RARE BONE DISEASE EXPERT COLLABORATIVE

Guideline for the Transition from Pediatric to Adult Care

for Individuals with Childhood Rare Bone Diseases

Osteogenesis Imperfecta Foundation

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Abstract

Purpose: This work was conducted to establish a guideline intended to improve the transition from pediatric to adult care for people with childhood-onset rare bone diseases (RBDs).

Methods: Spearheaded by patients and patient advocates, an expert committee guided and informed all aspects of this work. An evidence-based process was established based on review of peer-reviewed literature, guidelines, and gray literature sources focused on pediatric-to-adult care transitions. Expert consensus was used to fill knowledge gaps. The committee-established recommendations underwent a patient-community and public review process.

Results: Current guidance exists, but mostly consists of consensus-based efforts, gleaning information from more prevalent disease areas. We noted, insufficient: RBD-specific evidence, validation of transition measures for rare diseases, post-transfer outcome data availability, and evidence on how to best implement current guidance, along with other issues such as workforce and access limitations.

Recommendations: In general, the group recommended efforts be increased to advocate for, support, conduct, and disseminate patient-centered research on pediatric-to-adult care transition in RBDs to generate evidence to fill these gaps.

In the interim, it is recommended that patient advocacy organizations (e.g., RBD-specific organizations), in collaboration with clinical and other partners, develop (or adapt from existing), disseminate, and encourage widespread use of a patient-centered:

- Transition and Care Guide to support individuals, families, and providers in navigating transition.
- Transition Tracking Sheet, supported by education-based companion tools, to facilitate ongoing tracking, shared understanding, and continuity of health information across the transition process.
- Transition Readiness Assessment that reflects the unique needs of individuals with RBDs and emphasizes patient empowerment, practical skills, self-advocacy, and access to resources.
- Planning Checklist to support proactive, realistic, and individualized transition planning.
- Transfer of Care Checklist to support a structured, timely, and comprehensive transfer process.
- Outcome-focused Transfer Completion approach that prioritizes the individual's experience, confidence, and connection to adult care.

1. Introduction

1.1 Background

The Rare Bone Disease Alliance (RBDA), in collaboration with the Osteogenesis Imperfecta Foundation (OIF), led this effort to develop a pediatric-to-adult care-transition guideline to support individuals with childhood-onset rare bone diseases (RBDs). Building on the OIF's *Somewhere to Go* (STG) pediatric-to-adult care transition initiative [1], this document represents a unified approach to improving lifelong care and continuity of care for people with RBDs. Our work builds on the "Got Transition" initiative, a comprehensive, U.S.-relevant, and widely accepted transition structure, supported by national professional organizations, with extensively published materials and practical implementation tools [2]. This document is intended to build on and not replace the Got Transition framework, which serves as a foundational model. Our efforts add the patient and family voice, and incorporate RBD-specific considerations, while serving as a bridge that individual disease groups can further adapt into disease-specific actions and toolkits.

In the U.S., rare diseases are defined as conditions affecting fewer than 200,000 individuals. People living with rare diseases often struggle to find clinicians with relevant expertise. Limited provider familiarity and scarcity of specialists experienced in treating rare diseases can lead to delays in diagnosis, mismanagement, and preventable complications—adding to the burden faced by the estimated 30 million Americans affected by rare diseases.[3]

Current focus on RBDs is timely given recent advancements in treatment and changes in epidemiology. For example, osteogenesis imperfecta (OI) remains incurable; however, early and proactive interventions—particularly bisphosphonate therapy and corrective orthopedic surgery using expandable rods—have improved bone mineral density and reduced fracture rates in children with moderate to severe OI [4–7]. These approaches, along with promising novel therapies targeting molecular mechanisms, are extending mobility, function, and quality of life across the lifespan. Further, increased patient advocacy and community engagement have amplified calls for evidence-based care, research on patient-reported outcomes (PROs), and inclusive approaches that address racial, ethnic, and geographic disparities in care. As with other rare diseases such as cystic fibrosis, where adults now outnumber pediatric patients, improved survival has shifted the demographic landscape and created an urgent need for systems designed to support lifelong management [8,9].

1.2 Objectives and Purpose

For the majority of people with a rare disease, their illness began in childhood [10]. While they may have received specialized pediatric care as children, upon adulthood, the healthcare system provides fewer resources for most [11]. Millions of adults with childhood-onset rare diseases face difficulty finding knowledgeable primary care and suitable specialty support [1,12,13]. Moreover, the rare disease population is expanding rapidly [14]. In 2016, the NIH identified 7,000 rare diseases; recent estimates place that number closer to 10,000 [15,16]. More than 95% of these disorders have no FDA-approved treatment [17]. However, improved care, and in some cases novel therapies, has resulted in many of these patients living longer and reaching adulthood [11,18]. These successes also mean that a dearth of appropriate, adult-focused rare-disease care is a growing national problem [3,19,20].

For people living with these and similar chronic, genetic conditions, access to coordinated, specialized care remains a major challenge. Many experience gaps in care and access to care, particularly during the transition from pediatric to adult care, when established supports often diminish and adult providers with

expertise in rare diseases can be difficult to find [21,22]. Navigating fragmented healthcare systems, securing insurance coverage, and maintaining continuity of care all add to the burden faced by patients and families [8,9,21–23].

People living with RBDs face significant challenges as they transition from pediatric to adult care. Many families report that preparation for this shift begins too late, leaving them uncertain about what adult care will look like and who will coordinate it [23,24]. Adult providers with expertise in RBDs are scarce, and multidisciplinary services—such as orthopedics, endocrinology, and rehabilitation—are often fragmented for adults as compared to pediatric care centers [25,26]. Important clinical information is sometimes lost during handover, and in the absence of a dedicated transition coordinator, families often have to take on the burden themselves of managing appointments, records, and insurance issues [12,23,24]. Adolescents may also struggle to develop self-management skills and confidence as parental roles change [12]. Practical barriers, such as travel distances and limited telehealth options, add further strain. These experiences mirror those of other rare disease communities, such as cystic fibrosis and Duchenne muscular dystrophy, underscoring the need for standardized transition policies, dedicated coordination, and adult systems equipped to support lifelong, multidisciplinary care [8,9,22]. Table 1 contains examples identified in the literature of the challenges and priorities reported by patients and families, which are similar to those noted by the RBD community [1,27].

Table 1. Transition Challenges and Family Priorities

1. Early Preparation Lacking	Families often feel unprepared for adult care—few know what to expect or meet adult providers in advance. Many clinics lack a clear, written transition policy. [8,28]
2. Limited Adult Care Expertise & Fragmented Care	Adult providers with expertise in RBDs are scarce. Families must find and coordinate multiple specialists, often leading to fragmented and inconsistent care. [29]
3. Poor Information Transfer	Important clinical data (imaging, surgery notes, genetics, dental records) are frequently lost or delayed between pediatric and adult teams. Families report weak collaboration across the handover.
4. Families as Default Case Managers	Without a funded transition coordinator, families frequently must or are forced to handle scheduling, record transfers, and insurance tasks themselves—creating stress and gaps in care.
5. Readiness & Independence Gaps	Adolescents often lack skills to manage their own care. Few programs use structured readiness tools or provide youth-alone time to build confidence and advocacy skills.
6. Emotional and Identity Impact	The shift away from trusted pediatric teams is emotionally difficult. Families report lower satisfaction and struggle with changing parent–youth roles without guided support.
7. Logistical Barriers	Adult clinics may be far away and harder to coordinate. Loss of clustered, same-day multidisciplinary visits increases travel and time burdens; telehealth options remain inconsistent.

8. Adult-Specific Needs Under-addressed	Reproductive health, pain, function, and rehabilitation issues gain importance in adulthood but are often not proactively addressed in transition planning.
9. Lack of Measurement and Accountability	Few clinics track or report transition outcomes (e.g., timely first adult visits). Quality improvement systems are rare, leading to slow progress and uneven practices.
10. Equity and Navigation Issues	Language barriers, health literacy, and insurance obstacles make transitions harder, particularly for families without strong advocacy or local support.

Patients and families/caregivers have reported that the following would help in pediatric-to-adult transitions:

- Meeting the adult team before transfer (even once or by telehealth) to reduce uncertainty. [8]
- Using a standardized transfer document and checklist so nothing critical gets lost (e.g., DXA/radiology/genetics/dental/operative history). [28]
- Having a named coordinator and direct contact route (phone/email/portal) for the first year. [28]
- Planning a first adult visit that is longer, covers goals, and confirms who to contact and how [28]
- Using a brief experience or satisfaction questionnaire every 6 months to resolve problems quickly. [8,28]

In response to these challenges and needs, the conference, “Somewhere to Go (STG) for Adults with Childhood-Onset Rare Diseases: A Conversation About How We Can Fill Gaps in Care,” was convened by the Osteogenesis Imperfecta (OI) Foundation over a two-day period (October 19-20, 2023) in Arlington, Virginia. The objectives for this patient-centered conference were to: bring together a multistakeholder, multidisciplinary group of experts for a working meeting on the topic of adult patients with childhood-onset rare bone diseases who find themselves with “nowhere to go” for care; hold a working meeting on transitioning from pediatric to adult care to enumerate and describe the current gaps, barriers, and challenges faced, and the potential causes behind them; think strategically about solutions to address these gaps, barriers, and challenges, and prioritize which issues and/or solutions could be addressed collaboratively over the next 2-3 years by the convened group assembled, as well as others.

At the end of the two-day meeting, a final full-group discussion was held to review, revise, refine, and prioritize action steps for the future. The group created a list of 21 issues that emerged from the discussion. (See Appendix 1) Lastly, participants were asked to prioritize the main issues to be addressed, specifically thinking about what this group should take on, collectively, in the next 2-3 years to achieve the goal of a smooth pathway from childhood to adult-care transition. A top issue prioritized by the group was the need for development of a pediatric-to-adult care transition guideline.

Thus, the question this guideline addresses is:

What are the recommended approaches for ensuring patients with RBDs (and their caregivers and families) experience a smooth transition from pediatric to adult care to ensure equitable and optimal patient outcomes?

The purpose of this guideline initiative was to gather and examine the evidence on approaches to transitions from pediatric to adult care for people with childhood-acquired RBDs and to offer recommendations on using those approaches in the management of these transitions for the RBD community. This collaborative effort aimed to leverage known evidence and identify critical evidence gaps to ensure all individuals with RBDs have access to consistent, informed, equitable, and patient-centered transition care across their lifespan.

Optimal patient outcomes are defined not only by clinical care indicators (e.g., continuity of care, access to appropriate specialists), but also by outcomes identified as meaningful by patients and families. These may include, but are not limited to, pain management, functional independence, participation in education, employment, and community life, psychosocial well-being, and reduced treatment burden.

The guideline recommendations are intended to focus on the needs of individuals with RBDs, as well as their caregivers and family members, providing practical tools and strategies to support successful transitions from pediatric to adult care. While people with RBDs are the primary focus for the work, our search for evidence, recommendations, and tools was broadened to include rare and complex disease because we were aware that a search for only RBD-related materials would likely be too narrow.

The primary audience for this guideline includes people living with RBDs and their families, along with the health care providers and allied professionals who care for them, adding synchrony among those needing care and those providing that care.

The patient community, including people with RBDs, their family members, and care partners are engaged in this work from inception to finalization. These guidelines address an issue of vital importance to this community. This document stresses the patient community’s voice and its pivotal role in successful transitions.

2. Methods

Guided by the OIF's leadership and supported by the collective expertise of RBDA member organizations, the Rare Bone Disease Expert Collaborative (RBDEC) was formed and used existing literature, resources, and best practices to create a foundational, disease-agnostic framework that can be tailored to specific rare bone conditions.

All funding for the administration of the project was provided by the OIF, which received unrestricted sponsorships for guideline development from the Foundation to Eradicate Duchenne and Ultragenyx Pharmaceutical Inc. Sponsors were not involved in guideline development but were invited to be observers at Committee meetings.

2.1 Advisory Committee

The RBDEC, a multidisciplinary expert collaborative, was led by the RBD patient community, and included patients, caregivers, clinicians, researchers, and representatives from the Rare Bone Disease Alliance's member organizations. See Appendix 2 for a full list of RBDEC member organizations and committee representatives. The committee provided guidance, input, oversight, and approval of the final guideline document.

Members contributed content expertise, assisted in literature and resource review, participated in discussions to refine recommendations, and contributed to and reviewed evolving sections of the guideline. The Committee was convened as part of the *Somewhere to Go* pediatric-to-adult care transition initiative and was charged with developing a comprehensive, RBD-agnostic transition guideline. Committee members served on a voluntary basis, meeting virtually 1–2 times per month, drawing on both professional experience and lived expertise to ensure the guideline reflected real-world challenges, existing models of care, and best practices across the RBD community. Particular attention was given to structuring outputs in formats accessible and time-efficient for clinicians (e.g., summaries, key recommendations, and practical tools), while also accessible for patients and families. OIF staff provided logistical, technical, and editorial support.

2.2 Evidence Searches

Evidence on existing, tested approaches for successful transition from pediatric to adult care in rare diseases (including RBDs) was sought from peer-reviewed literature, published existing guidelines, and gray literature*.

A summary overview of the methods for each search conducted is provided here. All sought English language documents and focused on pediatric-to-adult care transition, AND rare disease or medically complex conditions. Medically complex conditions were included to be sure we were casting a wide enough net. The searches included:

- Peer-reviewed research, identified as "research" in PubMed
- Peer-reviewed guidelines or guidances (on transition, not on disease treatment), clearly identified as a guideline, protocol, toolkit, consensus statement, model of care, or similar
- Gray literature research, reporting study findings
- Gray literature guidelines or guidances (on transition, not disease treatment), clearly identified as a guideline, protocol, toolkit, consensus statement, model of care, or similar

*Gray literature is defined by the U.S. National Library of Medicine as information produced by government, academia, business, and industry in formats not controlled by commercial publishing. It includes sources such as reports, conference proceedings, dissertations, newsletters, and blogs, with varying levels of review and reliability.

2.2.1 PubMed Peer-Reviewed Research/Evidence Search Strategy

Peer-reviewed literature was identified through two complementary PubMed searches, hereafter referred to as Search Strategy 1 and Search Strategy 2. Search Strategy 1 was designed to capture published peer-reviewed evidence on pediatric-to-adult health care transition in rare diseases, while Search Strategy 2 was developed to broaden capture to medically complex and chronic childhood-onset conditions with comparable transition challenges. Both strategies used predefined inclusion and exclusion criteria and were conducted between January 2010 and June 2025. See Appendix 3 for the specific search strategy and search terms used for each PubMed Search. Data were managed using Covidence software[30], which supported application of the standardized inclusion/exclusion criteria, coding of inclusion/exclusion decisions, identification and documentation of duplicates, and organization and tracking of included documents.

The full-text articles for publications identified through the peer-reviewed literature search were independently reviewed by two reviewers, one RBDEC member and one OIF staff member. Articles were randomly assigned to reviewers. Each member reviewed full-text articles between August 26, 2025 – September 19, 2025 and made a recommendation on whether or not the publication was appropriate for inclusion, with a rationale for the decision. Articles rated as “include” or “exclude” by both the committee and staff member were included or excluded per the same ratings. Articles that had two different ratings were reviewed by the committee chairs as tie breakers.

2.2.2 AI-Assisted Tool/Resource Search Strategy

A structured open-web, gray literature search on health-care transition from pediatric to adult services for people with rare diseases was conducted. A standardized prompt was developed and applied across several generative AI platforms (Grok, Gemini, Claude, Copilot, and ChatGPT) to retrieve non-paywalled, non–peer-reviewed documents that met predefined inclusion and exclusion criteria, specified deliverables, and required functioning, verifiable URLs. AI was used for search purposes only and was not used for selection decisions. Given the increasing reliance of patients, caregivers, and the broader community on generative AI tools to locate health information, these platforms were intentionally included to identify resources that users are likely to encounter and utilize in real-world settings.

To broaden the evidence base, additional searches were performed in which “rare disease” was replaced with terms such as “special health-care needs” and “complex conditions,” thereby enabling the inclusion of transition resources developed for clinically comparable populations. The outputs generated by these tools were manually reviewed by staff to ensure relevance to RBDs or complex illnesses, remove duplicates, and confirm that each explicitly addressed transition rather than general rare-disease care, with priority given to documents from governmental agencies, professional bodies, and non-profit groups. All AI gray literature documents were reviewed by staff to assess relevance and to adjust AI search parameters as required. This review process also served to mitigate known limitations of generative AI, including the potential for inaccurate, incomplete, or “hallucinated” outputs, and to ensure that only verifiable and credible resources were included. An in-depth description of the search can be found in Appendix 4.

In addition to the systematic review of published and gray literature, the search process incorporated a targeted, AI-assisted search for other evidence (e.g., transition measurement tools, best-practice elements, and implementation frameworks) relevant to rare and medically complex conditions. To supplement our database strategy, we used ChatGPT-4o to identify validated general transition measures (such as TRAQ and STARx), surfacing key resources that were cross-referenced with existing systematic reviews and incorporated into the review matrix. Users should note that AI-generated outputs may vary over time as models evolve; therefore, verification of sources and critical analysis of results are essential when replicating similar searches in the future. The full prompt and search string are provided in Appendix 5.

2.3 Evidence Assembly and Assessment

After we identified evidence and other relevant materials in the peer-reviewed and gray literature, that included research, existing guideline documents, existing tools, and other resources, we organized the output and produced one table of all findings minus exclusions. (Appendix 6)

2.4 Framework Derived From Evidence

Systematic evaluation of the output was based on organizing findings into a standardized grid to assess applicability and alignment with project objectives. A guiding framework was selected for this assessment based on a systematic and transparent decision-making process. The committee established the following evaluative criteria to guide framework selection:

- **Applicable to the U.S. patient population and healthcare system**, including compatibility with the structure of U.S. pediatric and adult care provision.
- **Widely used, widely accepted, or nationally/internationally recommended** for use in clinical practice.
- **Supported/endorsed by major professional societies**, particularly those relevant to pediatrics and primary care.
- **Well described and readily accessible publicly or in published literature**, including availability of clear documentation and practical examples. (e.g., no paywall)
- **Comprehensive in scope and inclusive of implementation tools**, such as readiness assessments, tracking forms, and transition planning guides.
- **Flexible and adaptable** for use across different clinical settings, populations, and childhood-onset conditions.

This process blended identification of a sound conceptual framework with applicable and actionable components of transition programs that have demonstrated utility across diverse clinical environments within the context of the selected care transition framework. Relying on the criteria, a working theoretical framework was selected and aligned tools and resources were chosen for inclusion. The framework, tools, and resources, if needed, were adapted for relevance to the RBD community by the OIF Project team and RBDEC. The output tables were reviewed iteratively by the Co-chairs and by the full committee for oversight and agreement, and incorporation into the guideline.

2.5 Guideline Document-Development Process

The OIF Project Team supported the writing and coordination, with RBDEC members and co-chairs providing iterative input and feedback on successive drafts. Members provided ongoing, iterative input by

email on the guideline development protocol, assessment of the evidence, generation of recommendations, draft content, and review and approval of drafts during the development of the guideline document.

The OIF Project Team followed a detailed, collaborative process to support the RBDEC in preparing the document. The Team met routinely with the Expert Panel co-chairs and corresponded with the Committee via e-mail to coordinate the process to completion. Four Committee meetings were held between June 2025 and March 2026. From October 22, 2025 through November 3, 2025, the OIF Project Team developed Draft V1.0, integrating the outline, draft text, tables, and references. This early draft was shared with the Co-Chairs on November 10, 2025, who reviewed and provided feedback between November 11–18, 2025. Following their input, the Team revised and expanded the draft to create Version 1.1 by December 17, 2025, which underwent another Co-Chair review before moving into Version 2.0 in early January. After a final round of Co-Chair review and approval by January 23, 2026, the full RBDEC reviewed Draft V2.0 between January 23 and February 10, 2026, submitting comments and recommendations.

2.6 Public Comment Period

A public comment period was held March 10 to March 19, 2026. The guideline document was posted on the OIF and RBDA websites for public comments.

Responders were encouraged to provide comments through a designated web form that asked questions about each section of the document. The form used the following response choices: “Agree as written,” “Agree with suggested modifications,” and “Disagree. See comments.”

RBDEC members reviewed comments and determined whether to maintain the original draft recommendations, revise with minor language changes, or make more comprehensive edits. The OIF Project Team then incorporated all feedback and produced the next draft on March 10, 2026 for use at the stakeholder consensus meeting.

