Rachel's Rule

Hereditary Risk Ownership and Surveillance

Interim Safeguard and Structural Proposal

---

1. Why this document exists

This proposal comes from lived experience.

My wife Rachel died after years in which significant medical indicators were recorded but never structurally reviewed together.

She did not have a strong family history of cancer.

What she had were patterns over time:

- Multiple cancers at a young age
- Multiple liver hamartomas
- Ongoing clinical indicators across different specialties

Each event was documented.

No one was formally responsible for stepping back and reviewing the cumulative pattern.

There was no defined checkpoint.

There was no accountable owner.

The system relied on individual clinicians recognising inherited risk opportunistically.

Rachel's case demonstrates a structural vulnerability, not a lack of technology.

---

2. What Government correspondence confirms

Recent Parliamentary responses confirm that:

- Hereditary cancer services operate through the Genomic Medicine Service.
- Referral is based on clinical and family history criteria.
- Clinicians, including GPs, are responsible for maintaining appropriate knowledge.
- Expansion of genomic capability forms part of the 10-Year Health Plan.
- Guidance relating to referral and management is under review.

These statements confirm direction and long-term ambition.

However, the correspondence does not describe:

- A named accountable owner for cumulative hereditary risk recognition.
- A mandated longitudinal review checkpoint when patterns emerge across time.

- An automatic hereditary re-review trigger following second primary cancers.
- A defined model for coordinated post-diagnosis surveillance ownership.

The absence of structural ownership is the central issue.

---

3. The structural gap

The issue is not awareness.

It is ownership and coordination.

When multiple indicators appear across time and specialties, there is no formal requirement for a coordinated hereditary risk review.

If responsibility sits with “all clinicians,” it risks sitting with none.

Without a named owner and defined trigger points, cumulative risk may not be reassessed.

This vulnerability exists regardless of genomic expansion.

---

4. The 10-Year Health Plan

The 10-Year Health Plan outlines expansion of genomic services, digital capability and prevention. This is welcome.

However, expansion of capability does not automatically create structural accountability.

Rachel’s case did not fail because genomic testing was unavailable.

It failed because patterns were not structurally reviewed and owned.

If the 10-Year Health Plan includes:

- a mandated longitudinal hereditary review checkpoint,
- a named accountable owner model, and
- a defined framework for comprehensive surveillance coordination,

clarification would be welcome.

If these elements are not clearly defined, then waiting for long-term reform may leave the same structural vulnerability in place.

Long-term programmes are subject to delivery timelines, fiscal pressures and parliamentary cycles. Interim safeguards reduce exposure during extended implementation.

---

5. Interim Safeguard: One Owner. One Review. One Plan.

A proportionate safeguard can be introduced without waiting for full reform.

It has two parts: structured risk recognition and coordinated surveillance ownership.

5.1 Named accountable ownership

When defined trigger criteria occur — for example:

- cancer diagnosed at a younger age,
- a second primary cancer,
- unusual pathology such as hamartomatous findings,
- repeated cross-specialty indicators —

a named clinician holds responsibility for coordinating a hereditary risk review.

Clear ownership prevents diffusion of responsibility.

5.2 Structured cumulative review

A defined review of:

- full cumulative history (not limited to family history),
- pattern across specialties and time,
- existing referral criteria,
- clear documentation of decision and next steps.

Absence of family history must not prevent review.

5.3 Post-diagnosis re-review and surveillance ownership

Diagnosis should not close the question of inherited risk. It should reopen it.

Second primary cancers, significant new pathology, or unusual benign findings associated with inherited syndromes should automatically trigger hereditary reassessment.

In addition, there should be:

- one named owner for the surveillance plan, and
- one written, coordinated plan bringing together imaging, monitoring and follow-up across specialties.

This does not require a single universal scan.

It requires proportionate, coordinated surveillance so that monitoring is not fragmented and critical findings are not missed because each service assumes another is covering it.

Fragmented surveillance was central to Rachel's outcome.

Ownership reduces that risk.

---

6. The full Rachel's Rule framework

Rachel’s Rule is not solely an interim safeguard.

A full pathway model has been developed including:

- defined ownership across the pathway,
- structured review triggers,
- post-diagnosis hereditary re-review,
- coordinated surveillance planning,
- “One Review. One Scan. One Plan.”

The interim safeguard represents immediate structural correction.

The full framework remains available to inform durable system design.

---

7. Accountability questions

This submission seeks written clarification on:

1. Who currently holds accountable responsibility for cumulative hereditary risk recognition when patterns emerge across time and specialties?
2. Does the 10-Year Health Plan include a mandated longitudinal hereditary review checkpoint?
3. Is there an automatic hereditary re-review trigger following second primary cancers?
4. What is the current expectation for comprehensive surveillance planning in suspected or confirmed hereditary predisposition, and who owns that plan?
5. Will NHS England consider piloting a defined hereditary risk ownership and surveillance model as outlined above?

Engagement is requested by written correspondence to allow careful and considered response.

---

8. Why urgency is appropriate

Rachel was eventually diagnosed.

However, the late recognition of cumulative risk meant that structural reassessment came too late to influence earlier intervention.

Six years after diagnosis, her cancer returned and she died.

Earlier structural review may not guarantee different outcomes in every case.
However, delay reduces available options.

When cumulative risk is recognised late, damage may already be done.

Each year that a known structural gap remains unmitigated represents continued exposure to delayed recognition for others presenting with similar patterns.

This is not a theoretical concern.

It is a practical consequence of fragmentation.

An interim safeguard reduces that exposure while longer-term reforms are developed.