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Measuring continuity after paediatric to adult sickle cell care transfer in Saudi Arabia: a critical narrative review

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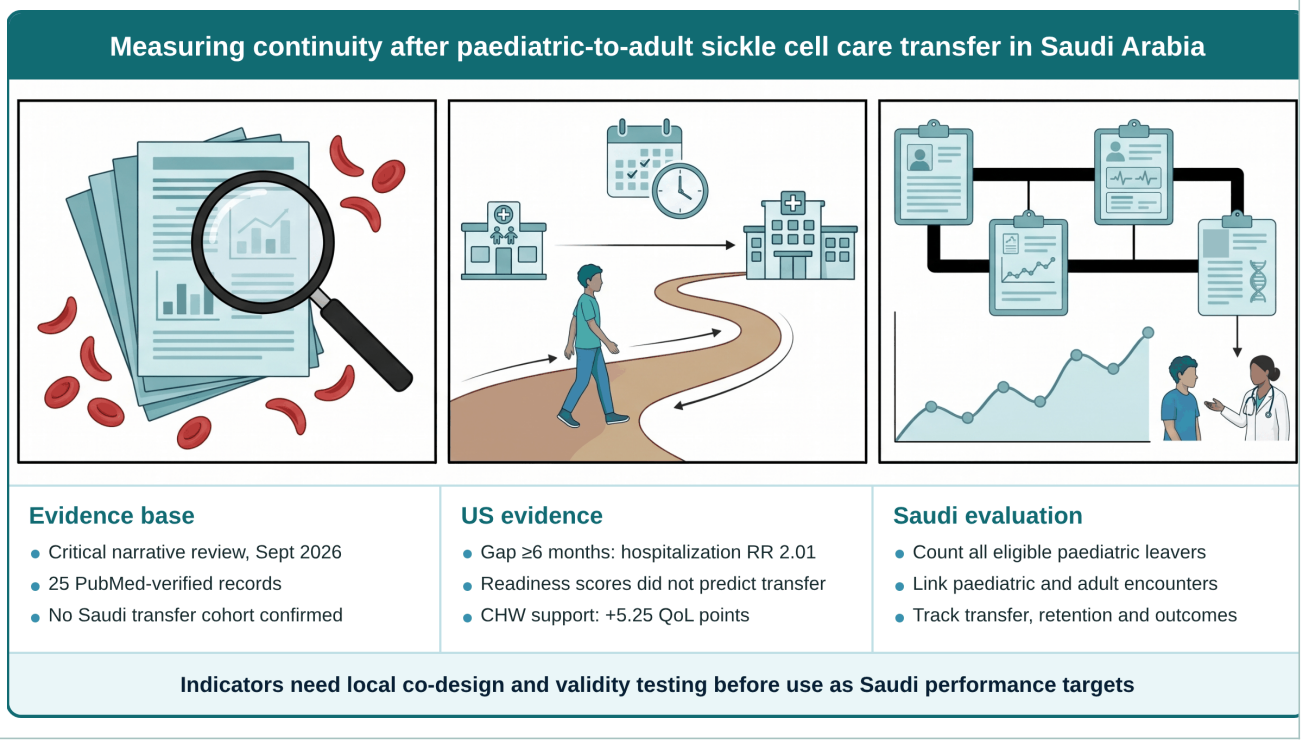
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Abstract

Graphical abstract



Background: A first adult appointment is only one part of continued care for young people with sickle cell disease (SCD). Saudi adult-service publications provide context but do not measure the paediatric-to-adult transfer interval.

