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## RadiantCompass™ Patient Journey Map

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### Executive Summary

RadiantCompass™ aims to transform every rare-disease diagnosis, from the first incomprehensible lab result to lasting remission, into a guided path of clarity, compassion, and choice. This journey map provides a detailed analysis of the patient experience across 12 critical stages, highlighting key activities, emotional states, pain points, and opportunities for intervention.

*"The RadiantCompass mission is to transform every rare-disease diagnosis, from the first incomprehensible lab result to lasting remission, into a guided path of clarity, compassion, and choice. While initially focusing on rare cancers, the mission is to expand reach to all 7,000+ rare conditions globally, accelerating today's and tomorrow's cures through the lived wisdom of millions."*

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

**400K**

U.S. patients receive a rare-cancer diagnosis each year

**10M+**

Global patients with rare cancers

**\$12B**

Global rare-disease RWE market value

**18%**

CAGR of rare-disease RWE market

### Core User Personas

RadiantCompass is designed to serve multiple stakeholders throughout the patient journey, each with unique needs and communication preferences.

**P** Patient

The individual diagnosed

#### Communication Preference

Varies between "Radical Optimist" and "Clinical Researcher" depending on personality and stage of journey

#### Example Update Style

"Great news: today's PET shows no new spots and several areas look a bit smaller. Chemo is doing its job—onward!"

**C**

#### Primary Caregiver

Spouse/partner or close family member

#### Communication Preference

Often "Clinical Researcher" or "Balanced Calm" depending on their role and coping style

#### Example Update Style

"PET (6/30): SUVmax down from 8.2 → 6.9 in omental mass; no new FDG-avid lesions. Plan: continue 2 more cycles, then restage lap."

**S**

#### Support Circle

Children, siblings, best friends

#### Communication Preference

Typically "Radical Optimist" or "Balanced Calm" depending on age and relationship

#### Example Update Style

"The latest scan shows the cancer is stable and even a little smaller in spots. The doctors say chemo is working, so we'll keep the same plan."

**O**

#### Outer Circle

Neighbors, co-workers, extended family

#### Communication Preference

"Just the Headlines" - brief, clear updates without medical details

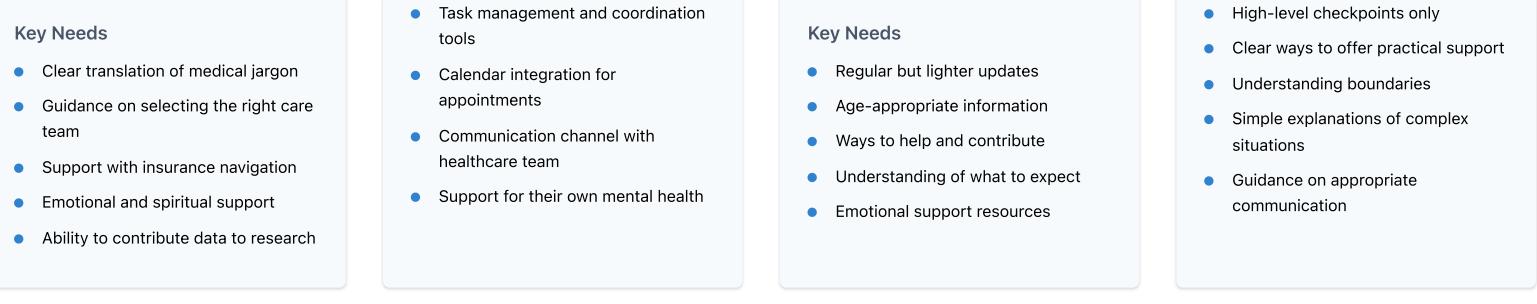
#### Example Update Style

"Update: Scan good. Tumor hasn't grown. Chemo continues."

Key Needs

#### Key Needs

- Detailed medical information



## Patient Journey Map

Based on Andrew Fegley's experience with Mesothelioma, this journey map outlines the 12 critical stages that rare disease patients typically navigate, from first symptoms to long-term survivorship.

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### First Hints & Initial Doctor Visit

Life feels normal until nagging symptoms appear, leading to a primary care or specialist visit and initial tests.