2.7 Stakeholder Consensus Meeting

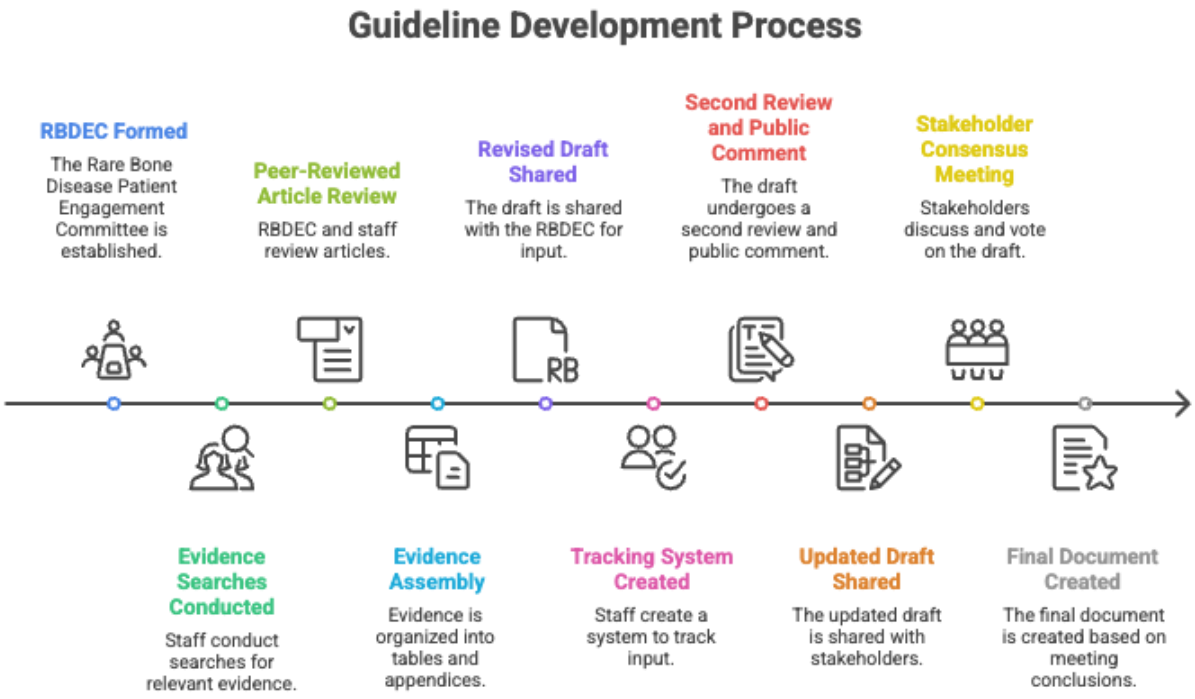
A stakeholder consensus meeting was held March 26–27, 2026 to achieve final agreement on the guideline content and recommendations. Participants were invited based on their expertise and contributions to the field. A broad range of stakeholders were sought, ranging from patients and families, clinicians, patient groups and advocates, government, and industry. (Participants and designated stakeholder group are listed in Appendix 7). It was anticipated, based on the expertise of the Committee, that there would be gaps in evidence. Therefore, one objective of the consensus meeting was to achieve agreement on all recommendations, especially those that were, in whole or in part, based on expert opinion.

The updated draft was circulated to all meeting attendees as a pre-read on March 19, 2026. Attendees reviewed materials ahead of the March 26 meeting, where the Guideline was presented and discussed in preparation for publication and implementation.

After the meeting, the OIF Project Team compiled comments and edits from the stakeholders, presented them to the RBDEC, which made final decisions on any revisions. The Guideline document was then finalized on June 25, 2026.

2.8 Guideline Development Process

Figure 1 outlines the steps followed by the RBDEC.



3. Results

3.1 Evidence Searches

3.1.1 PubMed Peer-Reviewed Research/Evidence Results

Search Strategy 1 returned 144 articles and Strategy 2 returned 48 articles, for a total of 192 records. One duplicate was identified between the two strategies, resulting in 191 unique articles for screening. The title and abstract screening of the **191** articles resulted in 146 excluded at the title/abstract stage based on inclusion/exclusion criteria. Five additional articles were excluded due to translation requirements. Thus, 151 articles were excluded resulting in 40 articles retrieved for full text review.

The 40 full-text articles were reviewed by the RBDEC and staff members, which resulted in 14 exclusions. The final list of 26 peer-reviewed articles is listed in Appendix 3. Reasons for exclusion are listed below in Table 2.

Table 2. Reasons for Full Text Review Exclusions for PubMed Article Search

NUMBER OF ARTICLES	REASON FOR EXCLUSION
3	Not applicable to rare bone disease
5	Limited generalizability due to methods issues
6	Lack of actionable guidance provided
14	**Total excluded articles**

The screening and selection processes are depicted in the PRISMA-style flow diagram in Appendix 3.

3.1.2 AI-Assisted Tool/Resource Search Results

In total, 27 gray-literature documents on transition from pediatric to adult care in the context of rare diseases or complex long-term conditions were identified and are summarized in Appendix 4. These comprised 12 toolkits and other practical resources and 15 guideline, policy, or commissioning documents, most of which were issued by national or regional health authorities, large charities, or condition-specific organizations.

3.1.3 AI-Assisted Other Evidence Search Results

A structured scan of the literature and supplemental AI-assisted search identified at least 13 unique transition measurement tools and frameworks relevant to pediatric-to-adult care, with applications spanning both general and rare disease populations (see tool table). Of these, 7 instruments were validated through peer-reviewed studies (TRAQ, STARx, HEEADSSS/YouthCHAT, OYOF-TES, UNC TRxANSITION Scale, RTQ, STARx-P), with most supporting structured self-assessment of transition readiness, self-management skills, or care experience. The remaining initiatives—including transfer summary tools, patient “passports,” customized checklists, and eHealth platforms—demonstrate a range of practical formats, though most lack published validation.

To further synthesize the landscape of available transition models and frameworks, the team compared key existing frameworks against the predefined selection criteria (Table 3). This Table highlights the unique strengths and gaps of each approach, informing final recommendations.

Table 3. Evaluation of Validated Transition Frameworks Against Selection Criteria

Tool	Description	US based/ Relevance to the US population	Broadly Accepted/ National or international standard	Broadly used/ Easily accessible information	Peer (P) and Gray (G)	Link/Source Article	Tool/ Toolkit/ Guideline/ Framework
Got Transition Six Core Elements (6CE)[2,31,32]	Structured framework defining six core elements for implementing and sustaining pediatric-to-adult health care transition programs.	Yes	Yes	Yes	P + G	ST3P-UP study transition quality improvement collaborative	Framework
SMART model [31]	Conceptual model outlining staged, goal-oriented transition planning and implementation.	Unknown	Emerging	Partial	P	Implementation of programs for the transition of adolescents to adult care	Framework
Key Driver Diagram [34]	Quality-improvement framework mapping key drivers required to achieve effective transition outcomes.	Yes	Emerging	Partial	P	Implementation of a Portable Medical Summary for AYAs with Medical Complexity	Framework
PANEL framework [35]	Rights-based conceptual framework applying participation, accountability, non-discrimination, empowerment, and legality to transition care.	Partial	Emerging	Partial	P	Growing Up Can Be Hard to Do	Framework

3.2 Evidence Assembly and Assessment

The identified peer-reviewed and gray-literature evidence, including research findings, existing guideline documents, tools, and other resources, was assembled and assessed, and the consolidated findings, minus exclusions, are presented in a single table of all findings in Appendix 6.

3.3 Framework Selection

Based on the evaluation, the committee reached consensus that Got Transition's Six Core Elements (SCEs) [2] best met the predetermined criteria and represented the most appropriate framework for this guideline. Got Transition provides a comprehensive, U.S.-relevant, and widely accepted structure supported by national professional organizations, with extensively published materials and practical implementation tools. The framework is also intentionally designed to be adaptable, making it suitable for tailoring to the needs of individuals with childhood-onset RBDs. While certain elements from other frameworks informed the committee's thinking, Got Transition most fully aligned with the selection criteria and was adopted as the primary organizing framework for this guideline. This comprehensive model addressed many of the issues of the RBD communities and we are grateful to the Got Transition staff and founders for their contribution in developing this framework.

According to the US Department of Health and Human Services, the health care transition from pediatric to adult care for adolescents with and without special health care needs is a recognized maternal and child health need.[36] While the SCE model has been introduced as a best practice for maternal and child health transition, it does not appear to adequately meet the needs of adolescents transitioning to adult care with a rare bone disease. Thus, the RBDEC concluded that customizing the SCEs for RBD transition relevance.

To customize the Got Transition SCEs [2], it is first important to note that the six core elements were written and accepted from the provider's perspective; we specifically looked to incorporate the patient voice in adapting the Got Transition tools. The recommendation of the RBDEC was to use the six core elements as a foundation and to fill important gaps in current recommendations.

The SCEs include transition and care policy guide; tracking and monitoring; transition readiness; planning; transfer of care and transition completion [37]. These six elements take place in three settings – transitioning youth to an adult health care clinician; transitioning to an adult approach to health care without changing clinicians, and integrating young adults into adult health care. Each of the three settings have an implementation guide for the six core elements of health care transition that the health care provider initiates. The first setting was chosen four our work, transitioning youth to an adult health care clinician.

3.4 Guideline Recommendations

Based on Got Transition's[1] SCEs [2] for transition of care from a pediatric to adult provider and as adapted by the RBDEC, the following recommendations are intended to guide patient advocacy organizations, healthcare providers, individuals, and families in supporting the transition from pediatric to adult care for individuals with RBDs. The RBDEC used the SCE framework to guide the process of ensuring recommended actions align with the needs of and empower people with an RBD.

[1] The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®. The version of the Six Core Elements used in this guideline has been modified from the original and is used with permission.

These recommendations are designed to be actionable and implementable, with clear roles for how tools are developed, shared, and used in real-world transition care.

In summary, they include:

Table 4. Summary of Recommended Core Elements, Purposes, and Suggested Tools

CORE ELEMENT THEMES	PURPOSE	SUGGESTED TOOL
1. Guide Transition and Care	Encourages and guides the pediatric-to-adult care transition process	Transition Guide “Getting Ready to See an Adult Doctor”
2. Track and Monitor	Encourages and supports ongoing documentation, tracking, and communication of health information across adolescence and early adulthood	Transition Tracking Sheet
3. Assess Transition Readiness	Encourages and supports assessing transition readiness, so care and transition support can be tailored to individual needs	Transition Readiness Assessment
4. Plan for Transition	Encourages and supports early and ongoing planning for adult care	Transition Planning Checklist
5. Transfer Care	Encourages and supports a structured, timely, and comprehensive transfer process	Transfer of Care Checklist
6. Transfer Completion	Supports confirmation of connection to adult care, beyond just process, with a focus on patient-centered outcomes that prioritize the individual’s experience, confidence, and connection to adult care	Transfer Completion Tool

Each of the six elements is described below in more detail:

1. Transition and Care Guide

i. Current Guidance from Got Transition's[2] SCE [2] – It is recommended that healthcare practice sites develop and implement a transition and care policy that defines when and how individuals transition from pediatric to adult care. This policy is typically introduced between ages 12–14, made accessible within the practice, and revisited over time. However, this approach is inconsistently implemented in real-world settings.[33,38,39] A Transition and Care Guide is needed by organizations and systems, but is not always actionable by all involved parties (such as patients and families).

ii. Recommendation from the RBDEC for current guideline – Patient advocacy organizations (e.g., RBD-specific organizations) should develop (or adapt an existing) and disseminate a patient-centered Transition and Care Guide to support individuals, families, and providers in navigating transition.

Rather than relying solely on practice-level policies—which are often unavailable—this guideline prioritizes use of a practical, patient- and family-centered user-facing tool (e.g., a checklist or guide) that can be actively used by patients and families across care settings.

This recommended Transition and Care Guide must:

- Provide a clear, developmentally appropriate overview of the transition process across adolescence and early adulthood
- Function as a practical checklist or roadmap, not just a policy description
- Support individuals and families in building knowledge, skills, and confidence over time
- Support the empowerment and growing capacity of the patient to take on, over time and as appropriate, the management of and decision-making in their own care.
- Clarify roles and responsibilities of the individual, parent/caregiver, and healthcare providers
- Connect directly to key transition activities and tools (e.g., readiness assessment, tracking tool, care summary)
- Reflect real-world variability in access to adult providers and care systems
- Emphasize actionable outcomes, including:
  - Identifying adult providers
  - Preparing for transfer
  - Maintaining continuity of care
  - Building confidence in self-management

Patients and families use this Transition and Care Guide with their healthcare providers in the relevant practice sites to support and structure transition discussions, particularly in settings where no formal policies exist.

iii. Action – Implementing the Recommendation from the RBDEC

To use this Transition and Care Guide, called, "Getting Ready to See an Adult Doctor," organizations, individuals, families, and providers should:

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PATIENT ADVOCACY ORGANIZATIONS:

- Develop and disseminate a version of the Transition and Care Guide (e.g., checklist-style tool) tailored for their patient community (e.g., organization developed or adapted from those suggested below)
- Make the guide widely accessible (e.g., through websites, toolkits, clinics, community programs, practitioner education programming, etc.)
- Encourage collaborative Guide use by patients, families, and providers
- Encourage patients to bring the Guide to their providers and for providers to introduce the Guide to their patients to expand collaborative use.

PATIENTS AND FAMILIES:

- Use the Guide to understand what to expect and track progress over time
- Bring the Guide to clinic visits to initiate and support discussions with providers, and for planning
- Use the Guide to identify next steps, gaps in care, and needed resources

HEALTHCARE PROVIDERS:

- Introduce the Guide to patients and families (if they don't already know about it)
- Review and discuss the Guide with patients and families during visits
- Use the Guide to:
  - Discuss timing of transition
  - Support education about the condition and care needs
  - Encourage increasing independence
  - Identify and help coordinate communication and consultation with adult care providers
  - Assist with completing and updating the tool to help navigate the timing of the transition
- Integrate the Guide into routine care (e.g., clinic workflows, handouts, or care planning discussions)

ACROSS ALL SETTINGS:

- Transition expectations are introduced early (ages 12–14) and revisited regularly
- The Guide is used as a shared tool to support communication and coordinated transition planning

iv. Tools for Use or Adaptation

PRIMARY RECOMMENDED TRANSITION AND CARE GUIDE TOOL:

- **Transition Guide** (Appendix 8)
  - A patient-centered, actionable tool designed for use by individuals, families, for collaborative use with providers
  - Intended to operationalize the traditional "policy" approaches by providing clear, usable steps

ADDITIONAL EXAMPLE(S):

- Sample Transition and Care Guide [40] (Appendix 8) — may be used by organizations as a reference for developing internal policies, but is not the primary tool for individuals and families

2. Tracking and Monitoring

i. Current Guidance from Got Transition's[3] SCE [2,41,42] – It is recommended that individuals maintain an up-to-date medical summary and transition tracking process to support continuity of care. However, existing tracking tools are inconsistently used in real-world settings and may not adequately support patient and family empowerment through early education, shared understanding, or coordination between individuals, families, and providers.

ii. Recommendation from the RBDEC for current guideline – Patient advocacy organizations (e.g., RBD-specific organizations) should develop (or adapt existing) and disseminate a patient-centered Transition Tracking Sheet, supported by education-based companion tools, to facilitate ongoing tracking, shared understanding, and continuity of health information across the transition process.

Rather than relying on static or provider-driven documentation—which is often fragmented or incomplete—this guideline prioritizes use of a practical, patient- and family-centered tool that can be actively used by patients and families, in collaboration with providers, across care settings.

THIS RECOMMENDED TRANSITION TRACKING APPROACH MUST:

- Support ongoing documentation, tracking, and communication of health information across adolescence and early adulthood
- Use developmentally and cognitively appropriate language
- Support the empowerment and growing capacity of the individual to take on, over time and as appropriate, management of and decision-making in their own care
- Encourage shared input from the individual, parent/caregiver, and healthcare providers
- Allow for integration of information from multiple sources (e.g., clinical records, family reported history, care plans)
- Connect directly to key transition activities and tools (e.g., readiness assessment, care summary, transition guide)
- Promote communication, coordination, and continuity of care across settings
- Emphasize practical use over time rather than one-time completion
- Encourage information to be regularly reviewed and updated by the individual, family/caregivers, and healthcare team to support timely, accurate, and coordinated care transitions

Patients and families use this Tracking and Monitoring tool with their healthcare providers in relevant care settings to support and structure communication, tracking, and transition planning.

iii. Action – Implementing the Recommendation from the RBDEC

To use the **Transition Tracking Sheet** and supporting materials, organizations, individuals, families, and providers should:

PATIENT ADVOCACY ORGANIZATIONS:

- Develop and disseminate a version of the Transition Tracking Sheet tailored to the needs of their patient community (e.g., organization developed or adapted from those suggested below)
- Develop/adapt companion educational and communication tools to support use and engagement

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- Make the tools widely accessible (e.g., through websites, toolkits, clinics, community programs, practitioner education programming, etc.)
- Encourage collaborative use of the tool by patients, families, and providers
- Encourage patients to bring the Transition Tracking Sheet to their providers and for providers to introduce the Transition Tracking Sheet to their patients to expand collaborative use.

PATIENTS AND FAMILIES:

- Use the Transition Tracking Sheet to document medical history, care needs, and transition progress over time
- Engage with companion tools to build knowledge and prepare for increasing independence
- Share the Transition Tracking Sheet with providers who do not know about it and ask them to work collaboratively on it
- Bring the tool to clinic visits to support discussion, planning, and updates
- Use the tool to identify next steps, gaps in care, and needed resources

HEALTHCARE PROVIDERS:

- Introduce and review the Transition Tracking Sheet with patients and families (if they don't already know about it)
- Use the tool to:
  - Support education about the condition and care needs
  - Encourage increasing independence and engagement
  - Guide longitudinal care planning and transition readiness
  - Assist with completing and updating the tool over time
- Integrate the tool into routine care (e.g., clinic workflows, handouts, or care planning discussions)

ACROSS ALL SETTINGS:

- Use begins early (ages 12–14) and is updated regularly over time
- The tool is used as a shared resource to support communication, coordination, and continuity of care
- The approach remains flexible and adaptable across a range of care settings, including those without formal transition programs

iv. Tools for Use or Adaptation

PRIMARY RECOMMENDED TRACKING AND MONITORING TOOL:

- **"Transition Tracking Sheet"** (adapted, patient-centered tool designed for use by individuals, families, and for collaborative use with providers) (See Appendix 8)
  - Designed to support ongoing tracking of health information and transition progress
  - Intended to operationalize tracking and monitoring through a practical, usable format

Additional Tools Patient Groups Should Consider Developing: (Appendix 8)

- Clinician discussion guide with recommended timing for transition conversations
- Parent/caregiver discussion guide
- Communication guide to support effective interaction between families and providers

3. Transition Readiness

i. Current Guidance from Got Transition's[4] SCE [2,43,44] – It is recommended that transition readiness be assessed using standardized tools to evaluate an individual's knowledge and skills in preparing for adult care. However, many existing tools are not tailored to the needs of people with rare bone diseases, are not consistently used in practice, and may not fully capture the skills, knowledge, and support needed for their successful transition in real-world adult care settings.

ii. Recommendation from the RBDEC for current guideline – Patient advocacy organizations (e.g., RBD-specific organizations), in collaboration with clinical partners, should develop (or adapt existing) and disseminate a patient-centered Transition Readiness Assessment that reflects the unique needs of individuals with RBDs and emphasizes patient empowerment, practical skills, self-advocacy, and access to resources.

Rather than relying on generic readiness measures—which may not reflect the lived experience of individuals with an RBD—this guideline prioritizes use of a practical, user-facing assessment that can be used collaboratively by individuals, families, and providers across care settings.

THIS RECOMMENDED TRANSITION READINESS ASSESSMENT MUST:

- Assess transition readiness across domains relevant to real-world transition and adult care, so that care and transition support can be tailored to individual needs
- Emphasize practical application of knowledge, not just knowledge acquisition
- Support the empowerment and growing capacity of the individual to take on, over time and as appropriate, management of and decision-making in their own care
- Include developmentally and adaptable language for individuals with varying communication abilities
- Distinguish between different types of support resources (e.g., advocacy organizations, peer support)
- Reflect the complexity of rare bone diseases, including lifelong care needs and variability in access to care
- Connect directly to key transition activities and tools (e.g., tracking tool, care summary, transition guide)
- Support identification of gaps in knowledge, skills, and access to resources

Patients and families use this Assessment with their healthcare providers to guide transition planning, monitor progress, and identify areas where additional support or education is needed.

iii. Action – Implementing the Recommendation from the RBDEC

To use the Transition Readiness Assessment, organizations, individuals, families, and providers should:

PATIENT ADVOCACY ORGANIZATIONS:

- Develop and disseminate an adapted Transition Readiness Assessment tailored for their patient community (e.g., organization developed or adapted from those suggested below)
- Ensure the assessment includes clearly defined, readiness-area specific measures relevant to real-world transition
- Make the assessment widely accessible (e.g., through websites, toolkits, clinics, community programs, practitioner education programming, etc.)

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- Encourage collaborative use by individuals, families, and providers
- Encourage patients to bring the Assessment to their providers and for providers to introduce the Guide to their patients to expand collaborative use.

PATIENTS AND FAMILIES:

- Use the Assessment to understand readiness for transition and identify areas for growth
- Engage with the Assessment over time, recognizing that readiness develops gradually
- Share the Assessment with providers who do not know about it and ask them to work collaboratively using it
- Bring results to clinic visits to support discussion and planning
- Use results to identify needed resources, supports, and next steps

HEALTHCARE PROVIDERS:

- Introduce and review the Assessment with patients and families (if they don't already know about it)
- Use the Assessment to:
  - Guide discussions about transition readiness and independence
  - Identify gaps in knowledge, skills, or access to resources
  - Support individualized transition planning
  - Monitor progress over time
- Integrate the Assessment into routine care (e.g., clinic workflows, care planning discussions)

ACROSS ALL SETTINGS:

- Assessment begins early (ages 12–14) and is revisited regularly
- The tool is used as a shared resource to support communication and coordinated transition planning
- The approach remains flexible and adaptable across a range of care settings and individual need
- Review and align with existing valid/tested tools where applicable
- Explore opportunities to validate adapted assessments within rare disease populations
- Consider partnerships (e.g., research organizations, patient-centered outcomes groups) to support proper development, modification, validation, and implementation of Assessment tools

iv. Tools for Use or Adaptation

PRIMARY RECOMMENDED TOOL:

- **"Transition Readiness Assessment"** (adapted for rare bone diseases) (Appendix 8)
  - A patient-centered assessment designed for collaborative use
  - Intended to operationalize readiness through practical, real-world measures

ADDITIONAL TOOLS PATIENT GROUPS SHOULD CONSIDER DEVELOPING:

- A checklist aligned with key readiness domains identified for a specific disease
- Validation framework and supporting literature
- Companion resources to support interpretation and use of results

4. Transition Planning

i. Current Guidance from Got Transition's[5] SCE [2,45,46] – It is recommended that transition planning begin in adolescence and include identifying adult providers, preparing for transfer, and addressing practical considerations such as insurance and care coordination. However, existing tools are inconsistently implemented and often do not fully support individuals and families in navigating real-world challenges, particularly for RBDs where adult care expertise may be limited.

ii. Recommendation from the RBDEC for current guideline – Patient advocacy organizations (e.g., RBD-specific organizations), in collaboration with clinical partners, should develop (or adapt existing) and disseminate a patient-centered Planning Checklist to support proactive, realistic, and individualized transition planning.