Objective: To examine transition measures and propose a bounded Saudi evaluation that separates transfer, sustained engagement and patient-important outcomes. Sources and approach: We conducted purposive PubMed and SciSpace-assisted searches in a targeted literature search and checked cited identities and five accessible pivotal full texts. This is a critical narrative review, not a systematic review or Saudi guideline. Synthesis: US consensus standards combine adult visits with identification of an adult SCD medical home, but have not been validated as Saudi thresholds. In a US cohort restricted to people reaching partner adult centres, a transfer gap of at least six months was associated with more inpatient and emergency use; selection and case mix limit causal inference. Three readiness-score cohorts did not consistently predict transfer or utilization. A US randomized trial found a statistically supported but modest quality-of-life score contrast from community health worker support, below its prespecified large-effect threshold.

Conclusion: A Saudi evaluation should enumerate eligible young people, link paediatric and adult encounters, retain missing and out-of-network care, and pair time-to-contact with sustained visits, patient experience, safety and clinical outcomes. Indicators require local co-design, feasibility and validity testing before they become performance targets.

Keywords: sickle cell disease; transition to adult care; continuity of care; quality measurement; Saudi Arabia; adolescent health; health services research

Introduction

Survival with sickle cell disease has made the handover from paediatric to adult services a recurring clinical task, not an exceptional discharge. Yet the moment that a young person leaves a familiar paediatric team is

also when they may be negotiating treatment, study, employment, transport and new responsibility for contacting clinicians. In SCD, delayed access to an adult hematology service can coincide with pain episodes, transfusion needs, organ complications and difficulty obtaining timely acute care. A first adult visit says little about whether the person can return when ill, trusts the new team, or has a plan that both services recognize. The international transition literature therefore distinguishes preparation, transfer and integration into adult care [1, 2].

Saudi Arabia has its own reasons to examine this handover carefully. SCD prevalence and phenotype vary markedly between regions, so a pathway designed for one clinic's case mix may be an awkward national template [3]. A Saudi position paper on transfusion services describes variation in specialist resources and calls for stronger national data, but it is not a transition study [4]. In one adult hospital cohort, emergency use and readmission were substantial [5]; an Eastern Province clinic survey identified limited perceived service access and communication concerns [6]. These observations make continuity worth investigating. They cannot show that a gap between paediatric and adult visits caused adult admissions, because those studies did not follow a defined transfer cohort.

The difference between a plausible programme and an evaluated programme matters. An adult clinic can report that it has a transition policy, and a paediatric clinic can record that a readiness form was completed, while a young person still receives no adult appointment. Conversely, a person who receives an early appointment may have repeated emergency attendance and no continuing relationship. The question of this review is therefore not which imported checklist Saudi clinics should adopt. It is what should be measured, for whom, and with what caveats if a Saudi clinical network decides to test whether paediatric-to-adult transfer has become safer and more continuous.

This question is deliberately narrower than the 2020 global perspective, the 2021 intervention scoping review and the 2025 US consensus statement [1, 7, 8]. Those publications provide essential designs and definitions. Here we examine their transport to Saudi data systems and clinical settings, particularly where an apparent performance indicator could hide people who never reached the receiving service. We do not claim a newly discovered local prevalence, a validated Arabic readiness instrument, or evidence that a specific time threshold is appropriate for every Saudi programme.

Sources and scope

We conducted purposive PubMed and SciSpace-assisted searches. A preserved PubMed audit at 16:42:46 UTC records the exact query "sickle cell disease"[tiab] AND (transition readiness[tiab] OR transition program[tiab] OR quality indicator[tiab]), translated by PubMed as the same three quoted Title/Abstract concepts joined by OR, with 60 returned records; we received the first 50 in that page. The query ("sickle cell disease"[tiab] OR "sickle cell"[tiab]) AND (transition[tiab] OR transfer[tiab]) AND "Saudi Arabia"[tiab] returned zero Title/Abstract matches at that timestamp. A narrower phrase variant for Saudi adult transfer also returned zero. These counts describe the stored query output, not all indexed or unpublished Saudi work; title/abstract wording, indexing and later database changes can miss relevant studies. We therefore cannot infer that no Saudi transition cohort exists. Additional focused PubMed queries, semantic discovery and citation tracing supplied candidate articles. We chose sources for transition definitions, measured outcomes, intervention contrasts, close prior reviews and Saudi service context; every cited identity was resolved to a PubMed record. We did not screen every result, execute a bilingual multi-database search, use paired eligibility decisions, appraise every paper formally or calculate a pooled effect. There is no PRISMA inclusion flow for this narrative review.

