

Rachel's Pathway

One Review. One Scan. One Plan. (OOO)



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Rachel's Pathway (OOO Model)

One Review. One Scan. One Plan.

A policy proposal extending Rachel's Rule (AHRR): Protecting Today, For Tomorrow

1. Introduction

Rachel's Pathway (OOO Model) builds upon the principles established in **Rachel's Rule: Annual Hereditary Risk Reviews (AHRR)**.

While AHRR identifies hereditary risk through annual structured reviews, **Rachel's Pathway provides the next step** — ensuring that risk is managed through a unified surveillance system: **One Review. One Scan. One Plan.**

This policy proposes a comprehensive, risk-stratified surveillance model for individuals with hereditary or multi-organ cancer predisposition. It addresses inefficiencies, fragmentation, and missed opportunities within current NHS surveillance structures, and outlines a cost-effective, humane, and technologically feasible solution.

2. Background and Context

Rachel Ball was just 47 when her breast cancer returned in 2024. Over two decades she faced multiple primary cancers — ovarian (2005, squamous carcinoma within dermoid cyst), 2012 Grade 1C Ovarian cancer, and 2019 Breast cancer — before being diagnosed with **PTEN Hamartoma Tumour Syndrome (Cowden Syndrome)**.

Her first breast cancer in 2019 was **HER2-negative, oestrogen-receptive**.

Her recurrence in 2024 was **HER2-positive, low oestrogen-receptive**, showing a biological shift from the previous tumour. Despite this complex history and known genetic predisposition, Rachel's surveillance remained fragmented across multiple clinics and imaging schedules.

Initial recurrence signs — a lump in the neck — led to inconclusive biopsies and repeated imaging, delaying diagnosis while the disease progressed. During this time, multiple scans were performed (neck, thorax, pelvis, liver) but not as part of a single coordinated plan.

This system design left her **technically monitored, but clinically unprotected**.

Rachel's story is not unique — it reflects systemic inefficiencies affecting hereditary cancer families across the UK.

Rachel's Pathway (OOO Model) seeks to prevent this outcome by introducing a unified, person-centred surveillance approach.

3. The Rachel's Framework: From AHRR to OOO

Component	Purpose	Outcome
Rachel's Rule (AHRR)	Annual Hereditary Risk Review	Identifies hereditary risk early and ensures continuous monitoring
Rachel's Pathway (OOO)	One Review. One Scan. One Plan.	Provides efficient, complete, and personalised hereditary surveillance

Together, these create a joined-up hereditary cancer policy framework:

AHRR identifies risk. OOO manages it.

4. The Case for Change

4.1 Fragmented Surveillance and Missed Recurrence

The current NHS surveillance model for hereditary cancer syndromes is fragmented and organ-specific. Patients may be monitored for thyroid, breast, or bowel risk separately — under different teams, guidelines, and timescales — with no unified record or review.

Even when guidelines are followed (such as those for Cowden Syndrome), this fragmentation creates **gaps in surveillance coverage**. In Rachel's case, the **liver**, one of the most common recurrence sites for breast cancer, was never imaged until recurrence appeared incidentally.

NHS guidelines state that scanning for recurrence “does not improve survival” and increases radiation exposure, but this reasoning is outdated. Modern MRI-first imaging eliminates radiation risk, and early detection of recurrence directly improves both survival and quality of life.

4.2 Human and Clinical Cost of Delay

Rachel underwent two biopsies of the same neck lesion, multiple scans and then a liver biopsy, before a clear result was achieved, 6 months later.

During these months, her cancer spread quietly, unnoticed by the fragmented surveillance system designed to protect her.

Even after diagnosis, she required separate CT and MRI scans to assess disease spread and treatment efficacy — each requiring new cannula insertions, long hospital stays, and repeat visits.

This delay wasn't caused by medical error but by **system design** — multiple partial scans rather than one comprehensive one. It runs directly counter to the NHS improvement principle of “**Get It Right First Time (GIRFT)**”, which aims to eliminate duplication, avoid repeat procedures, and deliver complete answers at the earliest opportunity.

The OOO model applies that principle to hereditary and recurrence surveillance — one review, one scan, one plan — so that families like Rachel's are no longer caught in cycles of inconclusive tests and lost time.

5. The OOO Model Explained

OOO = One Review. One Scan. One Plan.

A unified annual surveillance episode that brings all hereditary and recurrence monitoring under one multidisciplinary umbrella.

- **One Review:** Combined assessment of hereditary risk, symptom update, and clinical history.
- **One Scan:** MRI-first whole-body imaging (head-to-pelvis) — replacing multiple organ-specific scans.
- **One Plan:** Unified review by multidisciplinary specialists leading to a single, joined-up management plan.

OOO is not about scanning more — it's about **scanning smarter**.

6. Routine vs Risk-Stratified Surveillance

NICE guideline **NG101** advises against routine metastatic imaging for all breast cancer survivors, citing limited benefit in asymptomatic populations. However, that guidance does **not** apply to people with hereditary multi-organ cancer risk, multiple primaries, or overlapping tumour syndromes.

For these groups, a one-size-fits-all rule fails.

Rachel's recurrence was detected incidentally during thyroid imaging — not because of a symptom-led or guideline-driven process.

The OOO model replaces organ-by-organ follow-up with **risk-stratified, MRI-first whole-body review**, ensuring full coverage and eliminating the clinical “blind spots” of the current approach.

OOO is not “scan everyone more” — it’s “scan the right people once, properly.”

If recurrence has been confirmed, OOO adapts seamlessly to support more frequent surveillance for treatment efficacy and progression assessment.