Rather than relying on generalized planning frameworks—which may not reflect real-world constraints—this guideline prioritizes use of a practical, user-facing tool that can be actively used by patients and families, in collaboration with providers, across care settings.

THIS RECOMMENDED TRANSITION PLANNING CHECKLIST MUST:

- Support early and ongoing planning for adult care
- Reflect real-world variability in access to adult providers and health systems for people with rare bone diseases
- Encourage early proactive identification of adult-care options and potential barriers
- Support the empowerment and growing capacity of the patient to take on, over time and as appropriate, the management of and decision-making in their own care.
- Support development of a clear understanding of care needs and appropriate provider roles
- Connect directly to key transition activities and tools (e.g., tracking tool, readiness assessment, transfer checklist)
- Promote shared responsibility between individuals, families, and providers
- Emphasize practical, achievable steps rather than idealized care models

Patients and families use this Transition Planning Checklist with their healthcare providers to guide planning, identify gaps, and prepare for transition in a structured and realistic way.

iii. Action – Implementing the Recommendation from the RBDEC

To use the Transition Planning Checklist, organizations, individuals, families, and providers should:

PATIENT ADVOCACY ORGANIZATIONS:

- Develop and disseminate a Transition Planning Checklist tailored to their patient community
- Ensure the checklist reflects real-world care access and variability
- Make the tool widely accessible (e.g., websites, toolkits, clinics, community programs, practitioner education programming)
- Encourage collaborative use by patients, families, and providers

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- Encourage patients to bring the Transition Planning Checklist to their providers and for providers to introduce the Transition Planning Checklist to their patients to expand collaborative use.

PATIENTS AND FAMILIES:

- Use the checklist to guide planning for adult care beginning in mid-adolescence
- Identify potential adult providers using available resources (e.g., advocacy organizations, insurance networks)
- Consider future geographic location and care needs
- Use the checklist to identify gaps in care and needed supports
- Bring the tool to clinical visits to support transition discussions and planning

HEALTHCARE PROVIDERS:

- Introduce to and review the checklist during clinical visits with patients and families (if they don't already know about it)
- Use the checklist to:
  - Support identification of adult providers
  - Discuss timing and expectations for transition
  - Help address barriers to care (e.g., access, insurance, availability of specialists)
  - Guide completion of key planning steps
  - Encourage patient empowerment and capacity building
- Integrate the checklist into routine care and transition discussions

ACROSS ALL SETTINGS:

- Planning begins early (around age 16 or earlier, depending on transition timing) and is revisited regularly
- The checklist is used as a shared tool to support communication and coordinated planning
- The approach remains flexible and adaptable to individual needs and care environments

iv. Tools for Use or Adaptation

PRIMARY RECOMMENDED TOOL:

- **"Transition Planning Checklist"** (Appendix 8)
  - Designed to support proactive identification of providers, care needs, and transition steps
  - Intended to operationalize transition planning in real-world settings

ADDITIONAL TOOLS PATIENT GROUPS SHOULD CONSIDER DEVELOPING:

- Sample Plan of Care (Appendix 8)

5. Transfer of Care

i. Current Guidance from Got Transition's[6] SCE [2,47,48] – It is recommended that a structured transfer process be implemented, including preparation of key documents and coordination between pediatric and adult providers. However, current approaches often lack clarity on timing, expectations, roles, and required components, resulting in inconsistent implementation.

ii. Recommendation from the RBDEC for current guideline – Patient advocacy organizations (e.g., RBD-specific organizations), in collaboration with clinical partners, should develop (or adapt existing) and disseminate an RBD patient-centered Transfer of Care Checklist to support a structured, timely, and comprehensive transfer process.

Rather than relying on loosely defined processes—which may result in incomplete or delayed transfer—this guideline prioritizes use of a practical, user-facing checklist that ensures all critical elements are addressed prior to transfer.

THIS RECOMMENDED TRANSFER OF CARE CHECKLIST MUST:

- Support a structured, timely, and comprehensive transfer process
- Ensure all critical transfer elements are addressed and documented prior to transfer
- Structure the preparation of all required transfer documents and records in advance of the handoff
- Define clear timelines and milestones for completing transfer tasks
- Clarify the roles of pediatric and adult providers, individuals, and families throughout the handoff
- Facilitate direct communication and coordination between pediatric and adult care teams
- Identify and address gaps or barriers to a smooth, timely transfer
- Confirm completeness and shared accountability across all parties prior to transfer

Patients and families use this Transfer of Care Checklist with their healthcare providers to guide structured transfer preparation, ensure completeness, and coordinate the handoff to adult care.

iii. Action – Implementing the Recommendation from the RBDEC

To use the Transfer of Care Checklist, organizations, individuals, families, and providers should:

PATIENT ADVOCACY ORGANIZATIONS:

- Develop and disseminate a standardized Transfer of Care Checklist
- Provide templates and examples of key transfer documents
- Make tools widely accessible and adaptable (e.g., through websites, toolkits, clinics, community programs, practitioner education programming, etc.)
- Encourage collaborative use of the tool by patients, families, and providers
- Encourage patients to bring the Transfer of Care Checklist to their providers and for providers to introduce the Transfer of Care Checklist to their patients to expand collaborative use.

PATIENTS AND FAMILIES:

- Begin preparing for transfer early (approximately 1–2 years prior to transition)
- Use the checklist to track completion of key steps and required documents

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- Ensure they have copies of all relevant materials
- Share information with adult providers and confirm receipt
- Bring the tool to clinical visits to support discussion, planning, and updates
- Use the tool to identify next steps, gaps in care, and needed resources

HEALTHCARE PROVIDERS:

- Introduce to and review the checklist during clinical visits with patients and families (if they don't already know about it)
- Use the checklist to:
  - Guide preparation of the transfer package
  - Ensure completeness of documentation
  - Support coordination with adult providers
  - Track progress toward transfer
- Integrate the checklist into care workflows

ACROSS ALL SETTINGS:

- Transfer preparation begins early and is completed prior to transition
- The checklist is used as a shared tool to support communication and coordination
- The approach remains flexible while ensuring core components are completed

iv. Tools for Use or Adaptation

PRIMARY RECOMMENDED TOOL:

- Transfer of Care Checklist
  - Designed to support structured and complete transfer preparation
  - Intended to operationalize the transfer process

ADDITIONAL TOOLS PATIENT GROUPS SHOULD CONSIDER DEVELOPING:

- Sample transfer letter and medical summary templates
- Condition-specific fact sheets and patient advocacy resources

6. Transfer Completion

i. Current Guidance from Got Transition's[7] SCE [2,49,50]

Follow-up after transfer is recommended to confirm successful transition and maintain communication between pediatric and adult providers. However, these steps are often difficult to implement consistently and tend to focus on process completion rather than meaningful outcomes.

ii. Recommendation from the RBDEC for current guideline

Patient advocacy organizations and clinical partners should promote an outcome-focused Transfer Completion approach that prioritizes the individual's experience, confidence, and connection to adult care.

Rather than relying on process-based measures alone, this guideline prioritizes evaluation of meaningful, patient-centered outcomes and the use of practical tools to support ongoing connection to care.

We recommend the use of the Transfer Completion Tool as the primary method to assess whether transfer has been successfully achieved and is functioning in real-world settings.

THIS RECOMMENDED APPROACH TO TRANSFER COMPLETION:

- Focuses on functional, patient-centered outcomes rather than checklist completion alone
- Emphasizes the individual's confidence and ability to navigate care
- Confirms connection to adult providers and services
- Encourages follow-up (e.g., 3–6 months) to identify and address gaps after transfer
- Reflects variability in patient experiences and definitions of success
- Promotes accessible, usable formats for key health information
- Supports patients and families, in partnership with providers, in assessing progress and addressing gaps using the Transfer Completion Tool

Patients and families use this Transfer Completion Tool with their healthcare providers to assess transition outcomes, confirm connection to adult care, and identify any remaining gaps.

iii. Action – Implementing the Recommendation from the RBDEC

To support Transfer Completion, organizations, individuals, families, and providers should use the Transfer Completion Tool to guide follow-up, assess outcomes, and identify gaps:

PATIENT ADVOCACY ORGANIZATIONS:

- Develop, adapt, and disseminate the Transfer Completion Tool
- Promote patient-centered definitions of transition success
- Support education on how to use the tool across settings
- Make the tool widely accessible (e.g., through websites, toolkits, clinics, community programs, practitioner education programming, etc.)
- Encourage collaborative use of the tool by patients, families, and providers
- Encourage patients to bring the Transfer Completion Tool to their providers and for providers to introduce the Transfer Completion Tool to their patients to expand collaborative use.

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PATIENTS AND FAMILIES:

- Use the Transfer Completion Tool (with or without providers) to assess transition progress
- Confirm connection to an adult provider or point of contact
- Improve access to care (appointments, medications, insurance)
- Participate in follow-up and provide feedback on the transition experience.
- Use the tool to identify next steps, gaps in care, and needed resources

HEALTHCARE PROVIDERS:

- Introduce to and review the Transfer Completion Tool with patients and families during follow-up visits (if they don't already know about it)
- Use the Transfer Completion Tool during follow-up (e.g., 3–6 months post-transfer)
- Identify and address gaps in care continuity
- Encourage feedback from individuals and parent/caregivers
- Integrate the tool into routine follow-up care (e.g., clinic workflows, care planning discussions)

ACROSS ALL SETTINGS:

- Evaluate success using functional, patient-centered outcomes, including:
  - Confidence in managing health
  - Knowledge of how to access care
  - Ability to maintain continuity of care
  - Ability to pursue personal and life goals with appropriate support
- Maintain a flexible, adaptable approach responsive to individual needs and care settings

iv. Tools for Use or Adaptation

PRIMARY RECOMMENDED TOOL:

- Transfer Completion Tool – Recommended for assessing transfer completion, identifying gaps, and guiding follow-up care (Appendix 8)

ADDITIONAL TOOLS PATIENT GROUPS SHOULD CONSIDER DEVELOPING:

- Transfer Summary/Letter
- Follow-up survey or feedback tool
- Supplemental checklists or outcome measures aligned with the Transfer Completion Tool

COMMON THEMES ACROSS THE RECOMMENDATIONS INCLUDE:

- Transition planning should position the patient (and family, as appropriate) not only at the center, but as active, informed partners in the process, with increasing independence over time.
- Education is foundational—patients and families should be supported in building knowledge about the condition, care needs, and healthcare system, with tools and resources provided by patient advocacy organizations, healthcare providers, and others.
- Transition is a longitudinal process that begins early (typically ages 12–14) and is revisited regularly, with developmentally appropriate expectations and periodic assessment of transition readiness.
- Practical, patient-centered user-friendly tools (e.g., guides, tracking sheets, readiness assessments, checklists) are essential to support communication, coordination, and continuity of care across settings.

- Shared responsibility across patients, families, patient advocacy organizations, and healthcare providers is critical to successful transition planning and implementation.
- Recommendations and tools must reflect real-world variability in access to care, resources, and adult-provider expertise, particularly for rare bone diseases.
- Effective communication—supported by both general and disease-specific tools—should occur early and often, with an emphasis on usability, accessibility, and adaptability across care settings.
- Ongoing evaluation and refinement of tools and approaches, including opportunities for validation and evidence generation, are needed to strengthen implementation and impact.

Other Examples of Tools That Can be Adapted

The Osteogenesis Imperfecta Foundation (OIF) created three age-specific, patient-centered toolkits, one each for newly diagnosed individuals, school-aged children, and adults. The last particularly focuses on the problematic transition from the pediatric to the adult healthcare system. It includes trackers like the Basic Health History Tracker and Medication Tracker, and Surgical History Tracker, which can be adapted for other rare diseases.[51] (Located in Appendix 8)

Although OIF toolkits are referenced as examples, the consideration of additional tools developed by patient advocacy organizations, professional societies, or clinical institutions is strongly encouraged. These resources may be adapted, with appropriate permission, to meet the needs of specific populations.

4. Discussion

This document represents the first effort to develop a guideline on pediatric-to-adult care transitions for people with RBDs. It marks an important starting point, not the end of the discussion. Advancing the field will require coordinated efforts among patients, families, patient organizations, clinicians, researchers, policymakers, and funding agencies. Establishing a structured research agenda—including longitudinal outcomes research, implementation science studies, workforce analyses, and equity-focused investigations—will be essential to transforming recommended transition practices into evidence-based standards of transition care.

Despite increasing recognition of the importance of structured pediatric-to-adult transition processes, the evidence base specific to individuals with childhood-onset RBDs remains limited [28]. This guideline was developed using the best available evidence; however, significant research gaps were identified that warrant focused attention. Collectively, the evidence gaps identified underscore that pediatric-to-adult transition in RBDs remains an underdeveloped area of research.

We found that the evidence to guide evidence-based decision making on RBD care transitions mostly consists of consensus-based efforts, gleaning information from more prevalent disease areas. The evidence spans many diseases. Thus, it is hard to pull together a cohesive picture applicable to any one RBD. Admittedly, we have lumped all RBDs together for this starting point. But we are fully aware there may be nuances within any one disease that makes aspects of the evidence and/or these recommendations irrelevant or too general.

The studies we did find were typically not conducted in a patient-centered manner by including patients and families as active partners and collaborators. Patient-centered research does not mean “putting patients at the center” and doing research for or about patients. It means including patients in the conduct of the research itself, as partners not just as enrolled study subjects. Clinical experts play an important role. But patient and family experts know what it is like to experience a disease on a daily basis for specific diseases. Research needs to address what patients would tell you are the nuances for transitions specific to their disease. We have recommended patient groups customize for their specific disease the recommendations provided in this guideline, to address the nuances that might not be considered at all in the current published research. The different RBD patient groups will need to think about how they might need to address those specifics.

Evaluation of Adapted Tools and Resources

This guideline takes the major step of recommending the RBD adaptation of transition tools, including tracking sheets, transfer packages, and patient-facing planning documents. We have taken this step despite knowing that the effectiveness of these adapted tools has not yet been formally tested for people with RBDs. Rigorous evaluation—including pilot testing, validation studies, and implementation trials—is needed to determine whether these resources improve readiness, continuity of care, and patient satisfaction. [34] This evaluation cannot take place without the development, implementation and assessment of the tools and processes. Thus, the journey must begin with this first step.

A research agenda must be built to address, over the long-term, should include:

Limited RBD–Specific Evidence

We note that most transition research has been conducted in more prevalent and chronic conditions such as cystic fibrosis and diabetes. While these models provide valuable insights, their applicability to RBDs is not

fully established. Few studies specifically evaluate transition processes, outcomes, or models of care for individuals with osteogenesis imperfecta and other related RBDs. Disease-specific transition frameworks and outcome data are therefore urgently needed. [28]

Insufficient Validation of Transition Measures in Rare Diseases

Several tested transition readiness tools exist (e.g., TRAQ, STARx); yet these instruments were not developed specifically for rare diseases and have limited testing in RBD populations. There is a need to assess existing tools or develop new measures tailored to RBD contexts. This includes both readiness assessments and post-transfer experience measures.

Lack of Post-Transfer Outcome Data

One of the most significant gaps identified is the limited amount of data on outcomes following transfer to adult care. Few studies examine long-term clinical outcomes, care continuity, or patient-reported outcomes (PROs) (e.g., pain management, reproductive health, or functional status after transition). Additionally, there is minimal tracking of process measures such as health care utilization patterns and timeliness of first adult visits.

Prospective, longitudinal studies are needed to determine whether structured transition interventions meaningfully improve adult health outcomes. [33,34,52–54] Existing evidence has predominantly characterized transition from structural and process perspectives evaluating whether programs and protocols are in place, while evidence on their patient-centered effectiveness remains sparse. The recommendations put forth in this guideline are intentionally oriented toward establishing patient-centered outcomes to address this gap. They are intended to establish a measurable baseline from which future comparative effectiveness research can be conducted.

Implementation Science Gaps

Although frameworks such as the Six Core Elements developed by Got Transition[8] [2] provide a structured approach to transition, limited evidence exists regarding how best to implement these models in RBD settings. Pediatric providers caring for individuals with RBDs often face time, workforce, and resource constraints. Research is needed to evaluate scalable implementation strategies, identify which components of transition programs are most impactful, and assess cost effectiveness in both high-resource and community-based settings. [28,32,33,38,39,55–57]

Workforce and Access Limitations

The scarcity of adult providers with expertise in RBDs represents a major structural barrier. However, systematic data describing the adult RBD workforce, geographic distribution of expertise, and access disparities are lacking. Research examining workforce capacity, telehealth-enabled models of care, and shared-care networks could inform policy solutions aimed at improving adult care availability.[28,58,59] Beyond structural constraints, there is a recognized asymmetry in clinical engagement with transition: the drive for structured transition care has historically been concentrated among pediatric providers and patient advocates, with comparatively limited enthusiasm among adult clinicians. This disparity likely reflects

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differences in practice culture and time pressures between pediatric and adult care settings, as well as limited familiarity with RBDs among adult providers who may not encounter these conditions frequently. Addressing this gap will require deliberate efforts within the RBD clinical community to cultivate interest and build capacity among adult providers equipping them to not only receive transitioning patients effectively, but to provide comprehensive, ongoing care for the whole person across the adult lifespan.

Equity and Disparities in Transition

Although families report barriers related to insurance, language, health literacy, and travel burden, there is limited empirical research quantifying disparities in RBD transition outcomes across socioeconomic, racial, ethnic, and geographic groups. Future studies should explicitly examine equity in access to transition preparation, successful transfer, and adult specialty care engagement for the RBD community to improve understanding and address gaps.

Adult-Specific Clinical and Psychosocial Needs

The transition to adulthood introduces evolving needs related to pain management, mobility, reproductive health, mental health, identity development, and independent self-management. There is limited longitudinal research examining how these adult-specific issues emerge and how transition planning influences adult functioning and quality of life for people with RBDs. Limited ability to access insurance coverage and the right providers makes it difficult to address these clinical and psychosocial needs.

Measurement, Quality Improvement, and Accountability

Few institutions track standardized transition metrics or incorporate quality improvement systems focused on pediatric-to-adult care transition RBDs. The development of measurable quality indicators and benchmarking systems for RBD transition care would enable systematic improvement and accountability. [34,54,55]

Methodological Considerations

The use of AI-assisted gray literature searches revealed variability across platforms and highlighted the absence of standardized methods for incorporating AI tools into evidence synthesis. Future methodological research should establish reproducible standards for AI-supported guideline development.

Strengths of this work

The document has several strengths. It is the first time an RBD-specific care-transition guideline has been developed and should help to provide structure to transitions. It is a step forward for patients and families in that they are important and recognized partners in this work. The guideline is intended to support patient and family empowerment. We have attempted to provide a foundational template for the RBD community to work from and to customize and adapt as needed. Our findings have helped to inform a research agenda for the RBD community, government agencies, the research and clinical communities.

Limitations of This Work

This guideline was developed with a deliberate focus on people living in the United States who have RBDs, using a framework selected for its applicability within the U.S. healthcare and research context. It is not

intended to serve as a global, one-size-fits-all approach. Rather, it builds on existing efforts—including the work of the RBDEC and Got Transition[9]—and is meant to serve as a foundation for future disease-specific efforts, as well as for assessment, adaptation, and refinement by the RBD community outside the United States. While there is alignment with related work from European and Canadian patient groups, differences in healthcare systems, care delivery and payment models, and access to services limit direct applicability across settings. Including multiple RBDs within a single review also presents limitations, as differences in disease characteristics, care needs, and lived experiences may not be fully captured within a unified framework.

This guideline was developed using a systematic search strategy that included both peer-reviewed and gray literature. In reviewing additional resources suggested during the feedback process, we considered why some materials were not identified initially. In general, this reflects common limitations of evidence identification: some resources were published after the original search was completed, others were not indexed in databases such as PubMed, and gray literature searches were limited in scope (e.g., reviewing the first set of results), meaning some relevant materials may not have been captured.

While this process provided reassurance that there were no major gaps in the overall approach, it also highlighted a broader challenge: even with a dedicated, multi-month effort, it remains difficult to identify all relevant resources due to the fragmented and dispersed nature of available information. This presents a significant barrier for individuals, families, and clinicians seeking to access and navigate existing resources.

Additional limitations arise from the use of AI–assisted tools in the search and review process. The lack of standardization across tools can lead to variability in results, and outputs may depend on pay-walls, user familiarity, and search approach. Some tools do not retain timestamps, requiring real-time documentation of searches, and frequent updates to AI systems may result in different outputs over time.

Through this work, the authors compiled a substantial body of resources that effectively serves as a developing repository of knowledge in this area. However, this repository is not yet broadly accessible, highlighting an important opportunity for future efforts to improve organization and dissemination. This document is intended to be part of an evolving body of work, and the authors remain open to continued input as new evidence and experience emerge.

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5. Conclusions

Following the recommendations in this guideline can help make the transition from pediatric to adult care smoother for people with RBDs. However, this guideline is not the final destination—it is a starting point. Continued research and new policy approaches will be essential for implementing the guideline and strengthening future versions as we address existing knowledge gaps. Our goal is to move from the goos practices outlined here toward fully patient-centered, evidence-based best practices.

