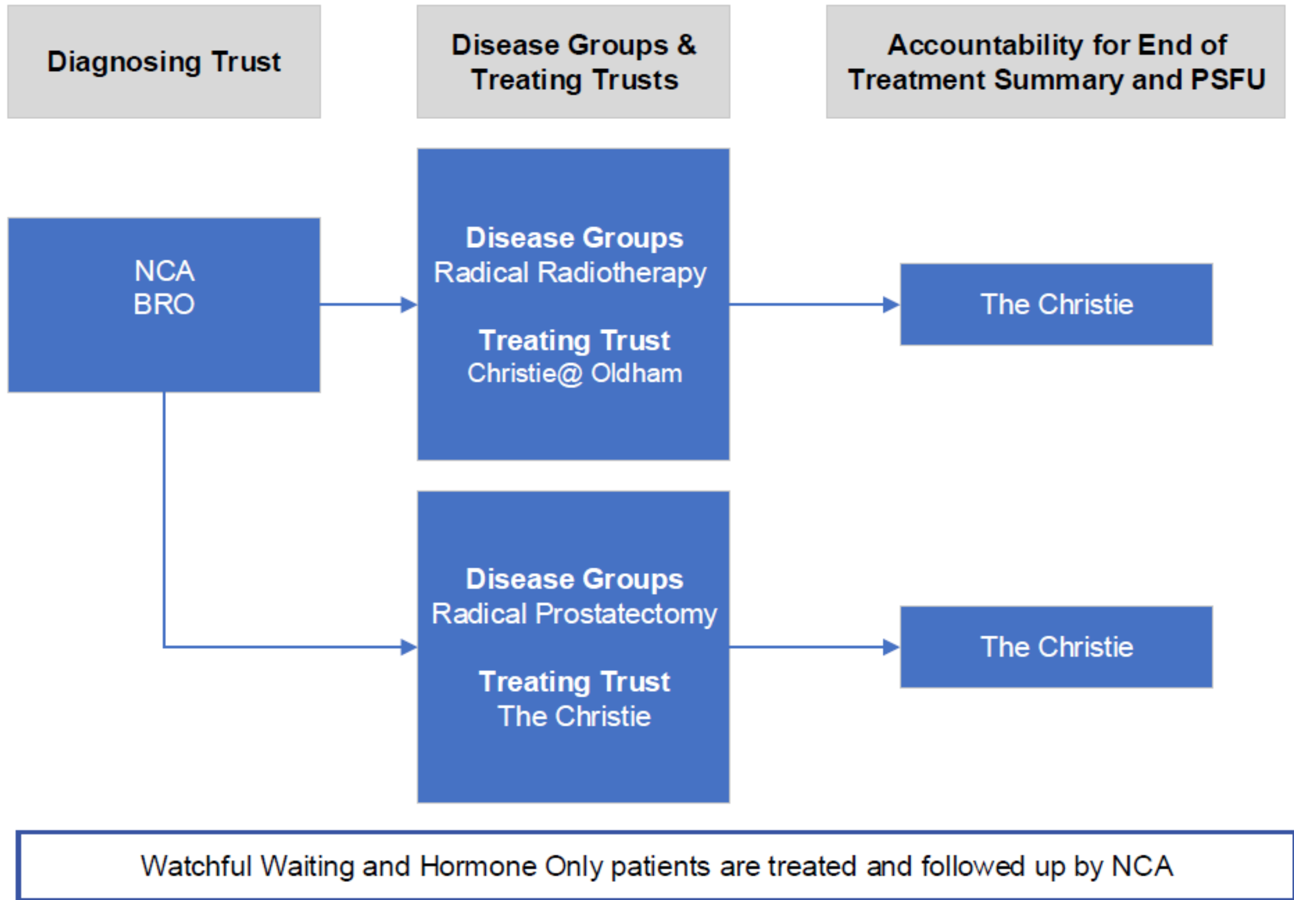


Figure 4. Northern Care Alliance (NCA) Pathways

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Christie@ Oldham
The Christie
Disease Groups
Radical Prostatectomy
Treating Trust
The Christie
The Christie
Watchful Waiting and Hormone Only patients are treated and followed up by NCA

