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Transition and Lifelong Follow-Up in Adult Congenital Heart Disease: Designing Services Around Attrition

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Introduction

Congenital heart disease (CHD) has become, over the past four decades, a survivable condition across the lifespan rather than a childhood one: roughly 90% of infants born with a heart defect now live to reach adulthood [8]. That success has created a population that did not previously exist in meaningful numbers -- adults whose repaired or palliated hearts remain at risk of arrhythmia, heart failure, valve dysfunction, and reintervention decades after their original surgery, and who therefore need lifelong, specialist follow-up rather than a discharge summary at eighteen. The clinical problem this review addresses is not whether that follow-up matters -- guideline bodies on both sides of the Atlantic agree that it does -- but how often it actually happens, and how much is genuinely known about which service design keeps patients engaged.

Multiple independent data sources, gathered in different countries with different definitions, converge on the same uncomfortable picture: a substantial minority, and in some cohorts a majority, of adults with congenital heart disease are not in the specialist follow-up their condition warrants. This review sets those prevalence estimates, their recurring and sometimes counterintuitive predictors, and the guideline and program-design literature that has grown up around the problem, side by side, to ask what a service planner or clinician can honestly conclude about designing care around attrition rather than assuming it away.

The honest complication that motivates this review is this: transition programs are now recommended by name in national guidelines, and a structured, age-staged curriculum for delivering them has been published in detail. But the best available synthesis of the evidence -- a systematic review and meta-analysis of seventeen studies -- found that the gap between having a transition program and not having one, while large in absolute terms, did not reach conventional statistical significance. Guideline consensus on the importance of transition care has, so far, outpaced trial-grade evidence on which specific program design most durably reduces attrition.

Material and Methods

This is a narrative review drawing on a population-based US surveillance cohort (CH STRONG), a twelve-centre US cross-sectional study of gaps in ACHD care (HEART-ACHD), a single-centre Australian cohort study with structured telephone follow-up of patients lost to care, a systematic review and meta-analysis of discontinuity of follow-up during transition, an American Heart Association scientific statement on transition program design, the 2018 and 2025 AHA/ACC-led ACHD management guidelines, and a further review of barriers to follow-up, identified through the sources cited here and citation tracking between them, without a pre-registered protocol or systematic search string. All percentages, sample sizes, hazard ratios, confidence intervals, and p-values reported here are taken directly from the cited sources; none has been invented, estimated, or extrapolated.

Results

How much attrition: converging estimates from four independent cohorts

Four independent bodies of evidence, gathered with different methods in different health systems, put the scale of the problem in comparable terms. CH STRONG, a population-based surveillance cohort of US adults born with CHD between 1980 and 1997, found that half of the sample were lost to follow-up (LTF) and more than 45% had not received any cardiology care in over five years; among those who did have a recent visit, only one in three had seen a physician trained in adult congenital heart disease, and only half recalled a doctor ever discussing the need for ongoing cardiac surveillance [1]. Figure 1 sets this estimate alongside three others discussed below.

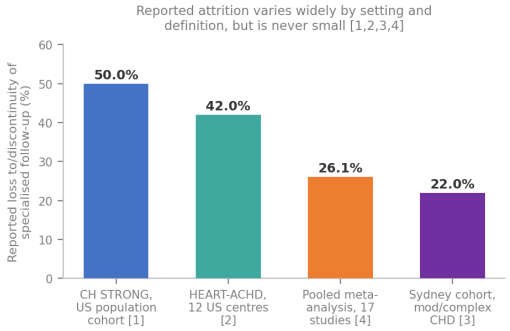

Figure 1: Reported loss to, or discontinuity of, specialised cardiac follow-up across four independent studies [1,2,3,4].

HEART-ACHD, a cross-sectional study of 922 patients across twelve US ACHD centres, found that 42% reported a gap in cardiology care exceeding three years, and 8% a gap exceeding a decade [2]. A single-centre Australian cohort of 1,842 patients with moderate or complex CHD found a smaller but still substantial 22% (407 patients) lost to specialised follow-up, defined the same way [3]. A systematic review and meta-analysis pooling seventeen studies and 6,847 patients estimated an overall discontinuity of 26.1% (95% CI 19.2-34.6%), rising to 31.9% (95% CI 24.8-40.0%) in a worst-case sensitivity analysis that counted untraceable patients as discontinued; individual study estimates ranged from 3.6% to 62.7% [4]. However the numerator and denominator are defined, no credible estimate in this literature describes attrition as a minor problem.