Twenty-five cited primary or review records were verified for title, DOI and publication identity in PubMed. Five pivotal full texts were retrieved through permitted PubMed Central routes: the US consensus standard, transfer-gap cohort, randomized intervention trial, Saudi position paper and Eastern Province service-barrier survey. Other claims were limited to the accessible abstract or source record. The evidence is thus unevenly inspected; the source archive preserves PMIDs and full-text-access status but is not publicly deposited. We use direct estimates only where population, design, uncertainty and direction are clear, and do not interpret an abstract's concluding recommendation as a demonstrated clinical effect. The 2025 Saudi position paper itself contains discordant national-prevalence figures between abstract and body, so no national prevalence estimate is used here. Table 1 identifies the studies that most directly shape the proposed evaluation and shows why none supplies a ready Saudi benchmark.

Table 1. Pivotal evidence for measuring SCD transition and its limits for Saudi transfer

Source and design	Direct observation	Boundary for local interpretation
US provider Delphi and later centre consensus [7, 9]	Proposed process indicators and operational definitions of adult transfer and integration.	Professional agreement establishes useful candidate definitions, not a Saudi validity study or universal time target.
US transfer-gap cohort, 183 of 356 identified leavers analysed [10]	A gap ≥6 months versus <2 months was associated with higher inpatient and early adult emergency-use rates.	The 173 excluded included transfer elsewhere, untraced adult care and adolescent deaths; the adjusted association is not a causal effect of scheduling.
US co-located service cohort and 14-site improvement collaborative [11, 12]	Adult retention was associated with co-location; documented process completion rose during the collaborative.	Non-randomized retention and process measures do not show which clinical outcomes would improve in Saudi networks.
US multicentre randomized trial, 375 participants [13]	Community health worker plus enhanced usual care produced a 5.25-point greater six-month SCD quality-of-life score change than enhanced usual care (95% CI 2.05–8.45); the prespecified ten-point large-effect threshold was unmet.	A modest score contrast is not proof that this workforce model or its clinical effects transfer to Saudi settings.
Three readiness-score cohorts [14, 15, 16]	Readiness measures described skills but did not consistently predict transfer success or acute use.	Do not use an imported readiness score as an exclusion gate or assume an Arabic version is validated.

Source numbers point to primary PubMed records. “US” identifies the source setting, not an MHJ or Saudi endorsement. The table is a purposive comparison, not a meta-analysis or formal risk-of-bias rating; the estimates and programme definitions are not pooled. SCD = sickle cell disease.

What Saudi sources establish

Local context is not interchangeable with local transition evidence. The older epidemiological review describes marked geographic variation in Saudi SCD frequency and phenotype [3]. The 2025 position paper discusses gaps in access to automated red-cell exchange, training and national guidance [4]. Those are service-organization concerns that a receiving adult clinic may encounter, but the paper's focus is transfusion management, not transfer. Its abstract and body use different national prevalence figures; we therefore avoid quoting a single national prevalence number from it. A locally planned transition evaluation would have to state which genotypes and clinical services are represented rather than assuming a uniform SCD population.

The adult-care studies define several relevant outcomes without tracing them back to paediatric transfer. A single-institution retrospective cohort of 160 admitted adults reported a mean of four emergency visits annually and a 24.5% 30-day readmission figure [5]. An Eastern Province cross-sectional survey of 272 adult clinic attendees reported that only 24.6% expressed a positive view of service accessibility, while communication and stigma were concerns for subsets [6]. A southern-region study also measured adult health-related quality of life [17]. These studies differ in setting, sampling and questionnaire; none provides the denominator of all young people leaving paediatric SCD care. Their proportions should not become national baseline transition rates.