Figure 5. Bolton NHS Trust Pathways

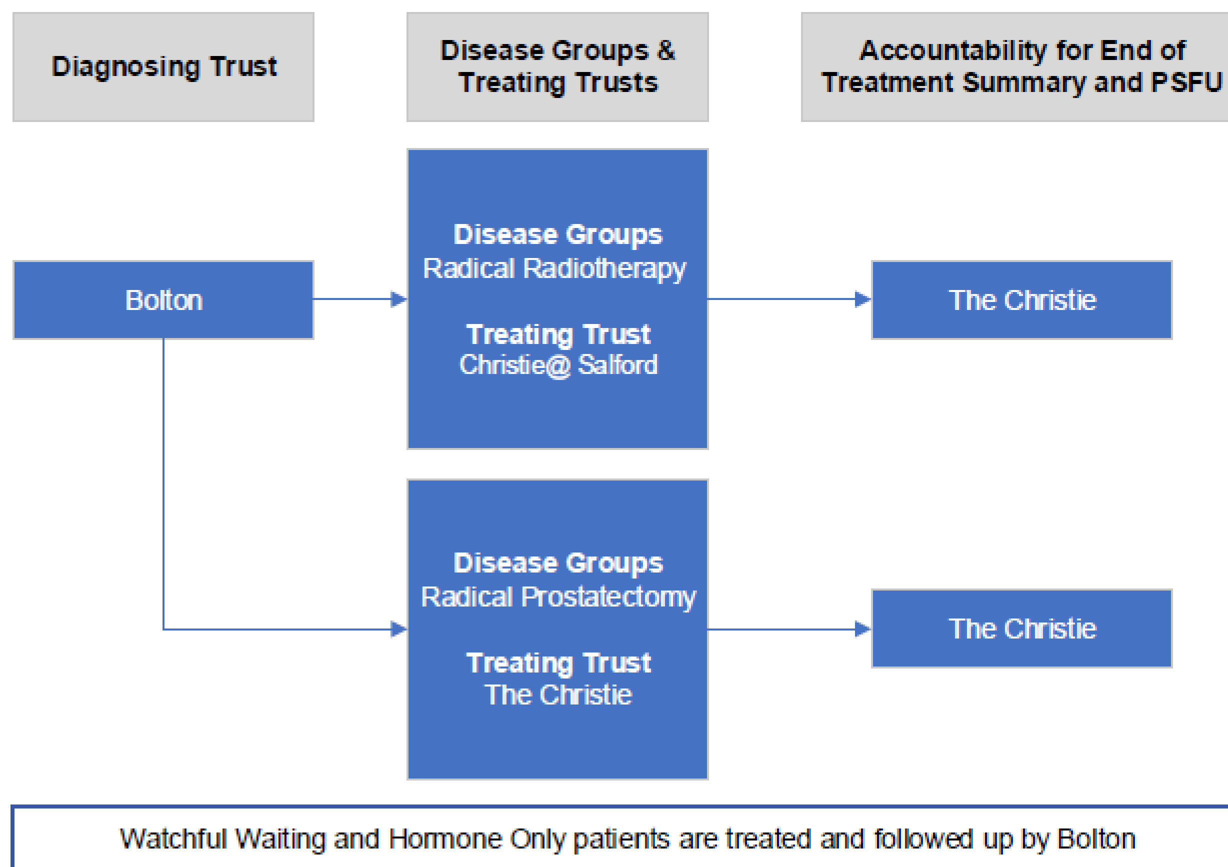
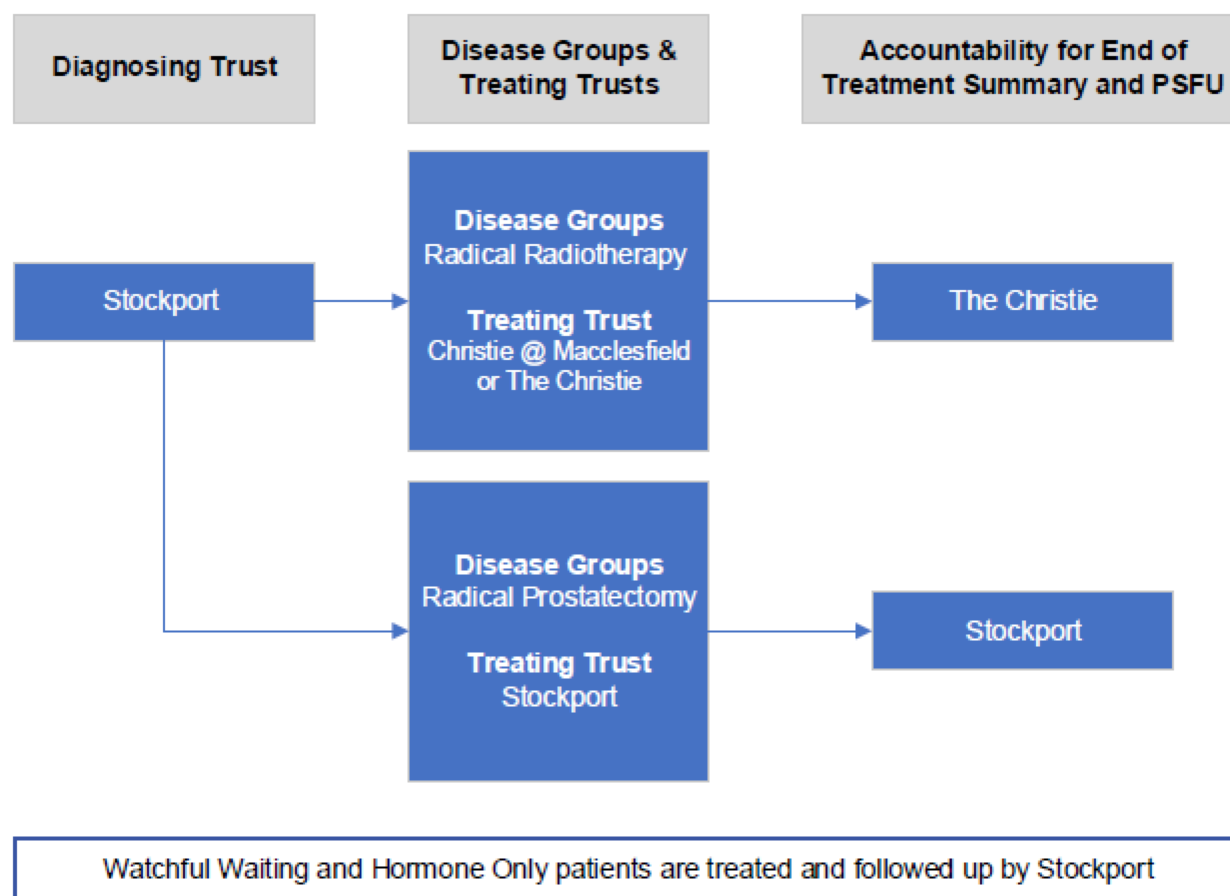


Figure 6. Stockport NHS Trust Pathways



References

NHS England & NHS Improvement (2020) **Implementing Personalised Stratified Follow-Up Pathways** [online]. Available at: https://www.england.nhs.uk/wp-content/uploads/2020/04/cancer-stratified-follow-up-handbook-v1-march-2020.pdf [Accessed 24th October 2023].

NHS England (2021) **NHS Long Term Plan** [online]. Available at: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf [Accessed 24th October 2023].

NHS Cancer Programme (2023) **Cancer Alliance Planning Pack**. London: NHS England.