Supplementary S1: Additional methods details

Baseline characteristics of the cohort at birth (n = 380)

Database field	Category, if applicable	N (%) or Median (Min to Max)
Gender identity	Female	168 (44%)
	Male	210 (55%)
	Unknown	2 (1%)
Identify as Indigenous/Torres Strait Islander	No	337 (89%)
	Yes	40 (11%)
	Unknown	3 (1%)
Birth height, cm	--	50 (36 to 57)
Birth weight, kg	--	3 (1 to 36)
Head circumference, cm	--	34 (24 to 40)
Antenatal diagnosis	No	163 (43%)
	Yes	217 (57%)
Sibling number	0	129 (34%)
	1	114 (30%)
	2	53 (14%)
	3	25 (7%)
	4+	29 (8%)
	Unknown	30 (8%)
Development disability in 1st degree family member	No	344 (91%)
	Yes	33 (9%)
	Unknown	3 (1%)
Gestational age, weeks	--	38 (26 to 42)
Highest maternal education	Tertiary	131 (34%)
	High School not completed	36 (9%)
	High School	93 (24%)

Database field	Category, if applicable	N (%) or Median (Min to Max)
	TAFE/Technical College	82 (22%)
	Unknown	38 (10%)
Highest paternal education	TAFE/Technical College	103 (27%)
	Tertiary	100 (26%)
	High School not completed	48 (13%)
	High School	85 (22%)
	Unknown	44 (12%)

Model assumptions

This model represents a typical care pathway for the majority of children and is not intended to capture the full diversity of individual care trajectories. Instead, it reflects the predominant pattern observed in clinical practice. For the purposes of this study, we focused on interactions within the CHD LIFE pathway related to longitudinal screening, follow-up assessments, and referrals to early intervention services.

It was assumed that screening and assessment are delivered through the public healthcare system using existing services. In the Australian context, public hospital appointments are typically fully or partially government-funded for Australian residents.

Additionally, we assumed that the "intervention – single domain" group includes only children with mild or moderate developmental concerns and does not include severe cases.