Provider experience may affect whether an early appointment becomes a useful relationship. In a Jazan convenience survey of 244 clinicians, attitudes towards people with SCD differed between staff groups and departments [18]. The study did not observe any particular patient's transfer and cannot prove that provider attitudes caused missed visits. It does, however, argue against evaluating success with appointment counts alone. Patient-reported trust and a route for urgent pain care deserve prospective measurement alongside recorded attendance. A Saudi cost-of-illness survey of 217 adults in one eastern region also documents a broader financial burden [19], but its extrapolated cost estimate is not the cost of transition and should not be entered into a local programme's cost-effectiveness model without new data.

No directly relevant Saudi paediatric-to-adult transfer cohort was confirmed by our targeted search. That sentence is a search-limit statement, not a claim that no such data exist in hospitals or unpublished records. A responsible local study would first discover whether the paediatric and adult services share identifiers, whether patients transfer between public, other-governmental and private providers, and whether a missed appointment can be distinguished from care received elsewhere. These are operational facts to verify with the data owners, not assumptions that a narrative review can fill in. Nor does a public aggregate yearbook establish an individual person's transfer history.

Transfer, integration and outcomes are different constructs

Transfer can be observed as a dated change in the service primarily responsible for care; integration requires sustained contact and a trusted adult SCD medical home. A US adult-provider Delphi study favoured communication between clinicians, first-visit timing, self-efficacy, quality of life and trust among its quality indicators; most respondents proposed a first adult visit within two months of the last paediatric visit [9]. The later US National Alliance of Sickle Cell Centers consensus defined successful transfer as two comprehensive adult SCD visits in the first year. It defined integration as completion of at least 50% of scheduled outpatient visits in the five years after transfer and the young person's identification of the adult centre as their SCD medical home [7]. Its Table 1 discusses annual visits; the overall integration definition uses the five-year period. These expert-derived US definitions are candidate audit concepts, not locally validated Saudi thresholds.

An interval threshold is attractive because it can be measured automatically. The most directly relevant US cohort analysed 183 of 356 identified paediatric leavers who reached one of two partner adult centres. Relative to a gap shorter than two months, a gap of at least six months was associated with a hospitalization rate ratio of 2.01 (95% CI 1.31–3.11) over up to eight years and 1.89 (1.17–3.04) during the first two adult-care years; the corresponding emergency-encounter rate ratio in the first two years was 1.75 (1.10–2.80) [10]. Negative-binomial models supplied these adjusted associations, not intervention effects. The 173 excluded comprised 80 transferred elsewhere, 91 lost to follow-up and two deaths in adolescence; “lost” does not establish absence of care elsewhere. Moving an appointment alone may not produce the

reciprocal rate reduction. Illness severity, support and healthcare access can influence both gap length and later use.

A separate US longitudinal record study of 339 adolescents and young adults found differing clinical-severity trajectories, including a subgroup whose severity increased over time [20]. That heterogeneity argues for measuring baseline and evolving illness burden when later encounters are compared, rather than attributing every difference to transfer timing. Its observed association between increasing severity and longer adult-care use also cautions against treating more contact as a simple marker of programme success or failure.

Other comparisons expose why site and cohort definitions are decisive. A US co-located-care analysis associated continued paediatric-provider involvement with higher 12- and 24-month adult retention among 311 transferred youth [11]. It was observational and the people taking part in a co-located model may differ from those who did not. In a Brazilian retrospective cohort of 472 eligible young adults, those who remained in paediatric care after 18 had fewer emergency and hospital encounters than those in adult care [21]. That contrast cannot be used to conclude that postponing adult transfer is protective: allocation to adult or paediatric care was not randomized, and indication, disease severity and service availability could shape both status and events. The studies point to continuity as a target for testing, not to a single safe transfer age.