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6. Appendices

6. Appendices

6.1 STG Proceedings Table 4: Top Priority Action Steps to be Addressed in 2024-2026 to Smooth Care Transitions
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6.2 RBDEC Committee Membership
APPENDIX 2

6.3 Peer-reviewed Evidence Search Strategy and Results
APPENDIX 3

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APPENDIX 4

6.5 AI-Assisted Other Evidence Search Strategy and Results
APPENDIX 5

6.6 Table of Evidence-Based Tools and Resources (Peer-Reviewed and Gray Literature)
APPENDIX 6

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6.8 List and Copies of Guidance-Recommended Tools
APPENDIX 8

APPENDIX 1

STG Proceedings Table 4: Top Priority Action Steps to be Addressed in 2024-2026

to Smooth Care Transitions

STG Proceedings Table 4: Top Priority Action Steps to be Addressed in 2024-2026 to Smooth Care Transitions [1]

TOPIC	
1.	Development of transition success measures
2.	Better leverage the use of telemedicine to improve transitions
3.	Gain better understanding of all that is happening in transition care. Develop an inventory/catalogue (who is doing what and where, that can be joined, built on, leveraged, disseminated, scaled)
4.	Build and better leverage the workforce needed for the future to support transition care
5.	Improve patient (and family/caregiver) preparedness/readiness; develop an accessible toolbox that helps provide a soft landing for transitions
6.	Advance transitions as a policy issue; develop a policy agenda
7.	Data, data, data: Develop standards and advance integration of EHRs with other sources to strengthen evidence generation and dissemination of information
8.	Develop a research agenda on transitions
9.	Address reimbursement, insurance, coding issues
10.	Improve the lack of standards, guidance, clinical practice guidelines, quality of care measurement
11.	Improve mental health support during transitions
12.	Improve lack of care coordination throughout and after transitioning
13.	Leverage AI and other technologies to support transitions
14.	Address transition fatigue (so many kinds of transitions at once)
15.	Better support caregivers/family members/friends/care team/advocates throughout transitions
16.	Better inform decisions about which provider(s) are needed when. Who drives decisions? When to use specialists?
17.	Pilot, expand on novel care models
18.	Increase and improve appropriate diagnosis (for prevalence, evidence, cost estimates). Might we be looking at the tip of the iceberg?
19.	Consider culture of care differences between adult and pediatric care on transitions

TOPIC	
20.	Consider stigma as part of transitions
21.	Consider the many different transitions happening over time: pediatric to adult to geriatric; Medicaid to Medicare

APPENDIX 2

RBDEC Committee Membership

RBDEC Membership

ORGANIZATION	REPRESENTATIVE	TITLE
Children's Nebraska	Esposito, Paul	Clinical Chief, Pediatric Orthopedic Surgery
GACI Global	Pechey, Brooke	Board Member
Hypoparathyroidism Association	Hood, Jaclyn	Registered Nurse
International FOP Association	Newport, Hope	Family Services Manager
Jansen's Foundation	Nizar, Neena	Founder and Executive Director
National Institutes of Health	Boyce, Allison	Chief, Metabolic Bone Disorders Unit
Osteogenesis Imperfecta Foundation	Coleman, Breanna	Board Member
Osteogenesis Imperfecta Foundation	Huang, Billy	Board Member
Ultragenyx	McCue, Jenny	Executive Director, Patient Advocacy
University of South Florida	Reynolds, Danielle	Medical Director, Pediatric Bone Program
Vanderbilt University Medical Center	Black, Margo	Research Projects Manager
XLH Network	Souza, JoBeth	President
Yale School of Medicine	Olear, Elizabeth	Senior Clinical Research Associate

APPENDIX 3

Peer-reviewed Evidence Search Strategy and Results

Purpose

To identify and synthesize peer-reviewed evidence describing research findings on structured guidance, models of care, and best practices for transition from pediatric to adult care in rare diseases and medically complex conditions, with specific relevance to rare bone diseases.

Methods

Search Design and Data Source

A structured literature search was conducted in PubMed to identify peer-reviewed publications addressing transition from pediatric to adult health care in rare disease and medically complex populations. Two complementary search strategies were developed to ensure comprehensive coverage of (1) rare disease–specific transition guidance and (2) transition models applicable to clinically complex populations with relevance to rare bone diseases.

Healthcare transition was defined as the purposeful, planned movement of adolescents and young adults from pediatric- to adult-oriented health care systems. Search terms targeted pediatric-to-adult transition concepts and did not specifically target handoff or transfer processes as standalone constructs.

Search Strategies

Two predefined PubMed search strategies were used, each corresponding to a distinct search string and result set.

Search Strategy 1 (Rare disease–focused search) was designed to capture transition guidance specific to rare diseases. This strategy used Search String 1, which combined pediatric-to-adult care transition terms with rare disease indexing terms:

Search String 1: "transition to adult care" OR "pediatric to adult care" OR "transition of care" OR "Patient Handoff" AND (Rare Disease OR Rare Disease[Title/Abstract] OR Orphan Disease[MeSH Major Topic] OR Orphan Disease[Title/Abstract])

Search Strategy 2 (Complex chronic condition–focused search) was designed to identify transition models and tools developed for medically complex or multimorbid populations that may be adaptable to rare bone disease contexts. This strategy used the following:

Search String 2: "transition to adult care" OR "pediatric to adult care" OR "transition of care" OR "Patient Handoff" AND ("complex disease" OR "complex chronic disease" OR "medically complex" OR "multiple chronic conditions" OR "multimorbidity" OR "Medically Complex Children")

Eligibility Criteria

Publications were eligible for inclusion if they met all three of the following criteria:

- Population relevance
  - Addressed individuals with a rare disease or medically complex chronic condition, with pediatric populations or cohorts spanning pediatric through adult care.
- Transition focus
  - The primary focus of the publication was transition from pediatric to adult care, rather than general disease management or adult-only care.
- Structured guidance or actionable content

- The publication was explicitly labeled as a guideline, protocol, toolkit, consensus statement, model of care, or similar; or
- Provided actionable, step-by-step guidance or explicit recommendations for clinicians, patients, or health systems regarding transition.

Publications that were purely descriptive or observational, without transition guidance, or focused solely on clinical treatment of the condition were excluded.

Screening and Study Selection

All identified records were imported into Covidence for screening and management. After duplicate removal, a two-stage screening process was applied:

- Title and abstract screening, conducted using predefined inclusion and exclusion criteria.
- Full-text review of potentially eligible articles to confirm relevance and eligibility.

Articles were coded as Include or Exclude during screening. Publications with discordant assessments were resolved through secondary review. All screening decisions and reasons for exclusion were documented in Covidence.

Data Management and Extraction

For included publications, key characteristics were extracted and organized into structured evidence tables, including:

- Type of guidance provided (e.g., guideline, model of care, toolkit)
- Transition domains addressed (e.g., readiness, planning, coordination)
- Measurement tools or outcomes referenced

Review of Full Text Articles by the Advisory Committee

Full-text articles identified through the peer-reviewed literature search were reviewed by an advisory committee composed of expert clinicians and researchers. Each committee member was assigned approximately two articles for review. Full-text article links were distributed through Covidence, and reviewers were provided instructions to create Covidence accounts in order to access the assigned materials. Reviews were conducted asynchronously.

To standardize feedback, reviewers completed a structured screening rubric administered via Google Forms for each assigned article. The rubric assessed relevance to pediatric-to-adult health care transition, rare disease applicability, and the presence of structured guidance or actionable recommendations. Reviewers were asked to indicate whether they recommended including or excluding each article from further consideration and were given the opportunity to provide additional qualitative comments. Responses were collected and used to inform final inclusion decisions and subsequent stages of guideline development.

Results

Search Yield

Search Strategy 1 returned 144 records, and Search Strategy 2 returned 48 records. From the combined 192 records identified, one duplicate was removed, resulting in 191 unique publications for title and abstract screening. Of these 191 articles, 40 were assessed for eligibility through full-text review. Following full-text assessment, 26 peer-reviewed articles met all inclusion criteria and were included in the final synthesis.

Each study was categorized as narrative review, systematic/scoping review, consensus/guideline, quality improvement/implementation, validation, or observational study. The included publications spanned a range of rare diseases and complex chronic conditions and represented multiple forms of research and structured transition guidance. Table 3.3 lists the 26 peer-reviewed articles included after final screening, which formed the evidentiary basis for all subsequent tool, framework, and measure extraction.

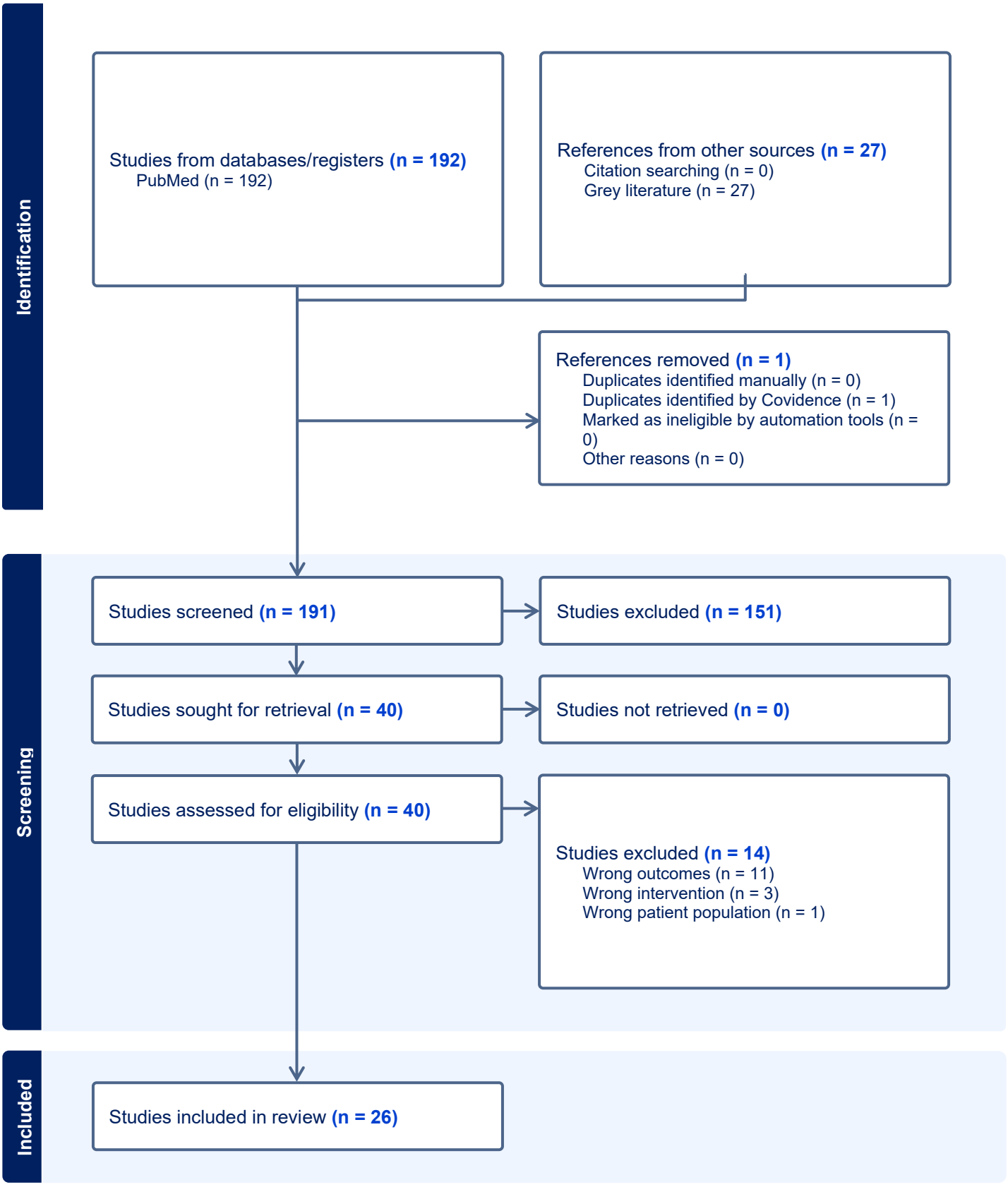
Identification
Studies from databases/registers (n = 192)
PubMed (n = 192)
References from other sources (n = 27)
Citation searching (n = 0)
Grey literature (n = 27)
References removed (n = 1)
Duplicates identified manually (n = 0)
Duplicates identified by Covidence (n = 1)
Marked as ineligible by automation tools (n = 0)
Other reasons (n = 0)
Screening
Studies screened (n = 191)
Studies excluded (n = 151)
Studies sought for retrieval (n = 40)
Studies not retrieved (n = 0)
Studies assessed for eligibility (n = 40)
Studies excluded (n = 14)
Wrong outcomes (n = 11)
Wrong intervention (n = 3)
Wrong patient population (n = 1)
Included
Studies included in review (n = 26)
Included studies ongoing (n = 0)
Studies awaiting classification (n = 0)

Table 3.1. All Identified Articles before Exclusions (n = 191)

#	TITLE	FIRST AUTHOR	YEAR
1	Left Ventricular Systolic Dysfunction in Patients Diagnosed With Hypertrophic Cardiomyopathy During Childhood: Insights From the SHaRe Registry.	Abou Alaiwi S	2023
2	Practitioner Review: Continuity of mental health care from childhood to adulthood for youths with ADHD - who, how and when?	Adamo N	2024
3	Transition to Adult Care in Childhood-Onset Epilepsy: A Retrospective Cohort Study at a Japanese Children's Hospital.	Aihara T	2025
4	Transition of care in a Danish context: translation, cross-cultural adaptation and content validation of CTM-15 and PACT-M.	Ajstrup M	2024
5	Transition in Sickle Cell Disease (SCD): A German Consensus Recommendation.	Alashkar F	2022
6	Safe handoff practices and improvement of communication in different paediatric settings.	Alcalá Minagorre PJ	2023
7	Improving Health Care Transition for Young Patients With Sickle Cell Disease Through Quality Network.	Alvarez OA	2025
8	Transitional care of adolescents with Multiple Osteochondromas: a convergent mixed-method study 'Patients', parents' and healthcare providers' perspectives on the transfer process'.	Amajjar I	2021
9	Improving paediatric movement disorders care: Insights on rating scales utilization and clinical practice.	Amato ME	2024
10	Optimization of the transition process of youth with liver disease in adulthood: A position paper from FILFOIE, the French network for paediatric and adult rare liver diseases.	Antonini TM	2020
11	Cystinosis in adult and adolescent patients: Recommendations for the comprehensive care of cystinosis.	Ariceta G	2015
12	ERN eUROGEN Guidelines on the Management of Anorectal Malformations Part III: Lifelong Follow-up and Transition of Care.	Aubert O	2025
13	A step-wise approach for establishing a multidisciplinary team for the management of tuberous sclerosis complex: a Delphi consensus report.	Auvin S	2019
14	[Discharge of infants with complex care needs from the neonatal intensive care unit : Ensuring continued inpatient care via the Bunter Kreis aftercare model].	Ballmann S	2024
15	Patients' association programs for adolescents and young adults: The JAP study.	Beaufils C	2019

#	TITLE	FIRST AUTHOR	YEAR
16	Transitioning from pediatric to adult multiple sclerosis care: Challenges, strategies and therapy.	Beniwal SS	2025
17	Health Care Transition of Adolescents and Young Adults with Haemophilia: the Situation in Germany and the Munich experience.	Bidlingmaier C	2020
18	Trends in Technology Assistance Among Patients With Childhood Onset Chronic Conditions.	Boggs EF	2021
19	Disease and medication burden of medically complex adolescents seen in an interdisciplinary transitional care clinic.	Bolesta S	2021
20	[Transition in sickle cell disease - recommendations of the transition initiative sickle cell disease].	Böll J	2024
21	Transition from pediatric to adult nephropathic cystinosis care: the structure, challenges and lessons learned.	Borsheim B	2025
22	Tuberous sclerosis complex: Concerns and needs of patients and parents from the transitional period to adulthood.	Both P	2018
23	Transitions of care in the perioperative period - a review.	Bougeard AM	2019
24	[Growing up with an EBH, an example of pediatric-adult transition in the field of rare diseases].	Bourrat E	2023
25	[Transition to adult care for patients with epilepsy].	Brandl U	2022
26	Management of Hypothalamic Obesity during Transition from Childhood to Adulthood.	Bretault M	2018
27	Development and design of a Blueprint for structured transitional care in adolescents and young adults in the academic hospital setting.	Buijs V	2025
28	Editorial: Transition care in primary immunodeficiencies.	Burns SO	2024
29	[A consensus report by the Working Group on Eating Disorders of Sociedad Española de Nutrición Clínica y Metabolismo (GTTCA-SENPE). Evaluation, medical and nutritional management of anorexia nervosa. Update 2023].	Campos Del Portillo R	2024
30	[Consenso del grupo de trabajo de los trastornos de la conducta alimentaria de SENPE (GTTCA-SENPE). Evaluación y tratamiento médico-nutricional en la anorexia nerviosa. Actualización 2023].	Campos Del Portillo R	2024
31	Reducing medication errors and transitions of care.	Cardwell K	2020
32	The Impact of Inflammatory Bowel Disease in Canada 2018: Children and Adolescents with IBD.	Carroll MW	2019

#	TITLE	FIRST AUTHOR	YEAR
33	Transition of patients with metabolic bone disease from paediatric to adult healthcare services: current situation and proposals for improvement.	Casado E	2023
34	Transition of patients with Duchenne muscular dystrophy from paediatric to adult care: An international Delphi consensus study.	Castro D	2025
35	Adapting to Adulthood: A Review of Transition Strategies for Osteogenesis Imperfecta.	Celli L	2024
36	Transition from pediatric to adult care in adolescents with hereditary metabolic diseases: Specific guidelines from the French network for rare inherited metabolic diseases (G2M).	Chabrol B	2018
37	Child-Adult Transition in Sarcoidosis: A Series of 52 Patients.	Chauveau S	2020
38	Mitigating Risk Associated With the Transition From Pediatric to Adult Kidney Transplant Care: Strategies to Promote Success.	Chen A	2021
39	Quality measures for primary care of complex pediatric patients.	Chen AY	2012
40	The Importance of a PM&R Consultation for Becker Muscular Dystrophy Patients Admitted with Cardiomyopathy.	Cherin N	2024
41	Resource use and costs of transitioning from paediatric to adult care for patients with chronic endocrine disease.	Choukair D	2024
42	Resource utilization and costs of transitioning from pediatric to adult care for patients with chronic autoinflammatory and autoimmune disorders.	Choukair D	2024
43	Resource use and costs of transitioning from pediatric to adult care for patients with chronic kidney disease.	Choukair D	2024
44	Implementation of a Portable Medical Summary for Adolescents and Young Adults With Medical Complexity in Transition to Adult Health Care.	Chouteau WA	2019
45	Implementation of a Transdisciplinary Team for the Transition Support of Medically and Socially Complex Youth.	Ciccarelli MR	2015
46	Center-Based Quality Initiative Targets Youth Preparedness for Medical Independence: HEMO-Milestones Tool in a Comprehensive Hemophilia Clinic Setting.	Croteau SE	2016
47	The Temple Star Transitional Model of Care for epilepsy; the outcome of a quality improvement project.	Crowley SL	2018
48	Transition From Pediatric to Adult Nephrology Care: Program Report of a Single-Center Experience.	Cybulsky AV	2023
49	Commentary: Lost in Transition? Future Directions for Healthcare Transition Research with Rare Diseases.	Dattilo TM	2024

#	TITLE	FIRST AUTHOR	YEAR
50	Caregivers' Perspective on Successful Health Care Transition Outcomes for Adolescents and Young Adults With Special Health Care Needs.	Dave M	2024
51	Endocrine and metabolic consequences of childhood-onset craniopharyngioma during the transition age: A literature review by the TALENT study group.	De Alcubierre D	2025
52	Caring for adults with congenital cardiac disease: successes and challenges for 2007 and beyond.	Dearani JA	2007
53	Comparison of paediatric and adult classification criteria in juvenile idiopathic arthritis during the transition from paediatric to adult care.	Debrach AC	2021
54	Transition from pediatric to adult care in patients with chronic intestinal failure on home parenteral nutrition: How to do it right?	Demirok A	2024
55	Transition readiness assessment in adolescents and young adults with chronic intestinal failure on home parenteral nutrition: A descriptive cross-sectional study.	Demirok A	2025
56	Young adults with SCD in US children's hospitals: are they different from adolescents?	Dickerson AK	2012
57	[Current and future care for diabetes in children: from insulin to immunotherapy].	Dirlewanger M	2011
58	"My child can't see"-workup and management of children with low vision: a joint workshop of the AAPOS Low Vision Rehabilitation and Genetic Eye Diseases Committees.	Ditta L	2025
59	Various aspects of transition of care for adolescents with urological conditions.	Dobrowolska-Glazar B	2022
60	From pediatric to adult care: strategic evaluation of a transition program for patients with osteogenesis imperfecta.	Dogba MJ	2014
61	'Don't let it hold you back' - The experience of transition to adulthood in young people with primary ciliary dyskinesia: An interpretative phenomenological analysis.	Dore R	2024
62	Parents' experiences with health care transition of their adolescents and young adults with medically complex conditions: A scoping review.	Ellison JL	2022
63	Clinical Manifestations and Challenges in Adolescent and Adult Females With Classic Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency.	Engberg H	2025
64	Practices, attitudes and barriers faced by internists and pediatricians in transitioning young adult patients to adult medicine.	Erspamer KJ	2019
65	Congenital Central Hypoventilation Syndrome: Diagnosis and Long-Term Ventilatory Outcomes.	Fain ME	2023