#### Key Activities

- Noticing persistent, unusual symptoms that don't resolve
- Scheduling appointment with primary care physician
- Undergoing initial basic tests (blood work, imaging)
- Receiving referral to specialist for further evaluation
- Researching symptoms online, often finding conflicting information

#### Emotional State

- Initial concern but generally optimistic
- Mild anxiety about what might be causing symptoms
- Frustration if symptoms are dismissed or minimized
- Relief at taking action to address health concerns

#### Pain Points

- Delay in getting appointments Medium
- Symptoms often attributed to common conditions first High
- Uncertainty about whether concerns are being taken seriously Medium
- Difficulty articulating symptoms precisely Low

#### Opportunities

- Symptom tracking tool to document progression and patterns
- Pre-appointment questionnaire to help articulate concerns
- Education on when to seek specialist care directly
- Guidance on preparing for initial doctor visits

"From the first time a patient has an inclination there is 'something wrong' or rather 'not right' they are forced into an information deficit loop. The patient must place all of their trust in their primary or specialist Dr. until a full diagnosis is known."

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

## Specialist Work-up & Diagnosis

Advanced imaging, biopsy, and formal diagnosis of the rare disease.

### Key Activities

- Consulting with specialist physicians
- Undergoing advanced diagnostic imaging (CT, MRI, PET)
- Completing biopsy procedures
- Waiting for pathology and lab results
- Receiving formal diagnosis of rare condition
- Initial discussion of treatment approaches

### Emotional State

- Shock and disbelief at diagnosis
- Fear and anxiety about prognosis
- Overwhelm from complex medical information
- Grief and sense of loss
- Urgency to take action

### Pain Points

- Complex medical terminology in pathology reports High
- Long wait times for results causing anxiety High
- Difficulty comprehending implications of diagnosis High
- Limited information about rare condition High
- Uncertainty about next steps Medium

### Opportunities

- AI translation of pathology reports into plain language
- Guided questions to ask specialists about diagnosis
- Connection to others with similar diagnosis
- Clear explanation of next steps in treatment journey
- Emotional support resources specifically for diagnosis phase

*"Clinical jargon ≠ comprehension: Pathology and genomic PDFs arrive in complex '12-grade medicalese'. Nine out of ten rare-disease patients search online to decode reports. Andrew's care mentors urged him to create a '12-question checklist before every consult' to manage this complexity."*

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

## Research & "Compare-Care" Phase

Learning about the disease, joining patient groups, requesting second opinions, checking insurance, and assessing travel logistics to select a care team.

### Key Activities

- Researching condition through medical websites, forums, and literature
- Joining online patient communities and support groups
- Identifying centers of excellence for rare condition
- Requesting and organizing medical records for second opinions
- Verifying insurance coverage at different treatment centers
- Evaluating travel logistics and accommodations for distant care
- Comparing treatment approaches and physician expertise

### Emotional State

- 
- Overwhelm from information overload  
 ● Anxiety about making the "right" choice  
 ● Empowerment through knowledge acquisition  
 ● Frustration with fragmented healthcare system  
 ● Hope when finding promising treatment options  
 ● Isolation despite connecting with others

### Pain Points

- Managing multiple patient portals and medical records High
- Difficulty comparing treatment centers objectively High
- Conflicting information about treatment approaches Medium
- Navigating insurance networks and coverage limitations High
- Time pressure to make decisions quickly Medium
- Financial concerns about travel and out-of-network care High

### Opportunities

- Compare-My-Care™ tool ranking hospitals by volume, outcomes, insurance status, travel burden, and culture
- Centralized medical record aggregation and sharing
- Insurance coverage analyzer and pre-authorization assistance
- Travel and accommodation planning support
- Curated patient experience reviews of treatment centers
- Decision support framework for evaluating options

*"Where do I even go?: From the first time a patient has an inclination there is 'something wrong' or rather 'not right' they are forced into an information deficit loop... A patient must 'cold-call multiple 'centers of excellence,' juggling intake portals and CD uploads' to help decide on care teams. Andrew Fegley, the patient co-founder, personally maintained three separate MyChart portals and spoke with coordinators at Penn, MSK, and AHN in the same week."*

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

## Full Staging & Baseline Testing

Comprehensive scans (CT/PET), PCI score, organ function tests, and genetic profiling.