Who is lost: a recurring, and counterintuitive, complexity paradox

Table 1 sets the four studies' design and headline attrition estimate out together, and Table 2 sets their identified predictors alongside each other. The single most consistent, and most counterintuitive, finding across independent cohorts is that patients with milder disease are not the ones staying engaged -- they are the ones most often lost. In HEART-ACHD, 59% of patients with mild CHD reported a care gap, versus 42% with moderate and only 26% with severe disease ($p<0.0001$) [2]. The meta-analysis found the same ordering: 33.7% discontinuity with simple defects, 25.7% with moderate, and 22.3% with complex defects [4]. Figure 2 sets both findings out as parallel trends, and places beside them a second, equally striking pattern from the same meta-analysis: a roughly five-fold regional gradient, from 6.5% discontinuity in European cohorts to 25.7% in Canada and 34.0% in the United States [4].

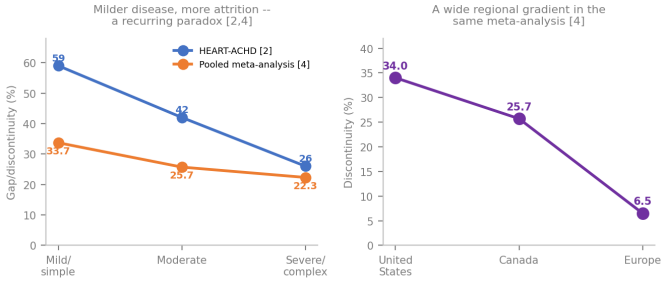

Figure 2: The disease-complexity paradox (milder disease, more attrition) replicated in two independent studies, alongside a wide regional gradient in discontinuity [2,4].

The Australian cohort adds patient-level texture to these population patterns. Cox regression identified younger age at last clinic visit (mean 30.9 years among the lost versus 35.0 years among the engaged), moderate disease complexity (hazard ratio 1.46 versus severe complexity), residence in a remote or very remote area (hazard ratio 3.12), and lower socioeconomic advantage (each one-point rise in advantage score reduced risk by 6%) as independent predictors of loss to follow-up [3]. Of 407 lost patients, researchers reached only 59 by telephone after more than 1,500 calls; those patients' own stated reasons for disengaging were feeling well (61%), simply losing track of time (36%), and believing continued care was unnecessary (25%) [3]. The meta-analysis converged on a similar list of risk factors -- male sex, lower socioeconomic status, younger age at transfer, fewer visits before transfer, and the absence of a written follow-up recommendation at the point of transfer [4]. Figure 3 illustrates, using the CH STRONG cohort, how this attrition compounds at successive steps between pediatric discharge and continued specialised adult care.

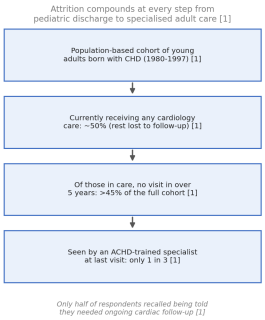

Figure 3: Attrition compounds at successive steps between pediatric discharge and continued specialised adult care, illustrated with the CH STRONG cohort [1].

Study	Setting / n	Attrition definition	Headline estimate
CH STRONG [1]	US population cohort, born 1980-97	No cardiology visit recorded / recalled	50% LTF; >45% no visit >5y
HEART-ACHD [2]	12 US ACHD centres, n=922	Self-reported gap in care >3 years	42% (8% gap >10y)
Sydney cohort [3]	1 Australian centre, mod/complex, n=1842	Database-confirmed gap in care >3 years	22% (407/1842)
Meta-analysis [4]	17 studies pooled, n=6847	Discontinuity of follow-up, varied def.	26.1% (worst-case 31.9%)

Table 1: Four independent studies of loss to, or discontinuity of, specialised ACHD follow-up [1,2,3,4].

What guidelines recommend, and what the program-design evidence actually shows

Both major ACHD practice guidelines treat transition and continuity of care as established priorities rather than optional extras. The 2018 AHA/ACC guideline gives a Class I, Level of Evidence B-NR recommendation to deliver developmentally-appropriate transition education to adolescents and young adults with CHD and their families, and a further Class I recommendation that clinicians ensure smooth transitions from pediatric to adult providers [6]. The successor 2025 ACC/AHA/HRS/ISACHD/SCAI guideline goes further in tone, explicitly framing continuity of care as "a core quality issue, not a 'nice to have,'" and naming disengagement during transition and loss of access due to geography or insurance as persistent, guideline-relevant problems rather than administrative footnotes [7]. Figure 4 sets the two guideline generations' framing of this domain out side by side.