Current NICE and NHS England protocols for advanced breast and other cancers recommend imaging every 3–6 months, depending on treatment response and tumour biology. Under Rachel’s Pathway, these follow-up scans would continue — but within the same unified “one plan” framework, avoiding the duplication and fragmentation that currently occur between oncology and hereditary teams.

The OOO principle therefore remains intact: whether annual for risk-based surveillance, or quarterly for treatment response, each imaging episode is designed to *get it right first time* — comprehensive, connected, and conclusive.

7. Technical Feasibility

Modern **whole-body MRI (WB-MRI)** scans can image head-to-pelvis within 40–50 minutes — comparable to two focused MRIs but replacing five or six fragmented studies.

MRI avoids radiation exposure, unlike CT or PET, and already underpins surveillance in:

- **Li-Fraumeni Syndrome**
- **Myeloma**
- **Metastatic disease protocols**

Therefore, the OOO model does **not require new technology** — only unified planning and commissioning.

8. Patient Burden and Quality of Life

Fragmented surveillance demands multiple hospital visits, repeated cannula insertions, and long waiting times between results.

OOO consolidates everything into a single hospital visit and single report.

Time in hospital reduces by **up to 80%**, days off work fall from 2–5 to less than one, and patient anxiety is markedly lower.

Every unnecessary scan avoided means:

- One fewer cannula
- One fewer car journey
- One fewer day away from family or work

OOO makes surveillance not only efficient but humane.

9. Cost and Efficiency

Fragmented surveillance currently averages **£900 per patient-year** — multiple scans, administrative duplication, and travel. The OOO model costs around **£550 per patient-year**, saving approximately **£350** annually. Across 10,000 hereditary-risk patients, this equates to **£17.5 million in savings** over five years, excluding treatment savings from earlier detection.

In Rachel's case, the NHS invested substantial resources in what was considered comprehensive Cowden Syndrome surveillance — including multiple organ-specific scans, consultant reviews, and long-term oestrogen-suppressing hormone therapy. Yet this entire programme failed to include one of the most common recurrence sites for breast cancer: the **liver**. When recurrence eventually appeared there, it was detected incidentally, not through planned surveillance.

As a result, the significant costs of years of follow-up, medication, and hospital activity were effectively **wasted**, because the system's design meant the surveillance could never achieve its intended outcome. This demonstrates the **false economy of fragmented surveillance**: a patient can be closely monitored yet remain unprotected.

The OOO model ensures every pound spent on follow-up delivers complete diagnostic value — **one review, one scan, one plan** — instead of a patchwork of partial tests that miss systemic recurrence.

Beyond direct NHS costs, fragmented surveillance carries substantial hidden costs — lost workdays, travel reimbursement, repeat imaging after inconclusive results, and extended clinical time spent coordinating multiple reports. Even two extra hospital visits for repeat imaging or biopsies can add **£400–£600** per patient in administrative and staffing overheads. Across a 10,000-patient cohort, this equals **£4–6 million** in avoidable annual cost.

The OOO model removes that duplication entirely, reducing total surveillance cost and freeing staff time for higher-need patients.

Cost comparisons in this policy refer to hereditary and recurrence-risk surveillance prior to active cancer treatment. Once recurrence is confirmed, imaging frequency increases in line with NICE oncology guidance — but under the same OOO coordination, preventing duplication even within treatment cycles.

10. Evidence Gap and Policy Justification

- **NICE NG101** and other UK guidelines were written based on CT-era evidence, before MRI-first surveillance became standard.
- The **NHS Genomic Test Directory (2024–25)** identifies who should be tested for hereditary risk but gives **no guidance** on follow-up or surveillance post-diagnosis.
- **ERN GENTURIS (2020)** acknowledges inconsistent global surveillance approaches for PTEN Hamartoma Tumour Syndrome — highlighting the need for national pilots.

Rachel's Pathway provides the framework to fill that gap within NHS England policy.

11. Implementation and Delivery

Implementation is entirely feasible within existing NHS infrastructure.

Proposed Actions:

1. **Pilot OOO across 3–5 NHS Trusts** (12–18 months).
2. **Commission a national tariff** for MRI-first hereditary and recurrence surveillance.
3. Develop a **standardised reporting template** and cross-specialty review framework.
4. Integrate results into **Genomic Medicine Service dashboards** for national data consistency.
5. Publish pilot outcomes and policy recommendations by **2027**.

This approach directly supports the **NHS Long Term Plan** goals for early diagnosis, efficiency, and equity of access.

12. Availability and Outsourcing Capacity

Whole-body MRI capacity already exists within the NHS and private partners.

Diagnostic providers such as **Vista Health**, **InHealth**, and **Alliance Medical** already offer head-to-pelvis MRI services at NHS tariff, used by trusts for backlog clearance and fast-tracked diagnosis.

The barrier is **not capacity** — it's the absence of a unified pathway and commissioning model.

OOO provides both.

13. Summary Table: Routine vs Risk-Stratified Surveillance

Traditional Approach	Rachel's Pathway (OOO Model)
Organ-by-organ follow-up	Whole-body MRI-first
Radiation-based scans (CT, x-ray)	No ionising radiation
Symptom-led recurrence checks	Proactive, structured annual review
Multiple appointments & reports	One appointment, one report
Fragmented accountability	Integrated multidisciplinary responsibility

14. Conclusion

Rachel's Pathway (OOO) builds directly on **Rachel's Rule (AHRR)**.

Together, they create a complete hereditary cancer policy framework — one that identifies risk and manages it with precision, efficiency, and compassion.

Rachel's Pathway is more than a model; it's the **route she should have had** — a single, joined-up journey to protect others from the same systemic failure.

Rachel's Pathway embodies what the NHS itself calls "*getting it right first time*" — clinically, economically, and humanly.

Rachel's Rule protects today.

Rachel's Pathway safeguards tomorrow.