### Key Activities

- Undergoing comprehensive imaging (CT, PET, specialized scans)
- Completing additional biopsies if needed
- Genetic and molecular testing of tumor samples
- Baseline organ function assessments (heart, lungs, kidneys)
- Specialized disease staging procedures
- Consultations with multiple specialists
- Establishing baseline health metrics

### Emotional State

- 
- Anxiety about test results and disease extent
  - Physical discomfort from procedures
  - Mental fatigue from multiple appointments
  - Relief at having a clear plan in motion
  - Hope that testing will reveal treatment options
  - Impatience with the pace of medical processes

### Pain Points

- Insurance denials for necessary scans High
- Scheduling complexity across multiple departments Medium
- Repeated explanations to different providers Medium
- Long waits for specialized genetic results Medium
- Difficulty understanding staging terminology High
- Physical and emotional toll of frequent procedures High

### Opportunities

- Insurance navigation assistance for scan approvals
- Coordinated scheduling across specialties
- Plain-language explanations of staging and test results
- Digital storage and organization of all test results
- Preparation guides for each procedure
- Tracking system for completion of required tests

*"Insurance & logistics roadblocks: Families grapple with 'time-sensitive scans denied' and manage 'PTO, travel, and germ control through ad-hoc text chains'. Andrew experienced multiple PET-scan denials with two separate insurance providers Cigna and Aetna (both of which were premium PPO coverage plans) that continue to delay imaging, despite his nurse practitioners and doctors efforts."*

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

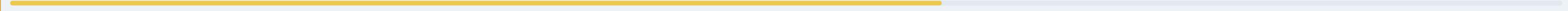
## Multidisciplinary Treatment Planning

Tumor board meeting to decide on first-line strategy (chemo, surgery, or clinical trial), followed by patient review and scheduling.

### Key Activities

- Case presentation at multidisciplinary tumor board
- Development of comprehensive treatment plan
- Consultation with multiple specialists (oncology, surgery, radiation)
- Discussion of standard-of-care vs. clinical trial options
- Consideration of treatment sequence (neoadjuvant vs. upfront surgery)
- Review of treatment goals and expectations
- Decision-making about first-line approach

### Emotional State

- 
- Relief at having expert consensus
  - Anxiety about treatment efficacy
  - Confusion about complex treatment options
  - Hope for positive outcomes
  - Pressure to make the "right" decision
  - Trust in medical expertise balanced with desire for control

### Pain Points

- Limited patient involvement in tumor board discussions High
- Difficulty understanding rationale for treatment recommendations High
- Conflicting opinions between specialists Medium
- Uncertainty about clinical trial eligibility and process Medium
- Balancing quality of life concerns with aggressive treatment High
- Limited time to process information before decisions needed High

### Opportunities

- Virtual tumor board facilitation with patient representation
- Treatment plan visualization and comparison tools
- Decision support frameworks with pros/cons of each approach
- Plain-language summaries of tumor board recommendations
- Preparation guide for treatment planning consultations
- Clinical trial matching and explanation service

"RadiantCompass can translate raw medical data into plain-language insights and 'ask-your-doctor' questions... Use of ChatGPT and Claude demonstrated conversion of Andrew's Penn pathology into 6th-grade prose and create a tailored consult checklist in seconds."

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

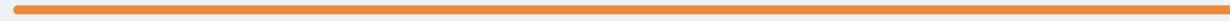
## Insurance Confirmation & Travel Setup

Pre-authorization for treatment costs and booking logistics for treatment away from home.

### Key Activities

- Submitting pre-authorization requests to insurance
- Navigating appeals process for denials
- Estimating out-of-pocket costs
- Exploring financial assistance programs
- Arranging transportation to treatment center
- Booking accommodations for extended stays
- Coordinating work leave and family care
- Planning for potential complications and extended stays

### Emotional State

- 
- Frustration with insurance bureaucracy
  - Anxiety about financial impact
  - Stress about logistics coordination
  - Worry about being away from support network
  - Relief when approvals are secured
  - Overwhelm from managing multiple arrangements