#	TITLE	FIRST AUTHOR	YEAR
66	Multicomponent, high-intensity, and patient-centered care intervention for complex patients in transitional care: SPICA program.	García-Hernández M	2022
67	[Transition from pediatric to adult care: Recommendations of the French network for autoimmune and autoinflammatory diseases (FAI(2)R)].	Georgin-Lavialle S	2021
68	The Association Between Trajectories of Self-reported Psychotic Experiences and Continuity of Mental Health Care in a Longitudinal Cohort of Adolescents and Young Adults.	Gerritsen SE	2024
69	Adaptation and validation of the On Your Own Feet - Transition Experiences Scale evaluating transitions to adult services among adolescent mental health service users in Europe.	Gerritsen SE	2024
70	Transition of care from post-acute services for the older adults in Quebec: a pilot impact evaluation.	Ghai S	2024
71	Spinal cord issues in adult patients with MPS: transition of care survey.	Ghotme KA	2018
72	Experiences of UK-based adult transition services for interstitial lung disease in childhood: "There's a lot less cushioning".	Gilbert C	2023
73	Transition of care in patients with anorectal malformations: Consensus by the ARM-net consortium.	Giuliani S	2017
74	Transitioning from paediatric to adult care in epilepsy: A qualitative study of adolescent experiences.	Goselink RJ	2024
75	An innovative educational program for adolescents on home parenteral nutrition for the "transition" to adulthood.	Goulet O	2024
76	Transition Care for Young Persons with Rare Bone Mineral Conditions: A Consensus Recommendation from the ECTS Rare Bone Disease Action Group.	Grasemann C	2025
77	Pulmonary fibrosis may begin in infancy: from childhood to adult interstitial lung disease.	Griese M	2024
78	Reflection on young adult transitional care in the Boston Children's Hospital Perioperative Care Coordination Clinic.	Grossklaus H	2022
79	Development and Testing of an Electronic Multidisciplinary Rounding Tool.	Gunter EP	2019
80	The lived experience of adults and parents: Transitioning from paediatric to adult health care with oesophageal atresia and tracheo-oesophageal fistula.	Haig-Ferguson A	2023
81	[The transitional care from pediatrics to adult medicine within the rare autoimmune and autoinflammatory diseases network].	Herasse M	2022

#	TITLE	FIRST AUTHOR	YEAR
82	Childhood to adult transition in youth patients with lysosomal acid lipase deficiency: 43 recommendations from experts.	Hermida-Ameijeiras A	2025
83	Maple syrup urine disease decompensation misdiagnosed as a psychotic event.	Higashimoto T	2022
84	The curious case of hemoglobin DC disease masquerading as sickle cell anemia.	Hirani S	2020
85	Transition of care of patients with eosinophilic gastrointestinal diseases: Challenges and opportunities.	Hiremath G	2022
86	The Use of Telehealth to Improve Handoffs Between Neonatologists and Primary Care Providers for Medically Complex Infants.	Hoffman K	2023
87	Exploring indicators of use of costly health services in community-dwelling adults with multiple chronic conditions.	Holland DE	2015
88	Initial observations of medically complex young adults transitioning to adult care: Revealing data regarding mental health, nutrition, and transition preparedness.	Hooker E	2023
89	The development of a transition medical home utilizing the individualized transition plan (ITP) model for patients with complex diseases of childhood.	Hopson B	2023
90	Transition of youth living with HIV from pediatric to adult-oriented healthcare: a review of the literature.	Hussen SA	2015
91	Experts' consensus on the management and treatment of individuals with X-linked hypophosphatemia across lifespan.	I BG	2025
92	Factors Surrounding the Healthcare Transition From Pediatric to Adult Care in 5p- Syndrome: A Survey Among Healthcare Professionals.	Ishizaki Y	2022
93	Recommendations for Transitioning Young People with Primary Immunodeficiency Disorders and Autoinflammatory Diseases to Adult Care.	Israni M	2024
94	Understanding young persons' experiences through healthcare transition. A qualitative study.	Janssens N	2025
95	Rare inherited disorders with renal involvement-approach to the patient.	Joly D	2015
96	Access to care in rare liver diseases: New challenges and new opportunities.	Jones DEJ	2018
97	[Cystinosis : Diagnosis, cystine-depleting therapy, and transition].	Kaufeld J	2018
98	Perspectives and experiences of parents of children with juvenile dermatomyositis: a semi-structured interview study.	Kelly AH	2025

#	TITLE	FIRST AUTHOR	YEAR
99	The management of neurofibromatosis type 1 (NF1) in children and adolescents.	Kerashvili N	2024
100	Transitions of care in Clostridioides difficile infection: a need of the hour.	Khanna S	2022
101	[Transition in cases of complex endocrine and diabetic diseases].	Kiewert C	2025
102	Interventions to support young adults and families with the healthcare transition between paediatric and adult nephrology health services: A systematic scoping review.	Kinch M	2024
103	Adherence to gluten-free diet and follow-up of pediatric celiac disease patients, during childhood and after transition to adult care.	Kori M	2021
104	Transition care to adolescent hepatology in a tertiary center for rare adult-child liver disease.	Laborde N	2024
105	Transition to adult care of young patients with neurofibromatosis type 1 and cognitive deficits: a single-centre study.	Lausdahl S	2022
106	Transition of young adults with endocrine and metabolic diseases: the 'TRANSEND' cohort.	Le Roux E	2021
107	Healthcare transition from childhood to adulthood in pseudoxanthoma elasticum: Patient experience and recommendations for health practitioners.	Lechevalier D	2022
108	Clinical care of children with primary ciliary dyskinesia.	Lucas JS	2017
109	[Transition of care from childhood and adolescence to adulthood in nephrology].	Macher MA	2022
110	Hospitalizations and emergency room visits for adolescents and young adults with muscular dystrophy living in South Carolina.	Mann JR	2015
111	Recommendations for Diagnosis and Treatment of Pseudohypoparathyroidism and Related Disorders: An Updated Practical Tool for Physicians and Patients.	Mantovani G	2020
112	Challenges in the transition of care for rare connective tissue diseases: results from the 2023 ERN ReCONNET Transition of Care Task Force survey.	Marrani E	2025
113	Transition from child and adolescent mental health care to adult services for young people with Attention-Deficit/Hyperactivity Disorder (ADHD) or Autism Spectrum Disorder (ASD) in Europe: Barriers and recommendations.	Maurice V	2022
114	The Epidemiology of Transition into Adulthood of Rare Diseases Patients: Results from a Population-Based Registry.	Mazzucato M	2018

#	TITLE	FIRST AUTHOR	YEAR
115	Clinical and Genetic Characteristics of Pediatric Patients with Inflammatory Bowel Disease Transitioning to Adult Medicine: A Single-Center Ten-Year Experience.	Mocci G	2025
116	Essential components of an effective transition from paediatric to adult neurologist care for adolescents with Duchenne muscular dystrophy; a consensus derived using the Delphi methodology in Eastern Europe, Greece and Israel.	Molnar MJ	2024
117	[The transition of children with rare diseases from pediatric to adult care].	Molnár MJ	2022
118	Implementation of programmes for the transition of adolescents to adult care.	Moreno-Galdó A	2023
119	Components of the transitional care model (TCM) to reduce readmission in geriatric patients: a systematic review.	Morkisch N	2020
120	Asia-Pacific Consensus Recommendations on X-Linked Hypophosphatemia: Diagnosis, Multidisciplinary Management, and Transition From Pediatric to Adult Care.	Munns CF	2023
121	Growing Up Can Be Hard to Do: Reimagining 1 Structurally Supportive Pediatric-to-Adult Transitions of Care from a Rights-Based Perspective.	Munyikwa M	2023
122	Comparison of emergency care delivered to children and young adults with complex chronic conditions between pediatric and general emergency departments.	Murtagh Kurowski E	2014
123	Outcome of childhood-onset epilepsy from adolescence to adulthood: Transition issues.	Nabbout R	2017
124	Transition of Care to Adult Neuroimmunology.	Narula S	2023
125	Clinician Knowledge of Societal Guidelines on Management of Gastrointestinal Complications in Esophageal Atresia.	O'Donnell JEM	2021
126	Transitional Medicine of Intractable Primary Dyslipidemias in Japan.	Ogura M	2024
127	Results of a healthcare transition learning collaborative for emerging adults with sickle cell disease: the ST3P-UP study transition quality improvement collaborative.	Osunkwo I	2024
128	Disparities in health care utilization by race among teenagers and young adults with muscular dystrophy.	Ozturk OD	2014
129	Congenital lung malformations.	Pederiva F	2023
130	An Adapted Model for Transition to Adult Care in Young Adults with Prader-Willi Syndrome.	Pedersen M	2021

#	TITLE	FIRST AUTHOR	YEAR
131	The basics of transition in congenital lifelong urology.	Peycelon M	2021
132	ERS statement on transition of care in childhood interstitial lung diseases.	Pohunek P	2024
133	The role of general practitioners in transitioning adolescents with chronic conditions to adult health care.	Puyraimond-Zemmour J	2025
134	Sex differences in clinical phenotype and transitions of care among individuals dying of COVID-19 in Italy.	Raparelli V	2020
135	Determinants of adherence and consequences of the transition from adolescence to adulthood among young people with severe haemophilia (TRANSHEMO): study protocol for a multicentric French national observational cross-sectional study.	Resseguier N	2018
136	Transition in inherited metabolic diseases: the dietitians, pediatricians and adult physicians' point of view: the results of an Italian survey.	Rossi A	2025
137	Turner syndrome: transition from pediatrics to adulthood.	Rubin KR	2008
138	Long-term clinical and socioeconomic outcomes of children with biliary atresia.	Sadiq J	2023
139	Transitional care of biliary atresia.	Samyn M	2020
140	Protocol for the development and validation procedure of the managing the link and strengthening transition from child to adult mental health care (MILESTONE) suite of measures.	Santosh P	2020
141	Validation of the Transition Readiness and Appropriateness Measure (TRAM) for the Managing the Link and Strengthening Transition from Child to Adult Mental Healthcare in Europe (MILESTONE) study.	Santosh P	2020
142	[Rare diseases: the role of internal medicine].	Sauerbruch T	2025
143	Exploring the role of hospitals and office-based physicians in timely provision of statins following acute myocardial infarction: a secondary analysis of a nationwide cohort using cross-classified multilevel models.	Schang L	2019
144	[Transition from neuropediatrics to neurology in neuromuscular diseases].	Schara U	2018
145	Developing indicators for medication-related readmissions based on a Delphi consensus study.	Schönenberger N	2024
146	Fertility care among people with primary ciliary dyskinesia.	Schreck LD	2024

#	TITLE	FIRST AUTHOR	YEAR
147	Towards needed improvements in inherited metabolic medicine in adulthood: The SIMMESN adult metabolic working group and MetabERN Joint Position Statement.	Sechi A	2024
148	A structured review of chronic care model components supporting transition between healthcare service delivery types for older people with multiple chronic diseases.	Sendall M	2017
149	Transforming Nursing Practice to Optimize Care of Patients with Tuberculosis and Associated Comorbidities in the Kilimanjaro Region, Tanzania.	Shayo PMJ	2025
150	Mapping of the current transition of care practice for patients with pituitary disease at Endo-ERN reference centers.	Shishkov SR	2023
151	Architecture and functioning of child and adolescent mental health services: a 28-country survey in Europe.	Signorini G	2017
152	Protocol for a cohort study of adolescent mental health service users with a nested cluster randomised controlled trial to assess the clinical and cost-effectiveness of managed transition in improving transitions from child to adult mental health services	Singh SP	2017
153	Information Exchange Between Providers During Transitions of Surgical Care: Communication, Documentation and Sometimes Both.	Slager S	2017
154	Patient medication management, understanding and adherence during the transition from hospital to outpatient care - a qualitative longitudinal study in polymorbid patients with type 2 diabetes.	Solh Dost L	2024
155	Addressing the psychosocial aspects of transition to adult care in patients with cystinosis.	Stabouli S	2024
156	Barriers and facilitators in the transition from pediatric to adult care in people with cystic fibrosis in Europe - a qualitative systematized review.	Steinkamp C	2025
157	Transition of patients with Gaucher disease type 1 from pediatric to adult care: results from two international surveys of patients and health care professionals.	Stepien KM	2024
158	Transition of care between paediatric and adult gastroenterology. Autoimmune hepatitis.	Strassburg CP	2003
159	Optimizing Drug Selection in Children with Multiple Sclerosis: What Do We Know and What Remains Unanswered?	Suntornlohanakul R	2025
160	Facilitators and barriers to medication self-management for patients with multiple long-term conditions transitioning from hospital to home.	Syversen MO	2025
161	Liver disease in the young adult: the challenges and rewards.	Thompson FM	2019
162	Transition From Pediatric to Adult Neurologic Care.	Tilton AH	2018

#	TITLE	FIRST AUTHOR	YEAR
163	Building the foundation for a community-generated national research blueprint for inherited bleeding disorders: research priorities to transform the care of people with hemophilia.	Tran DQ	2023
164	The In-between: Time to Talk About Bronchiectasis in Adolescents and Their Transition to Adult Care.	Traversi L	2025
165	Grown-up congenital heart (GUCH) disease: current needs and provision of service for adolescents and adults with congenital heart disease in the UK.	Unknown authors	2002
166	Dyskeratosis congenita: natural history of the disease through the study of a cohort of patients diagnosed in childhood.	Uria-Oficialdegui ML	2023
167	Clinical, Sociodemographic, and Psychological Factors Associated with Transition Readiness in Patients with Epilepsy.	Vacca M	2023
168	The Health Care Transition of Youth With Liver Disease Into the Adult Health System: Position Paper From ESPGHAN and EASL.	Vajro P	2018
169	The Patient Protection and Affordable Care Act: implications for pediatric pharmacy practice.	Vallejos X	2013
170	The importance of clinicians' and parents' awareness of suicidal behaviour in adolescents reaching the upper age limit of their mental health services in Europe.	van Bodegom LS	2023
171	Transition from Child and Adolescent to Adult Mental Health Services in Young People with Depression: On What Do Clinicians Base their Recommendation?	van Bodegom LS	2023
172	Reality check: What happens when patients with anorectal malformations grow up? A pilot study of medical care transition from the adult patient perspective.	van der Bent A	2018
173	Consensus recommendations on organization of care for individuals with Phelan-McDermid syndrome.	van Eeghen AM	2023
174	Healthcare transition in patients with rare genetic disorders with and without developmental disability: neurofibromatosis 1 and Williams-Beuren syndrome.	Van Lierde A	2013
175	Pediatric to adult care transfer in rare liver diseases: Recommendations based on insights from a European omnistakeholder event.	Vanden Wyngaert K	2025
176	Health-related quality of life in young adults with congenital central hypoventilation syndrome due to PHOX2B mutations: a cross-sectional study.	Verkaeren E	2015
177	Health care transition for patients with vascular malformations: a French multicenter cross-sectional study.	Vermersch C	2021
178	Cystinosis: a new perspective.	Veys KR	2016

#	TITLE	FIRST AUTHOR	YEAR
179	Outcomes following a multi-disciplinary pediatric-to-adult transition and transfer clinic at a level four epilepsy center.	Vickery SS	2023
180	The importance of genetic counselling for turner syndrome transition.	Villarreal EML	2025
181	The Transition of Care for Patients with Anorectal Malformations and Hirschsprung Disease: A European Survey.	Violani C	2023
182	Living a normal life in an extraordinary way: A systematic review investigating experiences of families of young people's transition into adulthood when affected by a genetic and chronic childhood condition.	Waldboth V	2016
183	"Getting ready for the adult world": how adults with spinal muscular atrophy perceive and experience healthcare, transition and well-being.	Wan HWY	2019
184	Resident and Staff Satisfaction of Pediatric Graduate Medical Education Training on Transition to Adult Care of Medically Complex Patients.	Weeks M	2018
185	From "Longshot" to "Fantasy": Obligations to Pediatric Patients and Families When Last-Ditch Medical Efforts Fail.	Weiss EM	2018
186	Long-Term Management Challenges in Esophageal Atresia.	White A	2017
187	Overview of paediatric IBD.	Wilson DC	2017
188	Exploring the perspective of adolescent childhood cancer survivors on follow-up care and their concerns regarding the transition process-A qualitative content analysis.	Winzig J	2024
189	Adult care of children from pediatric urology.	Woodhouse CR	2012
190	Finding MyVOICE: A Mixed-Methods Examination of Health Outcomes of Young Adults with Chronic Illness Transitioning from Pediatric to Adult Health Care.	Wright S	2021
191	Challenges of transition to adult health services for patients with rare diseases.	Zurynski YA	2013

Table 3.2. Excluded Articles and Detailed Reason(s) (n = 14)

#	TITLE	EXCLUSION CATEGORY	DETAILED REASON FOR EXCLUSION
1	Transition to Adult Care in Childhood-Onset Epilepsy: A Retrospective Cohort Study at a Japanese Children's Hospital.	Limited generalizability due to methods issues	Does not add new content to existing literature, and is a single center experience lacking clear guidelines that could be considered transferable to other disorders and/or centers.
2	Transitional care of adolescents with Multiple Osteochondromas: a convergent mixed-method study 'Patients', parents' and healthcare providers' perspectives on the transfer process'.	Limited generalizability due to methods issues	Single-center study with small numbers.
3	A step-wise approach for establishing a multidisciplinary team for the management of tuberous sclerosis complex: a Delphi consensus report.	Not applicable to rare bone disease	Focuses on general clinic development, not transitional care.
4	From pediatric to adult care: strategic evaluation of a transition program for patients with osteogenesis imperfecta.	Limited generalizability due to methods issues	Very small sample size with mixed results; insufficient evidence.
5	Experiences of UK-based adult transition services for interstitial lung disease in childhood: "There's a lot less cushioning".	Lack of actionable guidance provided	Exploratory impressions only; lacks actionable transition guidance.
6	The development of a transition medical home utilizing the individualized transition plan (ITP) model for patients with complex diseases of childhood.	Lack of actionable guidance provided	Conceptual discussion without direction on transition program development.
7	Factors Surrounding the Healthcare Transition From Pediatric to Adult Care in 5p- Syndrome: A Survey Among Healthcare Professionals.	Lack of actionable guidance provided	Provides perspectives but no practical recommendations.
8	Healthcare transition from childhood to adulthood in pseudoxanthoma elasticum: Patient experience and recommendations for health practitioners.	Lack of actionable guidance provided	Small sample (11/21) focused only on satisfaction, not transition processes.

#	TITLE	EXCLUSION CATEGORY	DETAILED REASON FOR EXCLUSION
9	An Adapted Model for Transition to Adult Care in Young Adults with Prader-Willi Syndrome.	Limited generalizability due to methods issues	Useful checklist but based on a single hospital's experience; limited generalizability.
10	Protocol for the development and validation procedure of the managing the link and strengthening transition from child to adult mental health care (MILESTONE) suite of measures.	Not applicable to rare bone disease	Not rare-disease specific and not relevant to rare bone diseases.
11	Mapping of the current transition of care practice for patients with pituitary disease at Endo-ERN reference centers.	Limited generalizability due to methods issues	Multicenter, but significant variation between institutions; not generalizable.
12	Addressing the psychosocial aspects of transition to adult care in patients with cystinosis.	Not applicable to rare bone disease	Interesting content, but disease-specific and not broadly applicable to rare bone diseases.
13	Healthcare transition in patients with rare genetic disorders with and without developmental disability: neurofibromatosis 1 and Williams-Beuren syndrome.	Lack of actionable guidance provided	Good overview of needs but lacks solutions or implementation strategies.
14	"Getting ready for the adult world": how adults with spinal muscular atrophy perceive and experience healthcare, transition and well-being.	Lack of actionable guidance provided	Describes challenges but provides no guidance or actionable recommendations.

