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RARE IS DIFFERENT.

Why is your Medical Affairs playbook the same?

A critical Edge review of Field Medical excellence in rare diseases

THE EDGE PREMISE

In rare disease, a patient journey can be as individual as the patient's fingerprint. Medical Affairs needs to understand that variation without losing the shared scientific and system patterns it can help address.

PAPER REVIEWED**Ilma Nascimento**

Field Medical excellence in rare diseases: A narrative review and six-pillar conceptual framework
Research, Society and Development. 2026;15(7):e8215751452.
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Why this paper matters

Rare disease should not be treated as conventional Medical Affairs delivered to fewer stakeholders. Nascimento describes a context shaped by small and dispersed populations, heterogeneous disease, incomplete natural history, diagnostic delay, fragmented referral pathways, concentrated expertise and uneven centre readiness. The combination changes what good Field Medical practice looks like.

Edge's interpretation is that a rare-disease patient journey can be as individual as a fingerprint: the same diagnosis can sit within very different routes to recognition, referral, expertise, evidence and support. Medical Affairs therefore needs to understand variation as well as common patterns, build judgement rather than knowledge alone, and measure credible contribution rather than activity volume.

EVIDENCE STATUS

This is a narrative review and proposed conceptual framework. It is not a systematic review, not a validated competency instrument and not evidence that adopting the framework improves patient outcomes.

The 60-second summary

Nascimento proposes six interdependent Field Medical pillars: Scientific Mastery, Insight Intelligence, Center Development, System Navigation, Strategic Partnership and Impact Measurement. The author emphasises scientific independence, contextual interpretation of uncertain evidence, longitudinal stakeholder engagement, translation of field insights into action and outcome-oriented indicators rather than activity counts alone.

Why rare disease creates a different operating context

Evidence	Small trials, surrogate outcomes, natural-history studies, registries, external comparators and RWE can all matter. Uncertainty must be explained, not disguised.
Expertise	Clinical experience is often concentrated in a small number of centres, while early recognition may sit with non-specialists.
Patient journeys	Routes to diagnosis and referral can vary by phenotype, geography, testing access and local health-system design.
Centres	Scientific capability, multidisciplinary infrastructure and research readiness can differ markedly between sites.
Impact	Activity counts are easy to measure, but contribution to insight use, capability and pathway readiness is harder - and more meaningful.

The six-pillar framework - at a glance

The paper presents the six domains as interdependent rather than sequential. The Edge infographic below adapts that framework for a rare-disease Medical Affairs audience and makes patient and caregiver perspectives explicit at the centre of the discussion.

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RARE DISEASES

A distinct world for Medical Affairs

A Field Medical perspective on evidence, expertise and care pathways



WHY THE CONTEXT IS DIFFERENT

- Small, dispersed populations**
Limited recruitment and patients spread across regions.
- Heterogeneous disease**
Variable presentation and incomplete natural history.
- Evidence uncertainty**
Small trials, endpoint limitations and reliance on other evidence sources.
- Diagnostic and referral gaps**
Multiple specialties, delayed recognition and fragmented pathways.
- Uneven centre readiness**
Differences in specialist, multidisciplinary and research capability.



SIX INTERDEPENDENT FIELD MEDICAL PILLARS

Proposed contributions for rare-disease ecosystems – not sequential stages

- | | | |
|---|---|--|
| Scientific Mastery
Interpret small trials, natural history, endpoints and real-world evidence. Explain what is known, uncertain and transferable. | Insight Intelligence
Triangulate scattered observations. Distinguish recurring needs from isolated anecdotes, and document the decisions they inform. | Center Development
Support multidisciplinary capability, validated assessment tools and research readiness through sustained scientific engagement. |
| System Navigation
Identify diagnostic breakpoints and referral barriers. Inform scientific education and understanding of referral criteria. | Strategic Partnership
Bring external scientific realities into internal evidence-generation, research feasibility and education priorities. | Impact Measurement
Assess changes in capability, insight use and pathway readiness – not activity volume alone. Describe contribution, not sole causation. |



SCIENTIFIC INDEPENDENCE AND GOVERNANCE

Scientific and non-promotional. Centre development is not commercial account development. System Navigation is not individual patient management.