### Pain Points

- Unexpected insurance denials High
- Opaque cost estimates and billing practices High
- Complex appeals processes requiring medical expertise High
- Financial toxicity from travel and accommodation costs High
- Difficulty coordinating family responsibilities Medium
- Uncertainty about length of stay needed Medium

### Opportunities

- Insurance navigation and appeals assistance
- Cost estimation and financial planning tools
- Curated accommodation options near treatment centers
- Transportation coordination service
- Family care and support network organization
- Work leave documentation and management

"70% of rare-disease families report financial toxicity within 12 months. Understanding the sequence of when scans, biopsies and treatments are required in the care journey, which ones are essential and which ones are not, and how insurance approvals, reviews, arbitration and denials impact the overall care journey (and what to do about it) is essential to ensure a patients overall treatment and health."

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

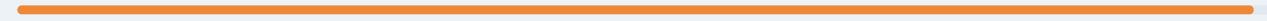
## Up-front (Neoadjuvant) Therapy

Completing initial chemotherapy cycles, monitoring side-effects, and potentially T-cell collection.

### Key Activities

- Undergoing port placement procedure
- Starting chemotherapy or immunotherapy regimen
- Managing treatment schedule and appointments
- Monitoring and reporting side effects
- Completing interim scans to assess response
- Adjusting medications to manage symptoms
- Potential T-cell collection for future therapies
- Maintaining nutrition and physical activity

### Emotional State

- 
- Anxiety about treatment side effects
  - Physical discomfort and fatigue
  - Hope that treatment is working
  - Fear of disease progression despite treatment
  - Determination to complete therapy
  - Gratitude for medical care
  - Isolation during treatment periods

### Pain Points

- Severe treatment side effects High
- Difficulty managing daily activities during treatment High
- Uncertainty about when to report symptoms Medium
- Anxiety waiting for response assessment High
- Balancing treatment with quality of life High
- Coordinating multiple medications and appointments Medium

### Opportunities

- Side effect tracking and management app
- Treatment calendar with reminders and preparation instructions
- Symptom severity assessment tool with guidance on when to contact providers
- Nutrition and hydration support during treatment
- Virtual support groups during treatment phases
- Medication management and interaction checker

"RadiantCompass will orchestrate every next step, including appointments, symptom alerts, PTO forms, meal trains, and prayer or mindfulness reminders, inside a single, secure hub shared with caregivers and clinicians."

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

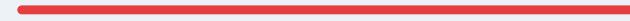
## Definitive Surgery or Local Treatment

Undergoing major surgery (e.g., cytoreductive surgery with HIPEC), followed by ICU and surgical ward recovery.

### Key Activities

- Pre-surgical testing and clearance
- Meeting with surgical team to review procedure
- Completing surgical consent process
- Undergoing major surgical procedure
- ICU recovery period
- Transfer to surgical ward
- Physical therapy and rehabilitation
- Discharge planning and home care setup

### Emotional State

- 
- Intense fear before surgery
  - Relief upon successful completion
  - Physical pain and discomfort
  - Vulnerability during recovery
  - Impatience with recovery timeline
  - Hope that surgery was curative
  - Gratitude toward surgical team

### Pain Points

- Severe post-surgical pain High
- Complications requiring extended hospitalization High
- Limited understanding of surgical outcomes Medium
- Difficulty coordinating post-discharge care High
- Emotional impact of physical changes High
- Caregiver strain during recovery period High

### Opportunities

- Pre-surgical preparation guide and checklist
- Virtual hospital tour and procedure explanation
- Recovery milestone tracker and expectations
- Discharge planning assistant
- Home care coordination platform
- Caregiver support and respite resources

"The Care-Circle Workspace + Vitals AI module provides role-based tasks and red-alert triage. Expansion could include wearable-integrated predictive hospitalization risk."

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

## Adjuvant or Maintenance Therapy

Post-surgical chemotherapy, immunotherapy, or CAR-T infusion to eliminate microscopic disease, with optional metabolic add-ons.