Table 3.3. Included Articles After Final Screening (n = 26)

#	TITLE	FIRST AUTHOR & YEAR	JOURNAL	STUDY-TYPE	SEARCH STRATEGY
1	Transition in Sickle Cell Disease (SCD): A German Consensus Recommendation.	Alashkar F, 2022	J Pers Med	Delphi Consensus / Expert Guideline	1
2	Improving Health Care Transition for Young Patients With Sickle Cell Disease Through Quality Network.	Alvarez OA, 2025	JAMA Netw Open	Quality Improvement / Implementation Study	1
3	Optimization of the transition process of youth with liver disease in adulthood: A position paper from FILFOIE, the French network for paediatric and adult rare liver diseases.	Antonini TM, 2020	Clin Res Hepatol Gastroenterol	Delphi Consensus / Expert Guideline	1
4	Transition of patients with Duchenne muscular dystrophy from paediatric to adult care: An international Delphi consensus study.	Castro D, 2025	Eur J Paediatr Neurol	Delphi Consensus / Expert Guideline	1
5	Adapting to Adulthood: A Review of Transition Strategies for Osteogenesis Imperfecta.	Celli L, 2024	Calcif Tissue Int	Systematic / Scoping Review	1
6	Transition from pediatric to adult care in adolescents with hereditary metabolic diseases: Specific guidelines from the French network for rare inherited metabolic diseases (G2M).	Chabrol B, 2018	Arch Pediatr	Delphi Consensus / Expert Guideline	1
7	Implementation of a Portable Medical Summary for Adolescents and Young Adults With Medical Complexity in Transition to Adult Health Care.	Chouteau WA, 2019	J Pediatr Nurs	Quality Improvement / Implementation Study	2
8	Center-Based Quality Initiative Targets Youth Preparedness for Medical Independence: HEMO-Milestones Tool in a Comprehensive Hemophilia Clinic Setting.	Croteau SE, 2016	Pediatr Blood Cancer	Quality Improvement / Implementation Study	1
9	Parents' experiences with health care transition of their adolescents and young adults with medically complex conditions: A scoping review.	Ellison JL, 2022	J Pediatr Nurs	Systematic / Scoping Review	2
10	Practices, attitudes and barriers faced by internists and pediatricians in transitioning young adult patients to adult medicine.	Erspamer KJ, 2019	Int J Adolesc Med Health	Observational Study (Cross-Sectional)	2

#	TITLE	FIRST AUTHOR & YEAR	JOURNAL	STUDY-TYPE	SEARCH STRATEGY
11	Transition of care in patients with anorectal malformations: Consensus by the ARM-net consortium.	Giuliani S, 2017	J Pediatr Surg	Delphi Consensus / Expert Guideline	1
12	Transition Care for Young Persons with Rare Bone Mineral Conditions: A Consensus Recommendation from the ECTS Rare Bone Disease Action Group.	Grasemann C, 2025	Calcif Tissue Int	Delphi Consensus / Expert Guideline	1
13	Reflection on young adult transitional care in the Boston Children's Hospital Perioperative Care Coordination Clinic.	Grossklaus H, 2022	J Pediatr Nurs	Narrative Review / Expert Commentary	2
14	Childhood to adult transition in youth patients with lysosomal acid lipase deficiency: 43 recommendations from experts.	Hermida-Ameijeiras A, 2025	Orphanet J Rare Dis	Delphi Consensus / Expert Guideline	1
15	Transition of care of patients with eosinophilic gastrointestinal diseases: Challenges and opportunities.	Hiremath G, 2022	Transl Sci Rare Dis	Narrative Review / Expert Commentary	1
16	The development of a transition medical home utilizing the individualized transition plan (ITP) model for patients with complex diseases of childhood.	Hopson B, 2023	Disabil Health J	Quality Improvement / Implementation Study	2
17	Recommendations for Transitioning Young People with Primary Immunodeficiency Disorders and Autoinflammatory Diseases to Adult Care.	Israni M, 2024	J Clin Immunol	Delphi Consensus / Expert Guideline	1
18	Interventions to support young adults and families with the healthcare transition between paediatric and adult nephrology health services: A systematic scoping review.	Kinch M, 2024	J Pediatr Nurs	Systematic / Scoping Review	1
19	Transition of young adults with endocrine and metabolic diseases: the 'TRANSEND' cohort.	Le Roux E, 2021	Endocr Connect	Observational Cohort Study	1
20	Essential components of an effective transition from paediatric to adult neurologist care for adolescents with Duchenne muscular dystrophy; a consensus derived using the Delphi methodology in Eastern Europe, Greece and Israel.	Molnar MJ, 2024	Orphanet J Rare Dis	Delphi Consensus / Expert Guideline	1

#	TITLE	FIRST AUTHOR & YEAR	JOURNAL	STUDY-TYPE	SEARCH STRATEGY
21	Implementation of programmes for the transition of adolescents to adult care.	Moreno-Galdó A, 2023	An Pediatr (Engl Ed)	Narrative Review / Expert Commentary	1
22	Transition of Care to Adult Neuroimmunology.	Narula S, 2023	Semin Pediatr Neurol	Narrative Review / Expert Commentary	1
23	Results of a healthcare transition learning collaborative for emerging adults with sickle cell disease: the ST3P-UP study transition quality improvement collaborative.	Osunkwo I, 2024	BMJ Qual Saf	Interventional Trial (Cluster Randomized QI)	1
24	Turner syndrome: transition from pediatrics to adulthood.	Rubin KR, 2008	Endocr Pract	Narrative Review / Expert Commentary	2
25	Validation of the Transition Readiness and Appropriateness Measure (TRAM) for the Managing the Link and Strengthening Transition from Child to Adult Mental Healthcare in Europe (MILESTONE) study.	Santosh P, 2020	BMJ Open	Instrument Development / Psychometric Validation	1
26	Pediatric to adult care transfer in rare liver diseases: Recommendations based on insights from a European omnistakeholder event.	Vanden Wyngaert K, 2025	JHEP Rep	Consensus Workshop / Expert Guideline	1

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APPENDIX 4

AI-Assisted Tool/Resource Search Strategy and Results

Purpose

This gray literature search was conducted to identify non-paywalled, non–peer-reviewed transition toolkits, practical implementation resources, and policy/commissioning guidances/guidelines (referred hereafter as “tool search” to inform the development of a guideline to improve transitions from pediatric to adult services for people with rare diseases.

Methods

A standardized prompt was developed to instruct generative AI tools to conduct a structured open-web (“grey-literature”) search on the health-care transition from pediatric to adult services for people with rare diseases. The prompt was written to maximize reproducibility, so that different users and different tools would be able to obtain broadly comparable results when applied under similar conditions. Particular emphasis was placed on: (i) restricting the search to non-paywalled, non peer-reviewed sources; (ii) specifying the required deliverables (number and type of resources, level of detail); (iii) defining inclusion and exclusion criteria; and (iv) requiring functioning, verifiable URLs and the prohibition of fabricated links or citations.

To test robustness and consistency, the finalized prompt was applied across several generative AI platforms (Grok, Gemini, Claude, Copilot, and ChatGPT). It was observed that the professional (subscription) version of ChatGPT produced more relevant and better-structured, grey-literature outputs than the free versions of other AI tools, particularly in terms of adherence to inclusion criteria and clarity of summaries. During this process, it must be noted that, when asked to generate references, generative AI tools occasionally modified elements of the cited references (especially the URL), which sometimes rendered the links unusable. The most reliable outputs were obtained when the tools provided URLs in a clickable format, rather than as manually retyped web addresses, as these were less prone to formatting errors.

The final prompt used is referenced below:

Task:
Conduct a structured internet scan (i.e., open-web “grey-literature” search; no paywalled or peer-review databases) on the health-care transition from pediatric to adult services for people with rare diseases.

Deliverables

- ≥ 20 distinct grey-literature resources, grouped under the two headings below. For each item give:
  • Title • Publisher / organisation • 1-sentence description of why it is useful for transition work • Live URL.
- Cite every statement with an inline reference to the source you opened (no fabricated links).

Headings & inclusion criteria
• A - Transition toolkits / practical resources – check-lists, care-pathway templates, patient-organization booklets, service-specifications, etc.
• B - Guidelines, policy, commissioning documents – e.g., national action plans, clinical quality standards, position statements, annual monitoring reports that explicitly mention transition.

Exclusions
• Peer-reviewed journal articles, conference abstracts, theses.
• Duplicate postings of the same document.

Formatting
Use a table or bullet lists under each heading; keep explanations concise (≤ 40 words each).

Quality control
• Prioritize government agencies, professional bodies, national charities, NHS service specifications, or comparable international organizations.
• Verify that every link resolves (HTTP 200) and that the document discusses transition (not just general rare-disease care).

Reminder: Do not invent links or citations.

To broaden the grey-literature results, other searches were run, in which **"rare disease"** was replaced with variations of **"special healthcare needs/conditions"** and **"complex conditions."** These searches resulted in wider ranges of complex diseases.

A structured open-web grey-literature search on health-care transition from pediatric to adult services for people with rare diseases was conducted. A standardized prompt was developed and applied across several generative AI platforms (Grok, Gemini, Claude, Copilot, and ChatGPT) to retrieve non-paywalled, non–peer-reviewed documents that met predefined inclusion and exclusion criteria, specified deliverables, and required functioning, verifiable URLs. The outputs generated by these tools were manually reviewed to assess relevance, remove duplicates, and confirm that each resource explicitly addressed transition rather than only general rare-disease care, with priority given to documents from governmental agencies, professional bodies, and major charities. To broaden the evidence base, additional searches were performed in which rare disease" was replaced with terms such as "special health-care needs" and "complex conditions," thereby enabling the inclusion of transition resources developed for clinically comparable populations.

All AI gray-literature items were screened by staff against predefined inclusion criteria (pediatric to adult transition, gray-literature only, rare disease). Based on these criteria 7 of 12 Toolkits and 2 of 15 guidelines were selected.

We applied two main inclusion rules for gray-literature sources: 1) documents that provided transition toolkits or other practical resources, and 2) documents that set out guidelines, policies or commissioning requirements.

- **Result section - The screening and selection process**

In total, 27 documents on transition from pediatric to adult care in the context of rare diseases or complex long-term conditions were identified. (See Table X below).

Of the 27 documents identified, they included:

- 12 toolkits and practical resources (1–12) and
- 15 guidelines, policy, or commissioning documents (IDs 13–27).

All AI gray-literature items were screened by staff against predefined inclusion criteria (pediatric to adult transition, gray-literature only, rare disease). Based on these criteria 6 of 12 Toolkits and 2 of 15 guidelines were selected. Toolkits and guidelines that didn't meet criteria for the following reasons (general disease and not rare transition, focus on multidisciplinary care but no focus on transitional care, redundant results, video instead of toolkit/guideline) were excluded.

Found: 27 (12 Toolkits and 15 Guidelines)

Excluded: 6 Toolkits and 13 Guidelines

Retained: 6 Toolkits and 2 Guidelines

Most items were issued by national or regional health authorities or commissioning bodies (e.g., HSE Ireland, UK Department of Health and Social Care, Welsh and Scottish Governments, NHS England, Health Quality Ontario), large charities and condition-specific organizations (e.g., Cystic Fibrosis Trust, International Rett Syndrome Foundation, Child Neurology Foundation, Sickle Cell Disease Association of America), and one European Reference Network (ERN RARE-LIVER). Material came mainly from the United Kingdom and Ireland, with additional documents from the United States, Canada and European networks.

Under rule 1, eligible resources consisted of structured transition toolkits, checklists, plans of care, self-management and advocacy tools, and information leaflets for young people and families. Some tools were designed to be applicable across rare or complex conditions (e.g. the HSE Transition Guide for Rare Diseases, Ready Steady Go, Got Transition[10] youth tools), while others focused on specific rare diseases such as sickle cell disease, cystic fibrosis, Rett syndrome, inherited metabolic diseases and rare liver diseases. Common elements included readiness assessment, goal-setting, shared care planning, and guidance on legal and administrative steps around transfer.

Under rule 2, national frameworks, rare-disease strategies and action plans, service specifications and quality standards were identified. Transition was treated as a system responsibility, with expectations for early planning, clear age ranges and milestones, written transition pathways, coordination between paediatric and adult teams, and named workers or key coordinators. Rare-disease action plans in the UK nations highlighted transition as a priority, and progress reports from Wales and Scotland described work on digital care plans and wider transitions-to-adulthood strategies. Service specifications for epidermolysis bullosa and adult inherited metabolic disease services in England and the Ontario quality standard on youth-to-adult transitions gave more operational direction, including requirements for referral pathways and audit. Outcome data were rarely reported in these documents, so no synthesis of transition outcomes from gray literature was undertaken.

In Table 1, each document is described by rule (1= toolkit/practical resource; 2 = guideline/policy/commissioning document), jurisdiction, main organization, year, focus, and a short citation label for use in the text or Appendix I.

Table 1. Gray-literature sources on transition from pediatric to adult services in rare diseases

	RULE	GEOGRAPHIC AREA	ORG (MAIN)	YEAR	FOCUS	CITATION
1*	1	Ireland – national	Health Service Executive (HSE)	2018	Rare diseases – generic	1

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	RULE	GEOGRAPHIC AREA	ORG (MAIN)	YEAR	FOCUS	CITATION
2	1	UK – regional (Southampton)	Univ. Hosp. Southampton / STPN	2020	Condition-agnostic	2
3	1	UK – national	NHS Genomics Education Prog.	2025	Rare diseases – generic	3
4*	1	USA – national	Child Neurology Foundation	2020	Neurological rare diseases	4
5	1	USA – national	Child Neurology Foundation	2020	Neurological rare diseases	5
6	1	USA – national	Child Neurology Foundation	2020	Neurological rare diseases	6
7*	1	USA – national	Got Transition (US HCT Resource Center)	n.d.	Multi-condition (incl. rare)	7
8*	1	USA – national	Sickle Cell Disease Assoc. / Got Transition	2020	Sickle cell disease	8
9*	1	UK – national	Cystic Fibrosis Trust	2020	Cystic fibrosis	9
10*	1	Int. (US-based NGO)	International Rett Syndrome Foundation	2024	Rett syndrome	10
11*	1	UK – regional (London)	Evelina London / Guy's & St Thomas' NHS FT	2020	Inherited metabolic diseases	11
12	1	Europe – international	ERN RARE-LIVER	2023-24	Rare liver diseases	12
13*	2	Ireland – national	Health Service Executive (HSE)	2018	Rare diseases – generic	13

	RULE	GEOGRAPHIC AREA	ORG (MAIN)	YEAR	FOCUS	CITATION
14	2	Ireland – national	Health Service Executive (HSE)	2025	Multi-condition (incl. rare)	14
15	2	UK – UK-wide	Dept. of Health and Social Care (UK)	2021	Rare diseases – generic	15
16	2	England – national	Dept. of Health and Social Care (England)	2024	Rare diseases – generic	16
17	2	England – national	Dept. of Health and Social Care (England)	2025	Rare diseases – generic	17
18	2	Wales – national	Welsh Gov. / NHS Wales	2022	Multi-condition (incl. rare)	18
19*	2	Wales – national	NHS Executive Wales	2024	Rare diseases – generic	19
20	2	Wales – national	NHS Executive Wales	2024	Rare diseases – generic	20
21	2	Scotland – national	Scottish Government	2022	Rare diseases – generic	21
22	2	Scotland – national	Scottish Government	2024	Rare diseases – generic	22
23	2	UK – national	NICE	2016	Multi-condition (incl. rare)	23
24	2	UK – national	NICE	2023	Multi-condition (incl. rare)	24

	RULE	GEOGRAPHIC AREA	ORG (MAIN)	YEAR	FOCUS	CITATION
25	2	England – national	NHS England – Highly Spec. Services	2018	Epidermolysis bullosa	25
26	2	England – national	NHS England – Spec. Services	2018	Inherited metabolic diseases	26
27	2	Ontario (Canada) – prov.	Health Quality Ontario	n.d.	Multi-condition (incl. rare)	27

***Retained articles**

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APPENDIX 5

AI-Assisted Other Evidence Search Strategy and Results

Purpose

The purpose of this AI-assisted evidence identification process was to identify authoritative, non–disease-specific evidence sources addressing health care transition (HCT) processes, implementation considerations, and measurement approaches that could inform best practices relevant to rare bone diseases but were not captured through the peer-reviewed PubMed search.

This approach was undertaken to address gaps identified during review of the peer-reviewed literature, particularly the limited availability of consolidated implementation frameworks and transition measurement syntheses applicable across conditions and care settings.

Methods

In parallel with the structured peer-reviewed literature search, a targeted AI-assisted evidence identification process was conducted using a conversational large language model environment. This process was exploratory and hypothesis-generating in nature and was not intended to function as a comprehensive search strategy or to replace formal database or gray literature searches conducted elsewhere in this guideline.

Structured, iterative prompts were used in ChatGPT4.0 (August 2025) to identify authoritative secondary evidence sources, including systematic reviews, government-commissioned evidence reports, and consensus syntheses addressing pediatric-to-adult health care transition. Prompts emphasized the identification of sources that catalogued or evaluated transition interventions, implementation strategies, and measurement approaches across conditions rather than disease-specific programs.

The prompt used in this process is provided below to support reproducibility:

“Identify authoritative systematic reviews, government reports, or evidence syntheses that evaluate or catalog validated health care transition measurement tools or transition interventions for pediatric-to-adult care, particularly for youth with chronic conditions or special health care needs.”

When potential sources were surfaced through the AI-assisted process, each source was independently verified by the investigator through direct review of the original publication, confirmation of authorship and institutional source, and assessment of relevance to health care transition processes, implementation strategies, and measurement constructs. Only sources produced by recognized governmental or academic entities and containing systematic or structured evidence synthesis were retained.

Results

The initial AI-assisted evidence identification pass surfaced a small number of authoritative secondary evidence sources relevant to health care transition. These sources are summarized in Table 1.

Table 1. Sources Identified Through Initial AI-Assisted Evidence Discovery

SOURCE	PRODUCING ORGANIZATION	EVIDENCE TYPE	RELEVANCE TO HCT	DISPOSITION
Interventions to Improve Care Transitions for Children and Adolescents With Special Health Care Needs (2020)	Agency for Healthcare Research and Quality (AHRQ); University of Minnesota Evidence-based Practice Center	Government-commissioned systematic review	Comprehensive synthesis of HCT interventions, implementation strategies, and measurement approaches	**Included**
Cochrane Reviews on transitional care (various topics)	Cochrane Collaboration	Systematic reviews	Focused on condition-specific or adult care transitions; limited pediatric-to-adult HCT scope	Excluded
NICE transition guidance	National Institute for Health and Care Excellence (UK)	Policy and guideline documents	Health system-specific (UK); limited transferability to U.S. implementation context	Excluded
Disease-specific transition program evaluations	Various academic institutions	Narrative or program evaluations	Narrow disease focus; not generalizable across rare conditions	Excluded

This targeted discovery process identified a 2020 evidence synthesis published by the Agency for Healthcare Research and Quality (AHRQ), prepared by the University of Minnesota Evidence-based Practice Center. This report provides a systematic review of interventions designed to improve transitions from pediatric to adult health care for children and adolescents with special health care needs.

The report includes:

- Definitions and conceptual frameworks for health care transition
- Descriptions of transition intervention types and implementation strategies
- Identification of barriers and facilitators to effective transition
- Summary tables of transition outcomes and measurement approaches

The AHRQ report was reviewed in full and used as a contextual and methodological reference to support interpretation of findings from the peer-reviewed literature and to inform consideration of implementation and measurement issues relevant to rare bone disease transitions.

Findings from this source were not pooled with peer-reviewed search results and were not subjected to formal screening or abstraction but were used to ensure alignment with established transition science, terminology, and evidence synthesis standards.

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APPENDIX 6

Table of Evidence-Based Tools and Resources

(Peer-Reviewed and Gray Literature)

Table 6.1. Evidence-Based Tools and Resources (Peer-Reviewed and Gray Literature)

		REASONS FOR SELECTING THIS TOOL					
Tool	**Description**	**US based/Relevance to the US population**	**Broadly Accepted/National or international standard**	**Broadly used/Easily accessible information**	**Peer (P) and Gray (G)**	**Link/Source Article**	**Tool/Toolkit/ Guideline/Framework**
Sample Transition and Care Policy/Guide	This transition policy template that explains how a clinic will shift teens into adult-style care (privacy/consent and growing independence) while they remain with the same provider.	YES	US	YES	P	https://gottransition.org/6ce/?staying-policy	Tool
Sample Individual Transition Flow Sheet	This tool helps practices track and document each step of a youth's transition to an adult clinician, from sharing the transition policy and readiness assessments, to updating the care plan and completing the transfer package.	YES	US	YES	P	https://gottransition.org/6ce/?leaving-flow-sheet	Tool
OI Patient Profile	This tool summarizes the person's key health history and lab values (e.g., vitamin D), current supplements/medications).	YES	US	YES	P	[Document will be attached in the Appendix]	Tool
Sample Transition Readiness Assessment for Youth	A checklist used to gauge what a young person knows and can do to manage their health care as they prepare to move to an adult clinician.	YES	US	YES	P	https://gottransition.org/6ce/?staying-readiness-assessment-youth	Tool
Sample Plan of Care	This tool helps youth/young adults (with their caregiver and care team) set and track transition goals and action steps, informed by readiness/self-care assessments.	YES	US	YES	P	https://gottransition.org/6ce/?staying-plan-care	Tool
Sample Transfer of Care Checklist	A checklist used by providers to ensure a complete transfer package (e.g., readiness assessment, etc.) is prepared and sent when transitioning a youth to an adult health care clinician.	YES	US	YES	P	https://gottransition.org/6ce/?leaving-transfer-checklist	Tool

		REASONS FOR SELECTING THIS TOOL					
Tool	**Description**	**US based/Relevance to the US population**	**Broadly Accepted/National or international standard**	**Broadly used/Easily accessible information**	**Peer (P) and Gray (G)**	**Link/Source Article**	**Tool/Toolkit/ Guideline/Framework**
Sample Health Care Transition Feedback Survey for Youth/Young Adults	This tool is a survey that collects anonymous input on what the pediatric-to-adult health care transition was like and what supports could be improved.	YES	US	YES	P	https://gottransition.org/6ce/?leaving-feedback-survey-youth	Tool
Overview: Transitioning Youth to an Adult Health Care Clinician	Framework for helping youth move from pediatric care to an adult health care clinician.	YES	US	YES	P	https://www.gottransition.org/6ce/?leaving-overview	Tool
SMART model	Conceptual model outlining staged, goal-oriented transition planning and implementation.	Unknown	Emerging	Partial	P	Implementation of programmes for the transition of adolescents to adult care	Framework
Key Driver Diagram	Quality-improvement framework mapping key drivers required to achieve effective transition outcomes.	Yes	Emerging	Partial	P	Implementation of a Portable Medical Summary for AYAs with Medical Complexity	Framework
PANEL framework	Rights-based conceptual framework applying participation, accountability, non-discrimination, empowerment, and legality to transition care.	Partial	Emerging	Partial	P	Growing Up Can Be Hard to Do	Framework
Transition Readiness Assessment Questionnaire (TRAQ)	Validated self-report questionnaire assessing adolescent readiness for independent health care management.	Yes	Yes	Yes	P	Implementation of programmes for the transition of adolescents to adult care; Transition of Care to Adult Neuroimmunology	Measure
Readiness to Transition Questionnaire (RTQ)	Validated readiness assessment identifying targets for education and self-advocacy.	Partial	Emerging	Partial	P	Interventions to support young adults in nephrology transition	Measure
UNC TRxANSITION Scale	Clinician-administered scale evaluating readiness across multiple self-management and system-navigation domains.	Yes	Emerging	Partial	P	Interventions to support young adults in nephrology transition	Measure