Continuity should also include what happens after the first appointment. A person can attend an adult clinic once for a formal handover and return only during crises. Counting “transferred” at that first encounter would overstate integration. Conversely, a young adult who missed a scheduled hematology visit because the clinic cancelled it should not be scored as an individual failure. A denominator should start with all eligible paediatric leavers, retain those with no adult contact, and classify death, relocation and verified care elsewhere separately. Numerators should distinguish an offered appointment, a completed visit, a sustained relationship and a clinically appropriate response to acute pain or fever. None of these distinctions is captured by a single readiness score.

Readiness is useful but not a proxy for successful care

Preparation involves knowledge of SCD complications, medicines and transfusion history, but also knowing when to seek help, how to speak with a new team and where the adult clinic is. The SMART model emphasizes patient, family, provider and system factors; interviews with young people and experts found that those factors interact rather than collapse into one age-based milestone [22]. Provider interviews identified adult-clinician relationships and prior negative emergency experiences alongside self-management skills [23]. A review of transition programmes likewise describes the six core elements of policy, tracking, readiness assessment, planning, transfer and adult integration [2]. These are plausible programme components, not proof that completing six forms changes utilization.

An instrument can organize a conversation and still have weak prognostic value. In a US clinic record review of 45 young people with SCD, Transition Readiness Assessment Questionnaire scores rose with age but did not correlate with emergency use or reliance [14]. A separate longitudinal study of 95 participants found that a self-management checklist and caregiver-rated executive function did not predict adult-care engagement [15]. A Canadian retrospective cohort of 32 using the French readiness questionnaire also found no significant global-score difference between timely and delayed transfer [16]. Sample sizes and endpoints differ, so these null associations do not show that skills are unimportant. They

do show that a high score must not be used to deny transition support or to declare a patient safe after the handover.

Saudi use of a readiness measure would need translation rights and validation in the population and workflow where it will operate. A score obtained with staff assistance may mean something different from a self-completed form. Family members may be essential care partners while young adults gain autonomy; excluding them from the interview, or letting them answer for the patient without noting proxy status, can distort both service design and measurement. The programme should record language, mode of completion, help received and missing items and ask young people whether the questions reflect obstacles they face. It should then test whether an instrument adds information beyond a short discussion and whether staff act on the result. No cited study here validates an Arabic readiness threshold for Saudi SCD transfer.

What interventions show and what they leave open

The 2021 scoping review identified 30 published transition-programme articles, only two randomized trials, and frequent gaps in feasibility reporting and single-site high-risk-of-bias designs [8]. A separate systematic review mapped 44 biopsychosocial studies and noted that apparent improvements in intervention reports coexisted with low retention and residual knowledge gaps [24]. These reviews are important overlap sources; this article does not repeat their inclusion process. The source field has advanced since their search windows, but it remains heterogeneous in age, genotype, sites, programme intensity and endpoint definition. That heterogeneity makes a pooled “transition programme effect” an unsafe basis for a Saudi service commitment.

The 2025 five-site US randomized COMETS trial offers stronger intervention evidence. Among 375 randomized young adults, six months of community health worker support plus enhanced usual care yielded a 5.25-point greater SCD quality-of-life score change than enhanced usual care at six months (95% CI 2.05–8.45), with contrasts of 5.56 (1.52–9.61) and 6.14 (1.75–10.54) points at 12 and 18 months. A mobile-health arm showed a smaller six-month contrast only. Neither intervention reached the prespecified ten-point threshold for a large clinical effect, and secondary outcomes did not differ significantly [13]. The statistically supported score contrast is encouraging for this US intervention and endpoint, but is not proof of equivalent clinical benefit or effect in a Saudi clinic. Before translation, patients and clinicians would need to specify what support a navigator can deliver, including appointment coordination and responses to acute symptoms.