### Key Activities

- Recovery from surgery before starting adjuvant therapy
- Beginning post-surgical treatment regimen
- Managing treatment schedule while recovering
- Monitoring for cumulative side effects
- Exploring complementary approaches (nutrition, exercise)
- Completing post-treatment scans
- Discussing maintenance therapy options
- Gradual return to normal activities

### Emotional State

- 
- Fatigue from cumulative treatments
  - Hope that end of treatment is approaching
  - Anxiety about cancer recurrence
  - Determination to complete therapy
  - Frustration with ongoing side effects
  - Anticipation of return to normalcy
  - Uncertainty about future health

### Pain Points

- Cumulative fatigue and side effects High
- Difficulty balancing recovery and treatment High
- Limited guidance on complementary approaches Medium
- Uncertainty about treatment effectiveness High
- Financial strain from ongoing treatment High
- Emotional toll of prolonged treatment High

### Opportunities

- Integrated recovery and treatment planning
- Evidence-based complementary therapy guidance
- Treatment completion countdown and milestone celebration
- Long-term side effect monitoring and management
- Transition planning to survivorship
- Financial assistance navigation for ongoing costs

*"Andrew himself blocks 30 minutes daily for meditation and scripture to stay centered. He also has worked with a dietician and breathing specialist to ensure all avenues for giving him the best possible outcomes are understood and available to him are paramount in his care journey."*

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

## Early Recovery (First Three Months)

Managing incisions, maintaining weight with dietitian support, and physical therapy, followed by a post-operative scan.

### Key Activities

- Wound and incision care
- Physical therapy and rehabilitation exercises
- Nutritional support and weight management
- Gradual increase in physical activity
- First post-treatment surveillance scan
- Managing lingering treatment side effects
- Psychological adjustment to post-treatment life
- Reintegration into family and social roles

### Emotional State

- Relief at completing active treatment
- Anxiety about first surveillance scan
- Impatience with pace of physical recovery
- Joy in resuming normal activities
- Uncertainty about "new normal"
- Gratitude for support during treatment
- Fear of recurrence or complications

### Pain Points

- Scanxiety (anxiety before scans) High
- Persistent physical limitations Medium
- Difficulty adjusting expectations to recovery timeline Medium
- Limited guidance on post-treatment lifestyle Medium
- Psychological impact of cancer experience High
- Navigating return to work and responsibilities Medium

### Opportunities

- Recovery milestone tracker with realistic expectations
- Personalized rehabilitation program
- Nutrition and exercise guidance for recovery
- Scan preparation and anxiety management tools
- Return-to-work planning assistance
- Post-treatment support group connection

"Over 60% of rare-cancer patients screen positive for anxiety or depression. Existing solutions for 'Prayer, meditation, or secular CBT live in separate apps, none connect to the medical timeline!'"

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

## Surveillance & Rehabilitation (Years 1-5)

Regular scans and lab work, treatment of late side-effects, lifestyle refinements, and eligibility for new trials.

### Key Activities

- Regular surveillance imaging (frequency decreases over time)
- Periodic lab work and tumor marker testing
- Managing late treatment effects
- Implementing lifestyle modifications
- Monitoring for recurrence signs
- Exploring clinical trial options for prevention
- Addressing psychological impacts of survivorship
- Rebuilding physical strength and endurance

### Emotional State

- Periodic anxiety around scan dates
- Relief with each clear result
- Gradual confidence in recovery
- Adjustment to "new normal"
- Survivor's guilt
- Gratitude for continued health
- Lingering fear of recurrence

### Pain Points

- Ongoing "scanxiety" cycles High
- Long-term treatment side effects Medium
- Reduced frequency of medical contact causing anxiety Medium
- Uncertainty about normal vs. concerning symptoms Medium
- Insurance changes affecting surveillance plan Medium
- Psychological impact of living with uncertainty High

### Opportunities

- Surveillance schedule management and reminders
- Symptom assessment tool for recurrence monitoring
- Long-term side effect tracking and management
- Survivorship care plan creation and updates
- Lifestyle optimization guidance for cancer survivors
- Connection to survivorship community and resources

"Real-world evidence (RWE) that could accelerate new drug development 'sits across siloed portals and spreadsheets'. Andrew's personal Google-Drive folders contain valuable scans, labs, and diary notes with no research pathway to ensure his learnings and experiences get incorporated into the corpus of knowledge used to help innovate and treat others."

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

## Long-term Living

After five years, shifting to annual check-ups focused on quality of life, heart/kidney health, prevention, and ongoing support for thriving in the "new normal".