EVIDENCE NOTE | Narrative review and proposed conceptual framework – not validated. Suggested contributions, not demonstrated outcomes.

Adapted from Nascimento I. Field Medical excellence in rare diseases: A narrative review and six-pillar conceptual framework. Research, Society and Development. 2026;15(7):e8215751452. DOI: 10.33448/rsd-v15i7.51452 | Adaptation: Edge Medical Library

Edge Medical Library adaptation of Nascimento (2026). Narrative review and conceptual framework - not validated.

The six pillars: what they mean in practice

1

Scientific Mastery

Explain uncertainty, not just the data.

In rare disease, scientific mastery may require integration of mechanism, trial design, endpoint limitations, natural history, observational evidence and local system context. The paper argues that credibility depends on communicating what is known, what remains uncertain and where evidence may not transfer cleanly across populations or settings.

EDGE APPLICATION Test whether an MSL can interpret incomplete evidence in context, respond appropriately to different stakeholder questions and recognise when a question needs escalation or additional evidence. A knowledge score alone will not show that.

2

Insight Intelligence

Respect the individual, test the pattern.

A field observation becomes more useful when it is documented with context, synthesised across sources, prioritised and linked to a possible decision. Rare disease creates a tension: a small number of observations may matter because populations are small, but scarcity does not make every anecdote generalisable.

EDGE APPLICATION Move from "what did we hear?" to "what pattern is supported, what decision might it inform, what would challenge our interpretation, and did anyone act on it?"

3

Center Development

Scientific capability, not account development.

The review explicitly separates centre development from commercial account development. The focus is longitudinal scientific support for multidisciplinary capability, validated assessment approaches, research readiness and scientific networks.

EDGE APPLICATION Identify a genuine capability gap before selecting an activity. The medical contribution might be education on assessment tools, peer exchange, registry standards or research-feasibility discussions - not commercial account development.

The six pillars: what they mean in practice

4 System Navigation

Understand the spaces between services.

System Navigation is the scientific identification and communication of diagnostic breakpoints, referral inefficiencies and access-related barriers. It is not the direct management of individual patients. This is particularly relevant when patients move through multiple specialties before diagnosis.

EDGE APPLICATION Map several plausible patient journeys rather than a single idealised pathway, then ask where recurring scientific, diagnostic or referral problems occur and which stakeholder groups need education or connection.

5 Strategic Partnership

Bring field reality into planning early.

The paper links external scientific observation with internal evidence-generation, feasibility, education and lifecycle planning. In rare disease, inaccurate assumptions about patient numbers, testing availability, centre maturity or outcome-measure readiness can have disproportionate consequences.

EDGE APPLICATION Involve Field Medical early enough to challenge assumptions. Document which planning question changed because external scientific reality contradicted an internal assumption.

6 Impact Measurement

Contribution, not activity volume.

The review separates outputs, intermediate outcomes and longer-term system outcomes. Attribution becomes weaker as outcomes move further from the direct activity, so the author recommends caution and triangulation rather than claims of sole causation.

EDGE APPLICATION Keep activity measures where useful, but pair them with a small number of contribution measures: documented use of an insight, progress against a centre-capability milestone, or evidence that a scientific pathway issue has been clarified.

A patient journey can be as individual as a fingerprint

This is Edge's editorial framing, not a tested statement from the paper. It is a useful way to challenge one of the most common simplifications in Medical Affairs planning: the single, neat patient-journey arrow.

Two people with the same diagnosis may enter the system at different points, be recognised by different specialties, have different access to testing or specialist centres and encounter different evidence or treatment conversations. Those differences matter - but they should not obscure recurring barriers that can be identified and addressed scientifically.

THE PRACTICAL CHALLENGE

Understand the individual journey without losing the shared pattern.