		REASONS FOR SELECTING THIS TOOL					
Tool	**Description**	**US based/Relevance to the US population**	**Broadly Accepted/National or international standard**	**Broadly used/Easily accessible information**	**Peer (P) and Gray (G)**	**Link/Source Article**	**Tool/Toolkit/ Guideline/Framework**
Transition Readiness and Appropriateness Measure (TRAM)	Web-based, multi-informant tool assessing readiness and appropriateness of transition between mental health services.	Partial	Emerging	Partial	P	Validation of TRAM (MILESTONE study)	Measure
Transition Related Outcome Measure (TROM)	Companion outcome measure designed to assess post-transition outcomes following transfer to adult care.	Partial	Emerging	Unknown	P	Validation of TRAM (MILESTONE study)	Measure
Transition Risk Assessment Score (TRAS)	Disease-specific risk stratification score supporting transition planning in anorectal malformations.	Partial	Emerging	Unknown	P	ARM-net consortium consensus	Measure
Knowledge & Lifestyle Questionnaire	Structured questionnaire assessing disease knowledge, lifestyle factors, and self-management readiness.	Partial	Emerging	Partial	P	FILFOIE liver disease position paper	Measure
HEMO-Milestones Tool	Age-based competency framework guiding progressive skill development and transition planning in hemophilia.	Yes	Emerging	Partial	P	HEMO-Milestones quality initiative	Toolkit
STARx	Structured tool assessing adolescent transition readiness and independence skills.	Partial	Emerging	Partial	P	Implementation of programmes for the transition of adolescents to adult care; Nephrology scoping review	Toolkit
STARx-P	Parent-proxy version of STARx for adolescents unable to self-report readiness.	Partial	Emerging	Partial	P	Nephrology scoping review	Toolkit
Good2Go	Patient-held transition summary supporting continuity of care and self-management.	Yes	Emerging	Yes	P	Implementation of programmes for the transition of adolescents to adult care; OI review	Toolkit

		REASONS FOR SELECTING THIS TOOL					
Tool	**Description**	**US based/Relevance to the US population**	**Broadly Accepted/National or international standard**	**Broadly used/Easily accessible information**	**Peer (P) and Gray (G)**	**Link/Source Article**	**Tool/Toolkit/ Guideline/Framework**
OI Transfer Summary Tool	Disease-specific transfer summary supporting safe handoff in osteogenesis imperfecta.	Yes	Emerging	Partial	P	Adapting to Adulthood: OI review	Toolkit
OI MyHealth Passport	Portable patient-held medical summary supporting autonomy and continuity in OI.	Partial	Emerging	Partial	P	Adapting to Adulthood: OI review	Toolkit
Teens OI (eHealth)	Digital self-management and transition support program for adolescents with OI.	Partial	Emerging	Partial	P	Adapting to Adulthood: OI review	Toolkit
Neuroimmune transition practice tool	Structured practice tool guiding transition readiness assessment for neuroimmune conditions.	Unknown	Emerging	Unknown	P	Transition of Care to Adult Neuroimmunology	Toolkit
Multidisciplinary Transition Summary (MTS)	Comprehensive template summarizing medical, psychosocial, and functional information for transfer to adult care.	Partial	Emerging	Partial	P	Duchenne muscular dystrophy neurology consensus	Toolkit
Individual Transition Plan (ITP)	Personalized structured plan outlining goals, responsibilities, and timelines for transition.	Partial	Emerging	Partial	P	ARM-net consortium consensus	Toolkit
Portable Medical Summary (PMS)	EHR-generated concise medical summary supporting standardized information transfer.	Yes	Emerging	Partial	P	Implementation of a Portable Medical Summary for AYAs with Medical Complexity	Toolkit
TS Transition Passport	Disease-specific patient-held summary facilitating transfer of care information in Turner syndrome.	Partial	Emerging	Partial	P	Turner syndrome transition review	Toolkit
Preoperative Anesthesia Evaluation Form (PAEF)	Structured preoperative assessment supporting coordinated perioperative transition planning.	Yes	Emerging	Unknown	P	Boston Children’s perioperative transition clinic	Toolkit

		REASONS FOR SELECTING THIS TOOL					
Tool	**Description**	**US based/Relevance to the US population**	**Broadly Accepted/National or international standard**	**Broadly used/Easily accessible information**	**Peer (P) and Gray (G)**	**Link/Source Article**	**Tool/Toolkit/ Guideline/Framework**
Transition Intervention Program—Readiness for Transition (TIP-RFT)	Disease-specific readiness assessment and intervention package used in sickle cell transition programs.	Yes	Emerging	Partial	P	Improving Health Care Transition for Young Patients With SCD	Toolkit
HealthTracker	Digital platform for administering and summarizing transition readiness and outcome measures.	Partial	Emerging	Partial	P	Validation of TRAM (MILESTONE study)	Toolkit
HEEADSSS	Structured psychosocial interview framework commonly used in adolescent health assessments.	Yes	Yes	Yes	P	Implementation of programmes for the transition of adolescents to adult care	Toolkit
YouthCHAT	Digital psychosocial screening tool adaptable for transition-related assessment.	Partial	Emerging	Partial	P	Implementation of programmes for the transition of adolescents to adult care	Toolkit
Transition Guide for Rare Diseases	Practical guide with principles,roles and actions tailored totransitioning young people with rare diseases from paediatricsto adult care.	NO	Ireland	YES	G	https://www.hse.ie/eng/services/list/5/rarediseases/summary-moc-for-transition-rare-diseases.pdf	Toolkit
Child Neurology Foundation –Transition of Care Toolkit	Comprehensive, free toolkit foryouth with neurological rarediseases, families and clinicians;includes workflows, forms, and readiness tools	YES	US	YES	G	https://www.childneurologyfoundation.org/wp-content/uploads/2020/10/CNF-2020-Transition-of-Care-Toolkit.pdf	Toolkit
Sickle Cell Disease Pediatric-to-Adult Health CareTransition Family Toolkit	Disease-specific toolkit withtimelines, checklists and parent guidance. Transferable approach for other rare conditions.	YES	US	YES	G	https://www.scdcoalition.org/resources/scdc-produced-resources/transition-toolkit/	Toolkit
Cystic Fibrosis – Transition toadult care (Guide for families)	Family-focused guidancedetailing what changes attransfer, planning tips, and MDTroles—useful exemplar for rare-condition pathways.	NO	UK	YES	G	https://www.cysticfibrosis.org.uk/sites/default/files/2021-02/Transition%20to%20adult%20care%20guide%20for%20families%20and%20carers%20November%202020.pdf	Toolkit

		REASONS FOR SELECTING THIS TOOL					
Tool	**Description**	**US based/Relevance to the US population**	**Broadly Accepted/National or international standard**	**Broadly used/Easily accessible information**	**Peer (P) and Gray (G)**	**Link/Source Article**	**Tool/Toolkit/ Guideline/Framework**
Rett Syndrome – AdultTransition of Care Toolkit(fillable)	Rare-disease-specific, fillabletoolkit that structures planning,documentation and responsibilities around transferto adult care	YES	US	YES	G	https://www.rettsyndrome.org/wp-content/uploads/2024/12/Adult-Transition-of-Care-Toolkit_fillable.pdf	Toolkit
Inherited Metabolic Diseases– Your transition fromchildren's to adult services(leaflet)	Practical patient leaflet for IMDs explaining what to expect,contacts, and planning steps—useful template for rare clinics.	NO	UK	YES	G	https://www.evelinalondon.nhs.uk/resources/patient-information/02-Linked/transition-process-for-inherited-metabolic-diseases.pdf	Toolkit
Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases	National rare disease transition model defining standards, roles and pathway elements for safe transfer.	NO	Ireland	YES	G	https://www.hse.ie/eng/services/list/5/rarediseases/rare-disease-publications/model-of-care-for-transition-from-paediatric-to-adult-healthcare-providers-in-rare-diseases.pdf	Guideline
Wales Rare Diseases Action Plan 2022–2026 (Refresh Jan 2024)	Action plan explicitly targets improved transition coordination between paediatric and adult care for rare conditions.	NO	Wales	YES	G	https://performanceandimprovement.nhs.wales/functions/networks-and-planning/rare-diseases/rdin-docs/action-plan-refresh-jan-2024/	Guideline
American Epilepsy Society epilepsy transition practice tool	Specialty-specific transition practice tool developed by a professional society.	Partial	Yes	Partial	G	Transition of Care to Adult Neuroimmunology	Toolkit
American Society of Hematology (ASH) SCD Readiness Assessment	Single-page disease-specific readiness assessment used in sickle cell transition care.	Yes	Yes	Partial	G	Improving Health Care Transition for Young Patients With SCD	Toolkit

		REASONS FOR SELECTING THIS TOOL					
Tool	**Description**	**US based/Relevance to the US population**	**Broadly Accepted/National or international standard**	**Broadly used/Easily accessible information**	**Peer (P) and Gray (G)**	**Link/Source Article**	**Tool/Toolkit/ Guideline/Framework**
Got Transition Six Core Elements (6CE)	Structured framework defining six core elements for implementing and sustaining pediatric-to-adult health care transition programs.	Yes	Yes	Yes	P + G	ST3P-UP study transition quality improvement collaborative	Framework
Got Transition Process Measurement Tool (PMT)	Quantitative scoring tool assessing implementation of the Six Core Elements over time.	Yes	Emerging	Partial	P + G	ST3P-UP study transition quality improvement collaborative	Measure
OYOF-TES	On Your Own Feet – Transition Experiences Scale; an 18-item self-/parent-report questionnaire measuring young people's experiences of transition from child/adolescent services to adult care, including alignment/collaboration and preparation for transfer. Adapted and validated for CAMHS-to-AMHS transitions in Europe.	Partial	Emerging	Partial	P+G	Gerritsen et al. (2024), Psychiatry Research: adapted/validated OYOF-TES for mental health service transitions; Van Staa & Sattoe (2014), Journal of Adolescent Health: original OYOF Transfer Experiences Scale validation.	Tool

APPENDIX 7

Stakeholder Consensus Meeting Participant List

Somewhere to Go for Adults with Childhood-Onset Rare Diseases: A Guideline for the Transition from Pediatric to Adult Care for Individuals with Childhood Rare Bone Diseases

March 26-27, 2026

IN-PERSON ATTENDEES

American Society for Bone and Mineral Research

Cherisa Martin

Children's National Hospital

TjaMeika Davenport*

Darcel Jackson*

Andrew Pennington

Oscar Taube, MD

Laura Tosi, MD

Children's Nebraska

Paul Esposito, MD

Consultant

Eleanor Perfetto, PhD, MS

Everylife Foundation

Annie Kennedy

Stephanie Riodan

FDMAS Alliance

Tovah Burstein

Hospital for Special Surgery

Cathleen Raggio, MD

Hypoparathyroidism Association

Patty Keating

Michelle Rayes

Jansens Foundation

Neena Nizar, PhD

National Institutes of Health

Allison Boyce, MD

Catherine Gordon, MD

Tracy King, MD

Soft Bones

Deborah Fowler

University of South Florida

Elaine Deval, RN

Danielle Reynolds, MD

Vanderbilt University Medical Center

Margo Black, MSN, RN, CCRP

Kathryn Dahir, MD

XLH Network

Elizabeth Olear

JoBeth Souza*

Staff

Kara Ayers, PhD, Board of Directors

Melissa Bonardi

Erika Carter

Kenna Coleman

Kenneth Finkel, Board of Directors

Tracy Hart

Michael Stewart

Emily Voorde, Board of Directors

** = Patient or family representative*

VIRTUAL ATTENDEES

Children's National

Barbara Speller-Brown, NP, DNP

Got Transition

Peggy McManus

Patience White, MD

Hypoparathyroidism Association

Jaclyn Hood*

Lymphangiomatosis & Gorham's Disease Alliance

Louise Murgia

Nemours Children's Health

Jeanne Franzone, MD

Phoenix Children's Hospital

Maegen Wallace, MD

Texas Children's Hospital

Reid Sutton, MD

Staff

Gabriela Beug

Breanna Coleman

Stacie Connors

Michelle Fynan, PhD, Board of Directors

Christine Rossi, Board of Directors President

* = *Patient or family representative*

APPENDIX 8

List and Copies of Guidance-Recommended Tools

APPENDIX 8

List and Copies of Guidance-Recommended Tools

8a. Recommendation 1: Transition and Care Guide 3
Tool: Transition Guide
Sample Transition and Care Policy/Guide (Got Transition®)

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Tool: Transition Readiness Assessment
Sample Transition Readiness Assessment for Youth (Got Transition®)

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Tool: Transition Planning Checklist
Sample Plan of Care (Got Transition®)

8e. Recommendation 5: Transfer of Care 28
Tool: Transfer of Care Checklist

8f. Recommendation 6: Transfer Completion 34
Tool: Transfer Completion Tool

RECOMMENDATION 1

Transition Guide Template

"Getting Ready to See an Adult Doctor"

IN THIS SECTION

- What to Do and When?
- What Success Looks Like
- Important Things to Know
- Final Note
- Tools That Can Help
- Support and Resources
- Sample Transition and Care Policy/Guide (Got Transition®)

8A. RECOMMENDATION 1 · TRANSITION GUIDE TEMPLATE

Transition Guide Template

"Getting Ready to See an Adult Doctor"

As you get older, you will need to switch from a doctor that cares for children to a doctor that cares for adults. This is a normal and important step.

It is not something that happens all at once—it happens slowly, over time. This Guide will help you and your family talk about and get ready for this important change in your care.

What to Do and When?

Everyone is different. This list will give you an idea of what the steps are and the age you will be when you hit these steps. Some people do them sooner. Some people do them later. It's up to you and your family to decide when you are ready.

AGES 12–14

Between Ages 12–14 years, you will:

- Begin learning more about **[fill in disease]**
- Start talking with your family about your health and care
- Know the names of your doctors and other care providers and why you see them
- Know the names of your medications and treatments, and why you use them

Up until now, your parents have most likely been leading the way, by answering all the doctor's questions, making all your appointments, and giving you medications at the right time. They will still be there to help you while you start to learn more.

AGES 14–17

Between Ages 14–17 years, you will:

- Begin to manage your own health information (e.g. tracking medications, appointments, access the online portal for your health records)
- Speak directly with your doctor during visits to ask questions and provide information
- Begin thinking about how you want to manage your healthcare as an adult
- Identify the support you need and trust to help you (parents, sibling, friends)

Your parents and other family members will still support you and stay involved as you become more and more independent.

WHAT TO DO AND WHEN? · CONTINUED

AGES 16–18+

Between Ages 16–18 years and older, you will:

- Use a **Transition Readiness Tool** to assess how prepared you are to take over your own care
- Begin identifying your new adult doctors (with help from your family and doctors)
- Start learning how to:
  - Schedule appointments
  - Refill medications
  - Understand your health insurance
- Begin organizing your medical information (e.g., summaries, emergency plans)

As you become a young adult and start taking the lead, your family will still provide support, guidance, and advice.

EARLY Adulthood

Early Adulthood – You may be in college, or you might have a job, you might be in a dorm, still living at home with your parents, or looking for your first apartment. Now, you are the primary decision-maker for your health care.

- You:
  - Know about your condition and treatment needs
  - Have an adult doctor and know who to go to for your healthcare needs
  - Communicate with doctors and other healthcare providers
  - Know how to get care (Make appointments, get prescriptions, contact the insurance company)

Your parents and family help as needed, based on what you want and your needs

What Success Looks Like

A successful move to an adult doctor is not just a checklist. It has to feel right to you. Measures of success might be:

- You feel confident managing your health.
- You know who to contact when you need care.
- You are able to access care without too much trouble.
- You feel supported and connected to your doctors and the others you need.
- You can do the things you want to do with the right support

Success can look different for each individual and family—and that's okay.

Important Things to Know

- Transition can take time and may not happen all at once
- There may be challenges (e.g., insurance changes, finding adult providers), and that is common
- It is okay to ask for help and take this step-by-step
- Having even one provider or point of contact in adult care can make a big difference

Final Note

This guide is a starting point. Your transition to an adult doctor will depend on you, what you need, your disease, and where you live. The goal is to help you feel ready, supported, and confident as you move into adult care.

Tools That Can Help

There are other tools that can support you through this process. The tools all work together:

- **Transition Readiness Tool** – Helps assess what you know and what skills you are building
- **Tracking Tool** – Helps you keep track of your medical history, medications, and care
- **Planning Checklist** – Helps you prepare for finding adult doctors and helping you know what to do next
- **Transfer Package** – Includes key documents you will need to be sure a new doctor gets from the old doctor (like a medical summary, transfer letter, care plan)

Contact [Patient Group Information here] to get copies of these Tools.

Support and Resources

You do not have to do this alone. Support is available from:

Your Pediatric Care Team

- Can help you locate your records
- Can guide you in identifying adult providers
- Can help prepare your transition documents

[Insert: Patient Advocacy Organization]

- Can help you find experienced providers
- Provide condition-specific education and resources
- Offer opportunities to connect with others with similar experiences
- Can help you find local in-person and online peer support groups

8A. RECOMMENDATION 1

Sample Transition and Care Policy/Guide (Got Transition®)

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Sample Transition and Care Policy/Guide

[Practice Name] cares about you.

We will help you move smoothly from a pediatric to an adult model of health care at age 18 to continue on with our practice as a young adult. This means working with you, starting at ages 12 to 14, and your parent/caregiver to prepare for the change from a pediatric model of care to an adult model of care. A pediatric model of care is where parents/caregivers make most choices. An adult model of care is where you will make your own choices. We will spend time during visits without your parent/caregiver in the room to help you set health goals and take control of your own health care.

By law, you are an adult at age 18. We will only discuss your health information with others if you agree. Some young adults choose to still involve their parents/caregivers or others in their health care choices. To allow your doctor to share information with them, consent is required. We have these forms at our practice. For young adults who have a condition that limits them from making health care choices, our office will share with parents/caregivers options for how to support decision-making. For young adults who are not able to consent, we will need a legal document that describes the person's decision-making needs. We will help you find community resources and specialty care, if needed.

Your health matters to us. As always, if you have any questions, please feel free to contact us.

Transitioning to an Adult Approach to Health Care Without Changing Clinicians
Six Core Elements of Health Care Transition™ 3.0

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RECOMMENDATION 2

Transition Tracking Sheet (Sample)

For Individuals and Families/Caregivers

IN THIS SECTION

- Individual Information
- How to Use This Tool
- Suggested Timing
- 1. Transition Awareness
- 2. Transition Readiness (Skills & Knowledge)
- 3. Advocacy & Support
- 4. Health Management & Tracking
- 5. Adult Model of Care (Preparing for Transition)
- 6. Planning for Adult Care
- 7. Transfer of Care
- 8. Transition Outcomes (What Success Looks Like)
- Notes / Follow-Up

8B. RECOMMENDATION 2 TOOL

Transition Tracking Sheet

(Sample)

For Individuals and Families/Caregivers

DRAFT

Individual Information

PREFERRED NAME

LEGAL NAME

DATE OF BIRTH

PRIMARY DIAGNOSIS

KEY MEDICAL/SOCIAL CONSIDERATIONS

HOW TO USE THIS TOOL

This tool helps track progress over time as you prepare for adult care.

- It should be updated regularly by **the individual and/or family/caregiver**
- Not all items will apply at the same time
- Focus on **progress, not perfection**

SUGGESTED TIMING

- Early Adolescence (12–14)
- Mid Adolescence (15–17)
- Late Adolescence/Young Adult (18–21+)

This tool is filled out by the individual and/or family/caregiver. At each visit or appointment, review items together with your provider. Check the box and enter the date when an item has been discussed or completed.

1 Transition Awareness

TASK	INDIVIDUAL	PARENT/ CAREGIVER	12–14	15–17	18–21+
I discussed the transition process with my doctor	☐	☐	DATE _____	DATE _____	DATE _____
I reviewed the Transition Guide with my doctor	☐	☐	DATE _____	DATE _____	DATE _____
I discussed my goals, concerns and needs for adult care with my doctor?	☐	☐	DATE _____	DATE _____	DATE _____

2 Transition Readiness (Skills & Knowledge)

TASK	INDIVIDUAL	PARENT/ CAREGIVER	12–14	15–17	18–21+
I completed readiness assessment (name: _____) today and discussed the results with my doctor	☐	☐	DATE _____	DATE _____	DATE _____
I can describe my condition	☐	☐	DATE _____	DATE _____	DATE _____
I know my medications and their purpose	☐	☐	DATE _____	DATE _____	DATE _____
I can describe personal medical history	☐	☐	DATE _____	DATE _____	DATE _____
I can list any allergies I have (medication, food, environmental)	☐	☐	DATE _____	DATE _____	DATE _____
I feel comfortable communicating with my doctors or other healthcare providers	☐	☐	DATE _____	DATE _____	DATE _____

3 Advocacy & Support

TASK	INDIVIDUAL	PARENT/ CAREGIVER	12–14	15–17	18–21+
I am connected with a patient organization	☐	☐	DATE	DATE	DATE
I know how to connect with peer support	☐	☐	DATE	DATE	DATE
I know where to find reliable information	☐	☐	DATE	DATE	DATE

4 Health Management & Tracking

TASK	INDIVIDUAL	PARENT/ CAREGIVER	12–14	15–17	18–21+
I am using a tracking tool (medical history, meds)	☐	☐	DATE	DATE	DATE
I have a medical summary that is up-to-date	☐	☐	DATE	DATE	DATE
I have an emergency care plan	☐	☐	DATE	DATE	DATE

5 Adult Model of Care (Preparing for Transition)

TASK	INDIVIDUAL	PARENT/ CAREGIVER	12–14	15–17	18–21+
I have discussed privacy, consent, decision-making with my new adult care doctor	☐	☐	DATE	DATE	DATE
I have discussed role changes (family vs individual) with my family	☐	☐	DATE	DATE	DATE
I am familiar with my health insurance and its implications for access to care	☐	☐	DATE	DATE	DATE

6 Planning for Adult Care

TASK	INDIVIDUAL	PARENT/ CAREGIVER	12–14	15–17	18–21+
I have started to identify potential adult providers (or have already found one) based on where I will be living (e.g., home, at school or job location)	☐	☐	DATE _____	DATE _____	DATE _____
	☐	☐	DATE _____	DATE _____	DATE _____
I have identified my primary doctor or other provider contact	☐	☐	DATE _____	DATE _____	DATE _____
I have an appointment scheduled with my new adult provider	☐	☐	DATE _____	DATE _____	DATE _____

7 Transfer of Care

TASK	INDIVIDUAL	PARENT/CAREGIVER	DATE
My transfer letter from my pediatric doctor is completed	☐	☐	☐
My medical summary has been shared with my new adult doctor	☐	☐	☐
My medical records have been transferred to my new adult doctor	☐	☐	☐
I have a copy of all records that have been shared with my new adult doctor	☐	☐	☐
A transfer package has been sent to my new adult provider	☐	☐	☐

8 Transition Outcomes (What Success Looks Like)

OUTCOME	YES	IN PROGRESS	NO
I have a new doctor or other provider (or point of contact) for adult care	☐	☐	☐
I know who to contact for care	☐	☐	☐
I can access care (make appointments, get medications)	☐	☐	☐
I feel confident managing my own health	☐	☐	☐
I feel like I am able to pursue my life goals with support from my family and/or others	☐	☐	☐

Notes / Follow-Up

NOTES / FOLLOW-UP

RECOMMENDATION 3

Transition Readiness Assessment

For Individuals with Rare Bone Diseases

IN THIS SECTION

- Purpose
- How to Use
- Transition Importance & Confidence
- Domain 1: Self-Advocacy & Communication
- Domain 2: Personal & Family Medical History
- Domain 3: Allergies & Safety
- Domain 4: Navigating Health Care Systems
- Domain 5: Medication Management
- Domain 6: Advocacy Resources
- Domain 7: Peer Support & Community Connection
- Domain 8: Support Systems & Care Coordination
- What Skills Do You Want to Work On?
- Scoring & Tracking
- Sample Transition Readiness Assessment for Youth (Got Transition®)

8C. RECOMMENDATION 3

Transition Readiness Assessment

For Individuals with Rare Bone Diseases

PURPOSE

This tool is designed to help individuals, families, and providers understand readiness for transition to adult care. It is not a pass/fail test—it is a guide that can be repeated over time to track progress and inform support needs.