### Key Activities

- Annual surveillance visits
- Monitoring for late treatment effects on organs
- Preventive screening for secondary cancers
- Maintaining healthy lifestyle practices
- Mentoring newly diagnosed patients
- Participating in survivorship research
- Managing long-term psychological impact
- Integrating cancer experience into life narrative

### Emotional State

- Gratitude for long-term survival
- Confidence in health stability
- Occasional recurrence fears
- Sense of purpose in helping others
- Appreciation for life perspective
- Acceptance of "new normal"
- Pride in resilience and survival

### Pain Points

- Lingering physical limitations Low
- Healthcare system transition to primary care Medium
- Limited long-term survivorship research Medium
- Insurance challenges for long-term monitoring Medium
- Balancing vigilance with moving forward Medium
- Explaining cancer history to new providers Low

### Opportunities

- Long-term survivorship care plan
- Mentorship program connecting survivors with new patients
- Lifelong health monitoring dashboard
- Research participation opportunities
- Legacy planning and documentation
- Comprehensive medical history for new providers

"Every interaction feeds an ever-growing rare-disease knowledge graph, so each patient's journey sharpens the guidance for the next and provides de-identified, consented real-world evidence to researchers seeking tomorrow's cures."

Source: RadiantCompass NotebookLM & Andrew Edits.pdf

## Key Journey Insights

Analysis of the patient journey reveals several critical patterns and opportunities for intervention that can significantly improve the rare disease experience.

### Information Deficit Loop

Patients consistently face an "information deficit loop" throughout their journey, where they lack the necessary knowledge to make informed decisions but are still required to navigate complex choices. This begins with the first symptoms and continues through treatment selection, insurance navigation, and into survivorship.

The most acute information deficits occur during diagnosis and the "compare-care" phase, where patients must evaluate treatment centers without objective comparison tools. Andrew Fegley's experience of managing three separate MyChart portals while communicating with multiple cancer centers illustrates this challenge.

This insight suggests that an AI-powered knowledge platform that translates medical information, compares treatment options, and provides decision support would address a fundamental patient need.

### Medical Translation Gap

The journey map reveals a persistent gap between clinical communication and patient comprehension. Pathology reports, treatment plans, and medical correspondence are typically written in "12th-grade medicalesse" that patients struggle to understand.

This translation gap is particularly problematic during critical decision points, such as diagnosis, treatment planning, and when evaluating clinical trial options. Nine out of ten rare disease patients resort to online searches to decode their medical reports, often finding conflicting or inaccurate information.

RadiantCompass's AI translation capability, which can convert complex pathology reports into 6th-grade prose and generate tailored consultation checklists, directly addresses this critical need and could significantly reduce patient anxiety and improve decision-making.

### Logistical Burden

The journey map highlights the overwhelming logistical burden placed on patients and caregivers. This includes coordinating appointments across multiple specialists, managing insurance approvals and denials, arranging travel and accommodations for treatment, and organizing family care and work leave.

This burden is particularly heavy during the insurance confirmation and travel setup stage, as well as during active treatment phases. Andrew's experience with multiple PET scan denials from two separate insurance providers (Cigna and Aetna) despite having premium PPO coverage illustrates how these logistical challenges can directly impact care quality and timing.

A comprehensive care orchestration platform that manages appointments, insurance navigation, and logistics coordination would address this significant pain point and allow patients to focus on their health rather than administrative tasks.

### Emotional & Spiritual Support Deficit

The journey map reveals significant emotional fluctuations throughout the patient experience, with particularly negative emotional states during diagnosis, active treatment, and before surveillance scans. Over 60% of rare cancer patients screen positive for anxiety or depression, yet emotional and spiritual support is often disconnected from medical care.

Andrew's personal practice of blocking 30 minutes daily for meditation and scripture, along with working with breathing specialists and nutritionists, demonstrates the importance of holistic approaches to maintaining mental well-being during treatment.

This insight suggests that integrating spiritual, meditation, and psychological support directly into the care platform—connected to the medical timeline—would address a critical gap in current care models and potentially improve both quality of life and treatment outcomes.