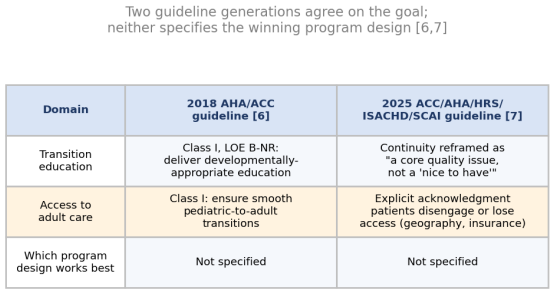

Figure 4: Successive ACHD guideline generations agree on the goal of continuity of care; neither specifies which program design achieves it most reliably [6,7].

The American Heart Association's 2022 scientific statement translates this guideline-level consensus into a detailed, age-staged transition curriculum, summarised in Figure 5: an early phase (roughly ages 12-14) focused on setting expectations and beginning independent visit time; a middle phase (15-17) in which the patient becomes the primary communicator with the care team and learns the basics of insurance and appointment-making; and a late phase (18-21) of fully independent visits, coordination of procedures, and introduction to the adult ACHD provider before transfer [5]. The same statement cites a single-centre report in which a structured, multidisciplinary transition clinic was associated with a lost-to-follow-up rate of 7%, compared with 26% among historical controls managed without such a clinic -- a large difference, though from one centre's before-and-after comparison rather than a randomized trial [5].

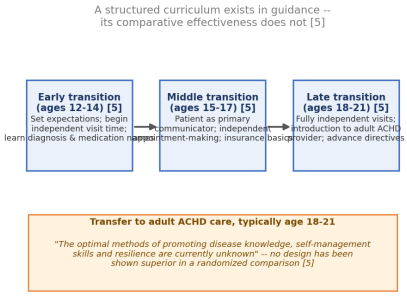

Figure 5: The age-staged transition curriculum recommended by the American Heart Association's 2022 scientific statement [5].

This is where the review's central tension becomes unavoidable. The same meta-analysis discussed above, pooling the best available comparative evidence across seventeen studies, found discontinuity of 12.7% (95% CI 2.8-42.3%) where a transition program was in place versus 36.2% (95% CI 22.8-52.2%) under usual care -- a difference of nearly threefold in absolute terms [4]. Figure 6 displays these estimates as a forest plot alongside the pooled all-studies estimate. Yet, because so few of the underlying studies were randomized and the pooled confidence intervals are wide, this difference did not reach conventional statistical significance (p=0.1119) [4]. The scientific statement itself is candid about the resulting gap: "the optimal methods of promoting disease knowledge, self-management skills and resilience are currently

unknown," because head-to-head studies comparing different program designs against each other have not been published [5]. Guideline consensus that transition programs matter has, in short, arrived well ahead of trial-grade evidence for which specific program design most durably reduces attrition.

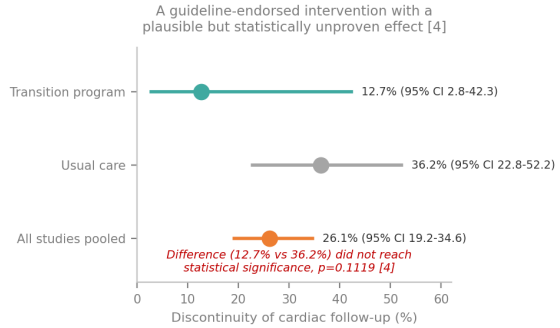

Figure 6: Discontinuity of follow-up with a structured transition program versus usual care, and the pooled all-studies estimate, with 95% confidence intervals [4].

Predictor	Direction of association	Source
Younger age at transfer / last pediatric visit	More attrition	Meta-analysis [4]; Sydney cohort [3]
Milder / lower disease complexity	More attrition (paradoxical)	HEART-ACHD [2]; Meta-analysis [4]
Lower socioeconomic status / advantage	More attrition	Sydney cohort [3]; Meta-analysis [4]
Remote/rural residence	More attrition (HR 3.12)	Sydney cohort [3]
Male sex	More attrition	Meta-analysis [4]
No written follow-up recommendation at transfer	More attrition	Meta-analysis [4]
Region: Europe vs US/Canada	Much less attrition in Europe	Meta-analysis [4]

Table 2: Predictors of loss to, or discontinuity of, specialised ACHD follow-up identified across independent studies [2,3,4].

Discussion

Taken together, this evidence supports three conclusions that a service planner or practising cardiologist can hold with genuine confidence, and one that they cannot. First, attrition from specialist ACHD follow-up is common by any measure available -- a population surveillance cohort, a multicentre cross-sectional study, a single well-characterised regional cohort, and a seventeen-study meta-analysis all put loss to, or discontinuity of, follow-up somewhere between roughly one in five and one in two patients [1,2,3,4]. Second, the patients most likely to disengage are not reliably the sickest or most complex; if anything, the opposite pattern recurs across studies designed and conducted independently of one another, which argues against dismissing milder disease as low-priority for structured follow-up planning [2,4]. Third, guideline bodies have moved decisively toward treating transition and continuity of care as a quality-of-care issue rather than a matter of individual clinician discretion, a shift visible in the difference of tone between the 2018 and 2025 ACHD guidelines [6,7].