Quality improvement studies can change documented practice without proving patient benefit. A 14-site US collaborative increased process-measure scores over 54 months and raised documentation of readiness assessments and emergency plans [12]. Those changes show that a structured programme can be embedded in participating clinics. They do not establish reduced admissions, lower mortality or improved trust in Saudi services. A small US transition clinic series of 22 patients reported that eight of ten scheduled young adults attended an initial adult visit within 2.4 months of their last transition encounter [25]. That descriptive result is vulnerable to selection and tiny denominators; it is most useful as a reminder to report the scheduled, attended and missing groups separately.

A proposed Saudi evaluation sequence

The first task is to define the population before choosing a target. Before extraction, each participating network would specify its paediatric-service age or clinical transfer rule, confirmed SCD definition, index

date and qualifying source clinics. It could then enumerate all eligible young people, including those never referred, and record genotype, baseline severity, prior acute use, comorbidities, source clinic, intended adult service and access constraints. These are proposed confounder and reach fields, not fields shown to exist in a Saudi transition register. Refusal, deferral and relocation need dated reason categories rather than disappearance from the denominator. Otherwise a clinic can appear to have perfect post-referral attendance by excluding the hardest-to-reach young adults. A named clinical data owner must decide whether and how encounters can be linked across institutions and what consent or institutional basis is required. No such linked Saudi cohort was assembled for this article.

The second task is to record dated events: transition discussion, shared plan, adult clinician identification, referral sent and accepted, appointment offered and scheduled, clinic cancellation, first and second visits completed, patient identification of an adult SCD medical home, and a functioning acute-care plan. Each event requires its own denominator and non-completion reason. Time from last paediatric to first adult visit should be described as a distribution, not only a percentage beneath an imported cutoff. A minimum linkage audit would count identifiers matched, unmatched, duplicate, and resolved by manual authorized review. “No contact found,” confirmed care elsewhere and truly unknown follow-up should remain separate. Death and relocation should be reported as competing/disposition events with dates; person-time analyses need a prespecified censoring rule, and missing linkage must never silently become a missed-visit event. The US transferred-only cohort shows why this matters [10]. Table 2 gives a compact measurement framework for local adaptation.

Table 2. Proposed dimensions for a Saudi SCD transition evaluation

Dimension and proposed indicator	Required denominator and data	Main interpretive safeguard
Transfer access: time to first completed adult SCD visit [7, 9, 10]	All eligible paediatric leavers; dates of last paediatric and first verified adult contact, including elsewhere when possible.	Report “no contact found” separately from delayed contact; do not silently exclude deaths, moves or unlinked care.
Early continuity: completed visits, medical-home identification and acute-care pathway over an initial 12–24 months [7, 11]	Defined leaving cohort; offered, scheduled, cancelled and attended visits; patient-identified adult home, person-time and prespecified censoring.	This pragmatic early window is not the US five-year integration standard; high visit volume can reflect worsening illness.
Patient experience: trust, ease of contact, participation and burden [6, 18, 23]	Young people offered care, including non-attenders where contact is lawful; language, proxy and response mode.	Do not interpret only respondents' views as the entire leaving cohort or equate a convenience score with care quality.
Clinical and safety outcomes: pain/fever plans, acute use, hospitalization and patient-reported quality of life [5, 10, 13]	Linked encounters and outcomes with baseline severity, genotype and care context.	Associations are not treatment effects; compare programmes only with a prespecified design and case-mix plan.
Equity and reach: who is not offered or does not complete transfer [3, 4, 19]	Eligibility, region/service, access needs, loss to follow-up and verified alternative care.	Small-cell privacy, referral availability and data-linkage gaps can mimic a disparity.

This is the authors' proposed research framework, not a Saudi guideline, endorsed quality measure or validated score. The 12–24-month window is an initial feasibility horizon; five-year retention and patient-identified medical-home status would need separate longer follow-up. Citation numbers identify source concepts, not evidence that these exact indicators work locally. Measures and release of any linked data require clinical, institutional, patient and rights review. SCD = sickle cell disease.