What this means for Medical Affairs capability

- Scientific exchange under uncertainty: can the team explain limitations, transferability and evidence gaps without over- or under-stating confidence?
- Insight-to-action discipline: can the team distinguish an observation from a recurring pattern and connect that pattern to a decision?
- Patient-journey and ecosystem thinking: can the team map multiple plausible journeys and identify the scientific breakpoints that recur across them?
- Centre capability: can Medical Affairs distinguish a scientific capability gap from a commercial opportunity and define an appropriate contribution?
- Strategic planning: can Field Medical challenge feasibility and evidence assumptions early enough to change a plan?
- Impact thinking: can the team describe credible contribution without claiming sole causation?

What this means for workshops

Attendance does not demonstrate capability. A stronger approach is to observe how teams reason through ambiguity: interpreting incomplete evidence, responding to stakeholders with different levels of expertise, distinguishing an anecdote from an insight, identifying a pathway barrier, and explaining what Medical Affairs can and cannot claim as impact.

This is where realistic cases, facilitated challenge and feedback are more useful than frameworks taught in isolation. The six pillars can structure discussion, but they should not be used as a validated scoring instrument.

Scientific independence is part of the capability

The paper keeps the non-promotional nature of Field Medical explicit. Centre development and system navigation can become sensitive if boundaries are poorly defined. The author calls for balanced scientific exchange, clear handling of unsolicited requests, transparent insight processes, separation of performance evaluation from sales outcomes and appropriate patient-engagement governance.

CENTRE DEVELOPMENT

Scientific capability building and research readiness - not commercial account development.

SYSTEM NAVIGATION

Identification and communication of pathway problems - not direction of an individual patient's care.

IMPACT

Evidence of contribution supported by context and triangulation - not claims of sole causation.

PATIENT ENGAGEMENT

Relevant patient and caregiver perspectives, with appropriate consent, privacy and transparency.

Where the paper stops

- Narrative, targeted and concept-driven search; not registered and not exhaustive.
- No duplicate screening, creating potential selection and interpretation bias.
- Six pillars have not undergone formal consensus validation, psychometric testing or prospective implementation.
- Some domains overlap and the proposed indicators need local definition and testing.
- The paper does not establish that adoption of the framework improves diagnostic readiness, care pathways or patient outcomes.

That limitation matters. Emerging literature should inform practice; it should not automatically become "best practice" because it has been published.

The Edge view

Rare is different - but not because every challenge is exclusive to rare disease. It is different because small populations, uncertain evidence, concentrated expertise, variable centre capability and highly individual patient journeys change the context in which Medical Affairs works.

The paper offers a useful organising model. Its six pillars can help leaders and teams ask better questions about scientific capability, insights, centres, pathways, planning and contribution. But it is not a validated standard and should not be used as one.

OUR POSITION

Use this paper to challenge the plan, not to certify it.

Five practical actions

1. Map more than one plausible patient journey. Identify where experiences differ and where recurring scientific, diagnostic or referral barriers appear.
2. Select one rare-disease capability to test in practice, such as communicating uncertainty, synthesising an insight or explaining a referral breakpoint.
3. Ask which planning assumption changed because of external scientific input and document that decision.
4. Use a small number of context-specific contribution indicators rather than trying to measure everything.
5. Keep scientific independence explicit: capability building and pathway understanding must remain non-promotional and appropriately governed.

How this informs Edge capability development

At Edge, our capability-uplift programmes and workshops are grounded in established Medical Affairs best practice and informed by emerging literature. We use new publications as inputs to critical appraisal: what is useful, what is unproven, what fits the team's context and what should change in practice.

For rare-disease teams, that can mean scientific exchange under uncertainty, patient-journey and stakeholder mapping, insight-to-action processes, cross-functional planning and appropriate measures of contribution. The goal is not to teach frameworks for the sake of frameworks, but to translate relevant evidence into practical capability.

Source and evidence note

Nascimento I. Field Medical excellence in rare diseases: A narrative review and six-pillar conceptual framework. Research, Society and Development. 2026;15(7):e8215751452. DOI: 10.33448/rsd-v15i7.51452.

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Rare is different. The Medical Affairs approach should show that we understand why.