### Data Fragmentation & Research Opportunity

The journey map highlights how valuable patient data becomes fragmented across multiple systems, portals, and personal storage solutions. Andrew's experience of maintaining personal Google Drive folders with scans, labs, and diary notes—with no pathway to incorporate these into research—exemplifies this problem.

This fragmentation not only complicates patient care but also represents a missed opportunity to accelerate rare disease research through real-world evidence (RWE). The global rare-disease RWE market is valued at \$12 billion with an 18% CAGR, indicating significant demand for this data.

RadiantCompass's vision of an ever-growing rare-disease knowledge graph that learns from each patient journey and provides de-identified, consented data to researchers addresses both the patient need for integrated records

### Personalized Communication Needs

The journey map and persona analysis reveal that different stakeholders require distinctly different communication styles throughout the patient journey. The four identified personas—Patient, Primary Caregiver, Support Circle, and Outer Circle—each have unique information needs and preferred communication tones.

Current solutions typically offer a one-size-fits-all approach to health communication, failing to address these varied needs. RadiantCompass's proposed tone and voice choices—Radical Optimist, Clinical Researcher, Just the Headlines, and Balanced Calm—represent an innovative approach to personalized health communication.

This insight suggests that allowing users to toggle between different communication styles for different audiences would significantly improve information sharing and reduce both information overload

and the research community's need  
for comprehensive RWE.

and anxiety among the patient's  
support network.

## Strategic Recommendations

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Based on the journey map analysis, we recommend the following strategic priorities for RadiantCompass platform development:

### **Develop the Compare-My-Care™ Module First**

The journey map clearly shows that the "Research & Compare-Care Phase" represents a critical decision point with significant pain points. Patients like Andrew struggle to objectively compare treatment centers while managing multiple patient portals and insurance considerations.

Prioritize development of the Compare-My-Care™ tool that ranks hospitals by procedure volume, trial access, insurance fit, travel burden, and bedside culture. This addresses the immediate "Where do I even go?" question that patients face and provides clear differentiation from competitors.

### **Integrate Medical Translation AI**

The journey map highlights persistent challenges with medical jargon comprehension across multiple stages. Leverage the demonstrated success of using AI to convert complex pathology reports into plain language and develop this into a core platform feature.

This translation capability should include pathology reports, treatment plans, clinical trial descriptions, and insurance documents. Each translation should be accompanied by a tailored consultation checklist to help patients get the most from provider interactions.

### **Build the Care-Circle Workspace**

The journey map reveals significant logistical burdens throughout the patient experience, particularly during insurance confirmation, treatment, and recovery phases. Develop the Care-Circle Workspace to orchestrate appointments, symptom alerts, insurance navigation, and support coordination.

This workspace should support role-based access for different personas and include the personalized communication tone options identified in the journey analysis. Prioritize features that address insurance navigation, as this represents a high-severity pain point across multiple journey stages.

### **Integrate Faith & Mind Studio**

The emotional journey map shows significant negative emotional states during diagnosis, treatment, and surveillance phases. Over 60% of rare cancer patients experience anxiety or depression, yet spiritual and emotional support is typically disconnected from medical care.

Develop the Faith & Mind Studio as a cross-cutting module that provides scripture, interfaith, or secular CBT support connected to the medical timeline. Include features for journaling, meditation guidance, and emotional tracking to address the "soul & mind care left behind" problem identified in the journey.

### **Establish the Knowledge Graph Foundation**

The journey map highlights how valuable patient data becomes fragmented across systems and how this represents both a care coordination challenge and a missed research opportunity. Begin building the rare-disease knowledge graph that will learn from each patient journey and provide the foundation for the RWE Marketplace.

Design this system with patient consent and data sharing controls from the beginning, and include the proposed 10% revenue-share model for patients who opt to share de-identified data with researchers. This addresses both immediate patient needs for data integration and long-term business model sustainability.

### **Implement Personalized Communication Styles**

The persona analysis reveals distinct communication needs across different stakeholders in the patient journey. Implement the proposed tone and voice choices (Radical Optimist, Clinical Researcher, Just the Headlines, Balanced Calm) as a core platform feature.

This unique approach to personalized health communication addresses the varying information needs of different audience segments and represents a distinctive feature not offered by competitors. It also aligns with the emotional support needs identified throughout the journey map.