The third task is to establish whether the pathway reaches those most at risk of interruption. A local service can map referral completion by clinic, age, genotype, prior acute use, distance to adult care, accessibility requirements and use of family support, subject to privacy and sufficient sample sizes. It should predefine

which differences matter and avoid labelling them patient non-adherence without examining cancelled clinics, referral rejection, transport or unavailable specialists. Some Saudi adult surveys suggest service access and clinician communication are worth asking about [6, 18], but their convenience samples do not supply a transition cohort's stratified baseline. Young people and families should test the proposed questions before routine collection.

The fourth task is to test effect rather than declare success from process compliance. A pragmatic stepped implementation or controlled before-after design may be feasible if clinics introduce a new shared handover at different times, but site differences and secular trends require explicit analysis. Outcomes should be chosen before seeing the data: completed adult contact, sustained engagement, patient-reported trust or quality of life, acute service use, safety events and unintended workload. An evaluation of community health worker support would need to define training, supervision, caseload and what usual care already provides; copying a US trial's label would not reproduce its intervention [13]. If a small single-site pilot is all that is feasible, its claims should remain feasibility and data-quality claims.

Finally, definitions should be reviewed with patients and service leaders before they become performance targets. The US consensus's two-visits-first-year rule can prompt local discussion, and the two-month timing preference from a US Delphi panel can motivate timely scheduling [7, 9]. Neither is an evidence-based Saudi pass mark. A 12–24-month pilot can test data capture and early continuity; it cannot certify the US five-year integration construct or replace the patient's own identification of an adult medical home. A person with severe disease may need many visits, while someone stable who can contact the adult team promptly may need fewer. An indicator should specify the clinical action after a missed visit and be tested for unintended consequences, including appointment inflation, delayed transfer to improve a metric, or extra work placed on patients. Long-term integration is a relationship with care, not merely calendar compliance.

Interpretation and limitations

This review did not find a directly verified Saudi transition cohort in its targeted sources and cannot establish that none exists. It did not perform systematic screening, a comprehensive Arabic-language search, formal study-quality rating or meta-analysis. Some cited evidence was read only at abstract level. The local adult studies concern different hospitals and populations; their outcomes are not pre-transfer baselines. The strongest intervention evidence comes from the United States, where care delivery and insurance pathways differ. Observational estimates may reflect severity, support and selection into linked care. Readiness results from small cohorts do not rule out better instruments or useful individualized conversations. The proposed Saudi indicators have not been tested for local feasibility, construct validity, case-mix adjustment, patient acceptability or predictive validity.

An accountable Saudi clinical and patient group must decide what information can be linked and whether a proposed indicator describes care actually available. The article cannot supply an ethics exemption, programme authority or implementation approval. Instrument owners may control translated items, and named authors must verify rights, exact sources and all clinical claims before submission. Its contribution is a falsifiable evaluation structure: enumerate the full leaving cohort, show transfer and retention separately, preserve unlinked care as uncertainty, and test whether support changes outcomes patients value. A human MHJ editor must determine whether that contribution is sufficiently distinct from existing global reviews and suitable for the journal's article type.

Conclusion

Saudi SCD services can learn more from an honest map of interrupted care than from a single “transition completed” percentage. The evidence supports tracking when young people first reach adult care and whether they remain able to use it, while keeping patient experience and clinical outcomes visible. Existing US timing, attendance and medical-home standards provide candidate definitions; they are not validated local thresholds. A linked, patient-informed Saudi cohort and a prespecified evaluation of any support programme are next empirical steps. The indicator set needs local co-design, feasibility and validity testing before use for quality judgments. Until then, no proposed indicator should be treated as a measured Saudi outcome or a judgment of an individual patient.

Declarations

Ethics and consent: Not applicable; this work uses publicly available literature or aggregate published information and does not involve newly collected individual patient data.

Data availability: All underlying cited sources are available online, as identified in the references.

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