HOW TO USE

- Complete initially between ages 12–14 (flexible) and revisit regularly
- Can be used in a clinic, at home, or integrated into Electronic Health Records (EHR) systems
- For each statement, select one: ☐ Yes ☐ No ☐ I want to learn more

Transition Importance & Confidence

How important is it to you to manage your own health care?

10	9	8	7	6	5	4	3	2	1

Extremely Important — Neutral — Not important at all

How confident do you feel in your ability to manage your health care?

10	9	8	7	6	5	4	3	2	1

Extremely confident — Neutral — Not confident at all

Domain 1 Self-Advocacy & Communication	YES	NO	I WANT TO LEARN MORE
I can explain my condition in a way others can understand	☐	☐	☐
I can describe my care needs to a new provider	☐	☐	☐
I know how to ask questions when I don't understand something	☐	☐	☐
I can speak directly with providers during appointments (in a way that works for me)	☐	☐	☐
I can help educate a provider about my condition (e.g., explain it, share resources, or provide information in a way that works for me)	☐	☐	☐
I feel comfortable correcting or clarifying information if something is wrong	☐	☐	☐
I can advocate for myself in a real situation (appointment, school, ER, etc.)	☐	☐	☐

Domain 2 Personal & Family Medical History	YES	NO	I WANT TO LEARN MORE
I understand my diagnosis and how it affects me	☐	☐	☐
I know my past surgeries and major medical events	☐	☐	☐
I understand my current treatments and why I receive them	☐	☐	☐
I know important imaging history (e.g., DEXA, X-rays)	☐	☐	☐
I understand my family medical history (if relevant)	☐	☐	☐
I can share my medical history with a new provider	☐	☐	☐
I can summarize my health history without relying on a parent/caregiver	☐	☐	☐

Domain 3 Allergies & Safety	YES	NO	I WANT TO LEARN MORE
I know my medication allergies	☐	☐	☐
I know food/environmental allergies	☐	☐	☐
I understand condition-specific risks (e.g., anesthesia considerations, latex if relevant)	☐	☐	☐
I know what to do in a medical emergency	☐	☐	☐
I carry or can access important health information	☐	☐	☐
I can communicate my risks clearly in an emergency situation	☐	☐	☐

Domain 4 Navigating Health Care Systems	YES	NO	I WANT TO LEARN MORE
I know how to make and cancel appointments	☐	☐	☐
I know how to contact my providers	☐	☐	☐
I know how to access my medical records (portal, summary, etc.)	☐	☐	☐
I know how to fill out forms and referrals	☐	☐	☐
I understand my health insurance and how to maintain it	☐	☐	☐
I have a plan for transportation to appointments	☐	☐	☐
I have independently completed at least one health care task (appointment, refill, etc.)	☐	☐	☐

Domain 5 Medication Management	YES	NO	I WANT TO LEARN MORE
I know my medications and what they are for	☐	☐	☐
I know when and how to take them	☐	☐	☐
I know how to refill prescriptions	☐	☐	☐
I understand side effects or when to ask for help	☐	☐	☐
I manage (or participate in managing) my medications	☐	☐	☐

Domain 6 Advocacy Resources	YES	NO	I WANT TO LEARN MORE
I know at least one patient advocacy organization for my condition	☐	☐	☐
I know how to find reliable condition-specific information	☐	☐	☐
I understand what advocacy organizations can and cannot provide	☐	☐	☐
I know how to access educational resources or toolkits	☐	☐	☐
I have used an advocacy resource (website, webinar, toolkit, etc.)	☐	☐	☐

NOTE

Access to advocacy resources may vary—providers should help identify alternatives if needed.

Domain 7 Peer Support & Community Connection	YES	NO	I WANT TO LEARN MORE
I know how to connect with others with my condition (online or in person)	☐	☐	☐
I understand the difference between peer support and medical advice	☐	☐	☐
I feel comfortable seeking support from others if needed	☐	☐	☐
I have connected with a peer or community resource (if desired)	☐	☐	☐

Domain 8 Support Systems & Care Coordination	YES	NO	I WANT TO LEARN MORE
I know who supports me in managing my health	☐	☐	☐
I understand how responsibilities are shared (me vs. caregiver)	☐	☐	☐
I know who helps coordinate my care (“quarterback”)	☐	☐	☐
I am involved in discussions about transition planning	☐	☐	☐
I can identify who to contact for different types of support	☐	☐	☐

What Skills Do You Want to Work On?

(Open-ended)

WHAT SKILLS DO YOU WANT TO WORK ON?

Scoring & Tracking

Scoring key

Yes = 2	**I want to learn more** = 1	**No** = 0

SCORING & TRACKING

- Track domain scores and progress over time
- Focus on growth and identifying areas for support

8C. RECOMMENDATION 3

Sample Transition Readiness Assessment for Youth (Got Transition®)

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Sample Transition Readiness Assessment for Youth

Please fill out this form to help us see what you already know about your health, how to use health care, and the areas you want to learn more about. If you need help with this form, please ask your parent/caregiver or doctor.

Preferred name *Legal name* *Date of birth* *Today's date*

TRANSITION IMPORTANCE & CONFIDENCE *Please circle the number that best describes how you feel now.*

How important is it to you to manage your own health care?

0 | 1 ○ | 2 ○ | 3 ○ | 4 ○ | 5 ○ | 6 ○ | 7 ○ | 8 ○ | 9 ○ | 10 ○

not ——— *very*

How confident do you feel about your ability to manage your own health care?

0 | 1 ○ | 2 ○ | 3 ○ | 4 ○ | 5 ○ | 6 ○ | 7 ○ | 8 ○ | 9 ○ | 10 ○

not ——— *very*

MY HEALTH & HEALTH CARE *Please check the answer that best applies now.*	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	☐	☐	☐
I know how to ask questions when I do not understand what my doctor says.	☐	☐	☐
I know my allergies to medicines.	☐	☐	☐
I know my family medical history.	☐	☐	☐
I talk to the doctor instead of my parent/caregiver talking for me.	☐	☐	☐
I see the doctor on my own during an appointment.	☐	☐	☐
I know when and how to get emergency care.	☐	☐	☐
I know where to get medical care when the doctor's office is closed.	☐	☐	☐
I carry important health information with me every day (e.g., insurance card, emergency contact information).	☐	☐	☐
I know that when I turn 18, I have full privacy in my health care.	☐	☐	☐
I know at least one other person who will support me with my health needs.	☐	☐	☐
I know how to find my doctor's phone number.	☐	☐	☐
I know how to make and cancel my own doctor appointments.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know how to get a summary of my medical information (e.g., online portal).	☐	☐	☐
I know how to fill out medical forms.	☐	☐	☐
I know how to get a referral if I need it.	☐	☐	☐
I know what health insurance I have.	☐	☐	☐
I know what I need to do to keep my health insurance.	☐	☐	☐
I talk with my parent/caregiver about the health care transition process.	☐	☐	☐
MY MEDICINES *If you do not take any medicines, please skip this section.*			
I know my own medicines.	☐	☐	☐
I know when I need to take my medicines without someone telling me.	☐	☐	☐
I know how to refill my medicines if and when I need to.	☐	☐	☐

WHICH OF THE SKILLS LISTED ABOVE DO YOU MOST WANT TO WORK ON?

Transitioning to an Adult Approach to Health Care Without Changing Clinicians
Six Core Elements of Health Care Transition™ 3.0

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RECOMMENDATION 4

Transition Planning Checklist

(adapted from the current *Transfer of Care Checklist*)
For Individuals, Families, and Providers

IN THIS SECTION

- Individual Information
- How to Use This Tool
- 1. Understanding My Future Care Needs
- 2. Identifying Future Adult Providers
- 3. Planning for Future Living Location
- 4. Developing a Transition Plan
- 5. Obtaining Required Transition Documents
- 6. Preparing for Independence in Care
- 7. Communication with Current Provider
- 8. Progress Toward Transition
- Notes / Next Steps
- Sample Plan of Care (Got Transition®)

8D. RECOMMENDATION 4 TOOL

Transition Planning Checklist

(adapted from the current *Transfer of Care Checklist*)

For Individuals, Families, and Providers

Individual Information

PREFERRED NAME _____

LEGAL NAME _____

DATE OF BIRTH _____

PRIMARY DIAGNOSIS _____

HOW TO USE THIS TOOL

This checklist is designed to support **planning for transition to adult care**, beginning around age 16 years (or earlier based on provider transition policies).

It should be completed **over time** with input from the individual, parent/caregiver, and provider.

1. Understanding My Future Care Needs

- ☐ I understand my diagnosis and how it may affect me as an adult
- ☐ I understand what my care team should look like in adulthood (e.g., primary provider, specialists)
- ☐ I know what type of adult providers I may need

2. Identifying Future Adult Providers

- ☐ I began researching adult providers in my area (around age 16 or earlier if needed)
- ☐ I used a provider lists from:
  - ☐ Patient advocacy organizations
  - ☐ Insurance provider networks
  - ☐ Current care team recommendations
- ☐ I identified at least one potential adult provider (“anchor” provider)
- ☐ I discussed options with my current provider

3. Planning for Future Living Location

- ☐ I discussed with my provider where I expect to live in the next 3–5 years
- ☐ I considered how location may affect access to adult care
- ☐ I identified care options in that location (if different from current area)

4. Developing a Transition Plan

- ☐ I developed a basic transition plan with my provider and family
- ☐ I identified next steps and timeline for transition
- ☐ I discussed potential barriers (e.g., provider availability, insurance, transportation)

5. Obtaining Required Transition Documents

- ☐ Medical summary created or updated
- ☐ Emergency care plan created or updated
- ☐ Health care proxy / guardianship discussed or completed (if needed)
- ☐ Medical records organized and ready for transfer
- ☐ Insurance information reviewed and understood

6. Preparing for Independence in Care

- ☐ I can explain my condition or direct providers to reliable information
- ☐ I know how to schedule appointments
- ☐ I know how to refill medications
- ☐ I know how to contact my providers

7. Communication with Current Provider

- ☐ Discussed transition timeline and expectations
- ☐ Reviewed readiness and planning progress
- ☐ Asked questions about adult care and next steps

8. Progress Toward Transition

- ☐ I feel prepared to begin care with an adult provider
- ☐ I know who to contact for my care
- ☐ I feel confident navigating the healthcare system

Notes / Next Steps

NOTES / NEXT STEPS

8D. RECOMMENDATION 4

Sample Plan of Care (Got Transition®)

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Sample Plan of Care

This sample plan of care is created jointly with the youth/young adult and their parent/caregiver to set goals and outline a plan of action that combines health and personal goals. Information from the transition readiness/self-care skills assessment can be used to develop goals. The plan of care should be updated often.

Preferred name | *Legal name* | *Date of birth*

Primary diagnosis | *Secondary diagnosis*

WHAT MATTERS MOST TO YOU AS YOU BECOME AN ADULT? HOW CAN LEARNING MORE ABOUT YOUR HEALTH NEEDS AND LEARNING HOW TO USE HEALTH CARE SUPPORT YOUR GOALS?

Youth/Young Adult's Prioritized Goals	Transition Issues or Concerns	Actions	Person Responsible	Target Date	Date Completed

Clinician/Care staff name | *Date plan created/Updated*

Clinician/Care staff contact information | *Clinician/Care staff signature*

Youth/Young adult signature | *Parent/Caregiver signature*

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RECOMMENDATION 5

Transfer of Care Checklist

For Individuals with Rare Bone Diseases

IN THIS SECTION

- Purpose
- How to Use
- Section 1: Patient Information
- Section 2: Building the Transfer Package (Start Early)
- Core Documents (Required)
- Strongly Recommended Documents
- Optional / Modular Components (Use as Needed)
- Section 3: Tracking Progress
- Section 4: Transfer Package Distribution & Documentation
- Section 5: Implementation Support (Practical Guidance)
- Key Principles
- Optional: Central Resource Note (For Program Use)

8E. RECOMMENDATION 5

Transfer of Care Checklist

For Individuals with Rare Bone Diseases

PURPOSE

This checklist supports a **structured, stepwise transfer of care** from pediatric to adult providers.

It is designed to:

- Ensure all critical documents and decisions are prepared
- Reduce gaps in care
- Increase confidence for individuals, families, and providers

This is not a pass/fail tool—it supports gradual progress over time

How to Use

WHEN TO START

- Begin **~2 years before planned transfer**
- Build the transfer package over time (not all at once)

WHO IS RESPONSIBLE

- Shared responsibility between:
  - Individual/family
  - Pediatric team
  - Adult provider (when identified)

HOW TO USE THIS TOOL

- Complete in sections (modular use is encouraged)
- Adapt based on setting:
  - Full care center vs. limited-resource clinic
- Use alongside the **Transition Readiness Assessment** to identify gaps

Section 1 Patient Information

PREFERRED NAME

LEGAL NAME

DATE OF BIRTH

PRIMARY DIAGNOSIS

Section 2 Building the Transfer Package (Start Early)

CORE DOCUMENTS (REQUIRED)

☐ **Transfer letter (with date of transfer of care)**

→ *Summary letter from pediatric provider introducing patient to adult provider*
→ *Include: diagnosis, key issues, current status, recommended follow-up*
→ *Template recommended*

☐ **Transition readiness assessment**

☐ Completed to demonstrate level of readiness

☐ Include a copy to highlight areas needing support

☐ **Plan of care (including transition goals and prioritized actions)**

→ *Disease-specific; may include patient advocacy resources*

SECTION 2 · BUILDING THE TRANSFER PACKAGE · CONTINUED

CORE DOCUMENTS (REQUIRED) · CONTINUED

☐ **Medical summary + emergency care plan**

→ *High-level summary including:*

- Diagnosis and key issues
- Surgical history
- Medications
- Imaging history
- Emergency considerations

STRONGLY RECOMMENDED DOCUMENTS

☐ **Guardianship / health proxy documents**

→ *Encouraged for all individuals; begin discussion early*

☐ **Condition fact sheet (1-page preferred)**

→ *Obtain from healthcare organization or disease-specific patient group*

→ *Front/back format; include key info + links to advocacy organizations*

☐ **Medical release forms**

→ *Required for sharing records between providers*

☐ **Additional clinician records (as applicable)**

→ *Examples:*

- IEPs
- Therapy notes
- Specialty consult reports

OPTIONAL / MODULAR COMPONENTS (USE AS NEEDED)

(Designed for flexibility across settings)

☐ Provider list (current + future providers)

☐ Medication list (updated and accurate)

☐ Equipment / vendors (if applicable)

☐ Insurance information summary

Section 3 Tracking Progress

(Complete over time—not all at once)

Transfer Package Status: (to be completed by the patient with support from family)

- ☐ I have not started
- ☐ I am in progress collecting and assembling what I need
- ☐ Completed – I am done!

Section 4 Transfer Package Distribution & Documentation

- ☐ **Sent to new/potential adult provider(s)**

  Date:
- ☐ **Uploaded to the medical record system**

  Date:
- ☐ **Copy provided to family or others who may need it**

  Date:
- ☐ **Direct communication with adult provider completed**

  Date:

Section 5 Implementation Support (Practical Guidance)

FOR CLINICAL TEAMS

- Assign a **point person (if available)**:
  - Care coordinator
  - Nurse
  - Social worker
- If no dedicated role:
  - Use checklist as a **shared responsibility tool**

SECTION 5 · IMPLEMENTATION SUPPORT · CONTINUED

FOR INDIVIDUALS & FAMILIES

- Focus on **one section at a time**
- Use readiness assessment results to:
  - Identify gaps
  - Set small, achievable goals
- Determine who is in charge of the documents, how you will manage and organize documents, who will have access, who will get copies

KEY PRINCIPLES

✓ Not dependent on a “perfect system”
✓ Designed for **real-world use across settings**
✓ Supports **incremental progress over time**
✓ Emphasizes:

- Shared responsibility
- Flexibility
- Practical implementation

OPTIONAL: CENTRAL RESOURCE NOTE (FOR PROGRAM USE)

Programs may consider maintaining a **central repository of templates**, including:

- Transfer letter template
- Medical summary template
- Condition fact sheets
- Advocacy organization resources

RECOMMENDATION 6

Transfer Completion Tool

For Individuals with Rare Bone Diseases

IN THIS SECTION

- Purpose
- How to Use
- Section 1: Transfer Confirmation
- Section 2: Care Continuity (Real-World Function)
- Section 3: Key Components in Place
- Section 4: Roles & Responsibility
- Section 5: Barriers & Support Needs
- Section 6: Patient Experience & Outcomes
- Section 7: Personal Goals
- Section 8: Caregiver / Family Perspective (Optional)
- Section 9: Overall Completion Status
- Notes / Next Steps
- Key Principles

8F. RECOMMENDATION 6

Transfer Completion Tool

For Individuals with Rare Bone Diseases

PURPOSE

This tool helps in the assessment of whether the transition to adult care has been completed, communicated, and is functioning in the real-world setting. It supports practical, stepwise implementation rather than a one-time, all-or-nothing event, and emphasizes patient-centered outcomes.

HOW TO USE

- Patient completes this after transfer occurs and revisits within 3–6 months
- Can be used by individuals/families and/or providers
- Adapt use to your setting
- Select one for each item: ☐ Yes ☐ No ☐ In progress

Section 1 Transfer Confirmation	YES	NO	IN PROGRESS
A new adult provider has been identified and seen	☐	☐	☐
The transfer of care date has been documented	☐	☐	☐
The adult provider has received the Transfer Package	☐	☐	☐
The individual/family has a copy of the key documents	☐	☐	☐

Section 2 Care Continuity (Real-World Function)	YES	NO	IN PROGRESS
The individual knows how to contact the adult provider	☐	☐	☐
Follow-up appointments have been scheduled or completed	☐	☐	☐
A primary care provider has been identified and/or seen	☐	☐	☐
Medications are continued without interruption	☐	☐	☐
There is a clear plan for ongoing care and monitoring	☐	☐	☐
Insurance is active and understood	☐	☐	☐

Section 3 Key Components in Place	YES	NO	IN PROGRESS
Provider list is current and accessible	☐	☐	☐
Medication list is accurate and up to date	☐	☐	☐
Medical summary is available and shared	☐	☐	☐
Emergency care information is accessible (including digital access if available)	☐	☐	☐

Section 4 Roles & Responsibility	YES	NO	IN PROGRESS
The individual understands their role in managing care	☐	☐	☐
The care team understands its role in supporting transition	☐	☐	☐

Section 5 Barriers & Support Needs	YES	NO	IN PROGRESS
Any barriers to care have been identified (e.g., access, insurance, transportation)	☐	☐	☐
There is a plan to address the identified barriers	☐	☐	☐
Additional support/resources have been identified if needed	☐	☐	☐

Section 6 Patient Experience & Outcomes	YES	NO	IN PROGRESS
I feel confident managing my health care	☐	☐	☐
I know who to contact when I need care	☐	☐	☐
I feel connected to my adult care team	☐	☐	☐
I feel in control of my health care decisions	☐	☐	☐
I can pursue my personal goals (school, work, independence, etc.)	☐	☐	☐
My health care supports my overall well-being	☐	☐	☐

Section 7 Personal Goals

WHAT ARE YOUR CURRENT HEALTH AND LIFE GOALS?

Personal Goals — continued	YES	NO	IN PROGRESS
Do you feel your current care supports these goals?	☐	☐	☐

Section 8 Caregiver / Family Perspective (Optional)	YES	NO	IN PROGRESS
My family feels the transition was successful	☐	☐	☐
My family feels that I am supported in adult care	☐	☐	☐

SECTION 9

Overall Completion Status

Transition Status:

☐ Not completed	☐ In progress	☐ Completed

Confidence in managing adult care:

☐ High	☐ Moderate	☐ Low

Notes / Next Steps

NOTES / NEXT STEPS

KEY PRINCIPLES

- Focus on function and outcomes, not just task completion
- Build and assess progress incrementally over time
- Adapt to available resources and staffing
- Emphasize shared responsibility across the individual, family, and care team
- Recognize that success may differ between individuals and caregivers
- Use alongside readiness and transfer tools to identify gaps and guide next steps