What cannot honestly be concluded, on the evidence assembled here, is which specific transition-program design most durably reduces attrition. The pooled meta-analytic comparison of transition-program care against usual care is the best synthesis available, and it points in the direction every guideline assumes -- less discontinuity with a program in place -- but it does so without reaching statistical significance, built as it is on a small number of mostly non-randomized, heterogeneous studies with wide confidence intervals [4]. The single before-and-after transition-clinic comparison cited in the 2022 scientific statement (7% versus 26% lost to follow-up) is suggestive but is one centre's historical comparison, not a controlled trial, and the statement's own authors say plainly that no randomized comparison of competing program designs yet exists [5]. A service that adopts a structured, age-staged curriculum along AHA lines is following the only detailed template guidelines currently offer, and is doing so on a reasonable inference from the available data -- but it is not thereby acting on proof that this particular template outperforms plausible alternatives.

The regional gradient identified in the meta-analysis -- 6.5% discontinuity in Europe versus 25.7% in Canada and 34.0% in the United States -- deserves comment precisely because it is not explained by anything reviewed here about program design [4]. It sits alongside patient-level predictors such as insurance status, geographic remoteness, and socioeconomic disadvantage that point toward structural and health-system features of continuity, not curriculum content, as at least part of the explanation [3,4,7]. A transition program built entirely around adolescent education, however well designed, addresses only one layer of a problem that also includes whether an adult patient can find, afford, and reach a specialist

once transferred.

Study limitations

This is a narrative review, not a systematic review with a pre-registered protocol, and its conclusions rest on a purposively assembled set of studies rather than an exhaustive search of the transition and follow-up literature. The four attrition estimates compared in Figure 1 and Table 1 use different populations, different countries, and different operational definitions of a care gap, so the apparent range from 22% to 50% partly reflects methodology rather than a single underlying truth about how common attrition is; none of the four should be read as a universal figure applicable to every ACHD service [1,2,3,4]. The complexity paradox described here is observational and consistent across studies, but neither HEART-ACHD nor the meta-analysis was designed as a causal analysis, so the mechanism -- whether milder-disease patients are told, correctly or not, that they need less surveillance, or simply feel well enough to stop attending -- remains inferred from patient-reported reasons rather than directly tested [2,3,4].

The central evidence gap this review foregrounds is itself a limitation worth restating plainly: the meta-analytic comparison of transition programs against usual care, at 12.7% versus 36.2% discontinuity, did not reach statistical significance (p=0.1119), and the seventeen pooled studies were themselves heterogeneous in design, population, and definition of both "transition program" and "discontinuity" [4]. This review cannot, and does not, claim that transition programs have been proven ineffective -- the point-estimate difference is large and consistent with every guideline's working assumption -- but it likewise cannot claim they have been proven effective in the traditional statistical sense, and a reader should not mistake guideline endorsement for trial-grade proof of effect. The one-centre transition-clinic comparison cited in the AHA scientific statement (7% versus 26% lost to follow-up) is similarly suggestive rather than definitive, being a historical rather than randomized comparison at a single site with its own local resources and referral patterns, features that may not generalise to a differently resourced service [5]. Finally, none of the sources reviewed here directly quantifies the downstream clinical or mortality cost of a care gap in a randomized or otherwise causally interpretable way; the case for closing these gaps rests on the plausibility of surveillance catching treatable late complications, on guideline consensus, and on patients' own stated reasons for disengaging, rather than on a directly measured difference in hard outcomes between gapped and continuously-followed patients in the studies assembled here [1,2,3,4].

Conclusion

Across a population-based US surveillance cohort, a twelve-centre cross-sectional study, a well-characterised single-centre cohort, and a seventeen-study meta-analysis, loss to or discontinuity of specialised ACHD follow-up affects roughly one in five to one in two patients, is not concentrated among the most complex patients, and shows a wide, largely unexplained regional gradient. Both current ACHD guidelines now treat transition and continuity of care as core quality issues, and a detailed, age-staged transition curriculum exists in published guidance. What does not yet exist is trial-grade proof of which specific program design most durably reduces attrition: the best available comparative estimate favours transition programs by a wide absolute margin without reaching statistical significance. Services designing transition pathways should treat structured, guideline-consistent curricula as a reasonable and well-motivated default, built around the expectation that a meaningful share of patients will disengage regardless, while remaining honest that the comparative effectiveness of one program design against another has not yet been settled by evidence.

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