TreeAge diagrams

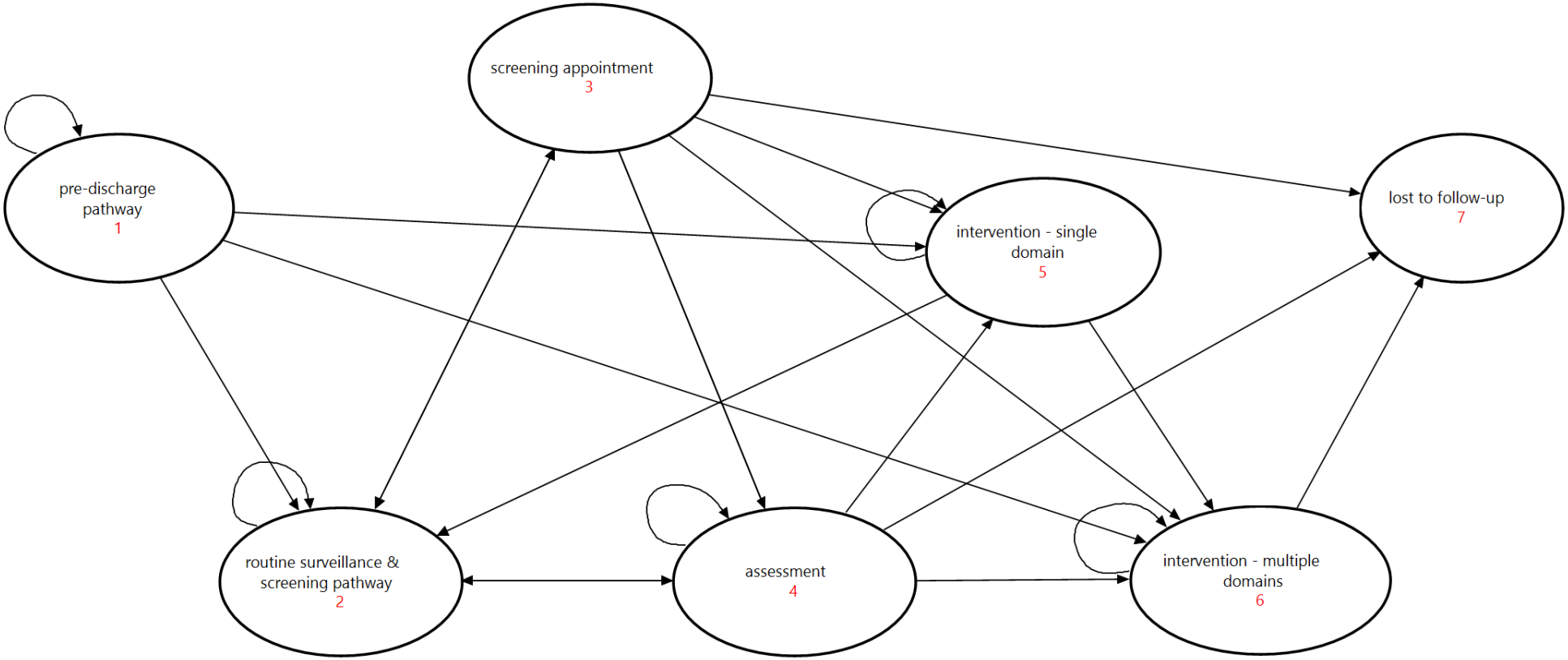


Fig 1. State transition diagram

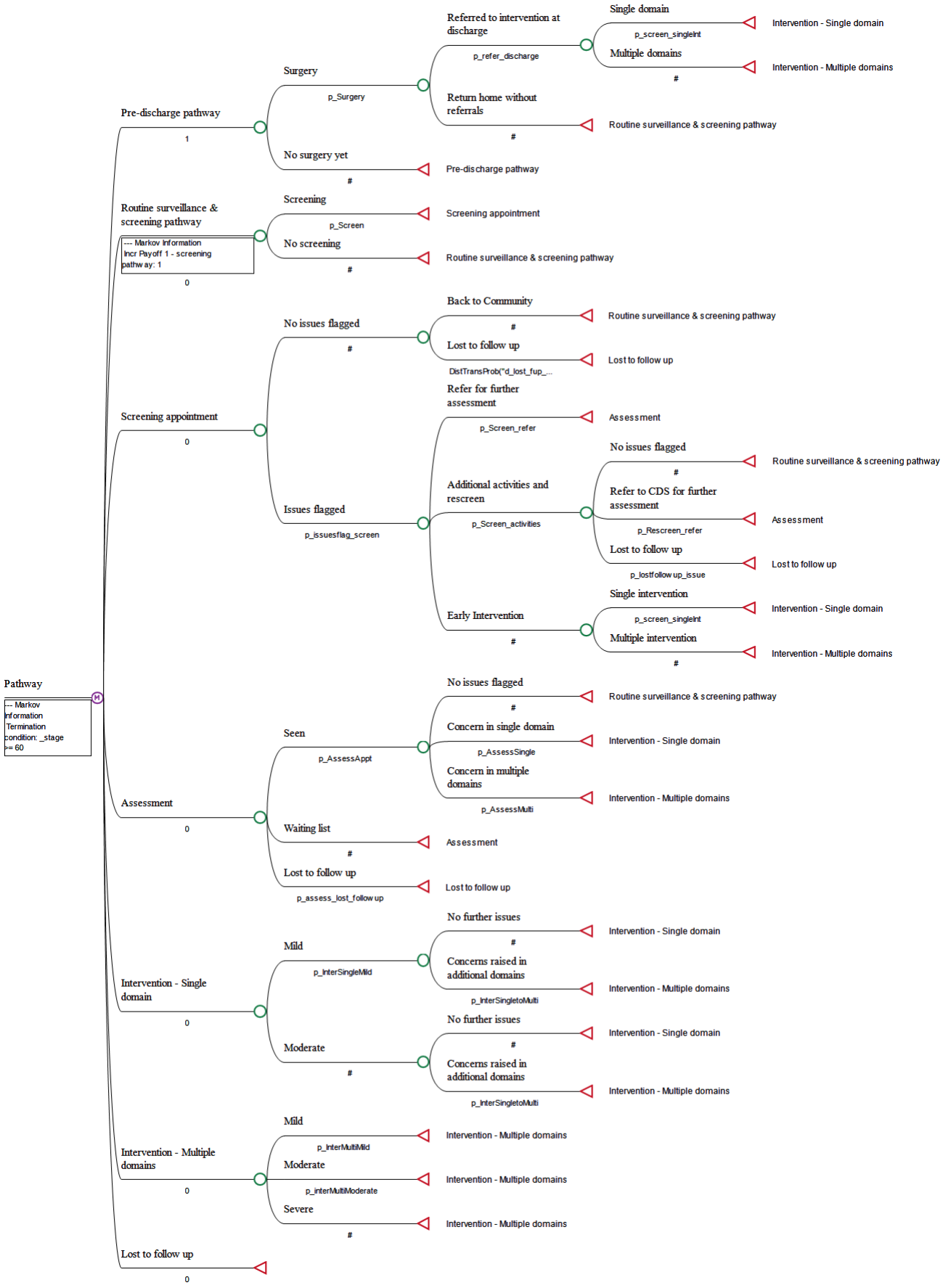


Fig 2. Possible events within each state depicting a complete overview of the pathway

Expert panel details

Expert input was sought on two occasions during the development of the model. Details of both consultations are provided below.

Expert Panel Discussion 1: Model Validation

The first expert consultation focused on validating the model structure and parameters. This was conducted through an in-person meeting with three clinical experts at Queensland Children's Hospital, Brisbane. These clinicians, who are also members of the broader research team, have experience in paediatric care and research. They reviewed all health states and associated event probabilities in the model (the final model structure is shown in Figure 2).

Key outcomes from this session included:

- The addition of a "Pre-discharge pathway" state.
- Refinement of events within the "Screening appointment" state.
- Validation of approximate values derived from the CHD LIFE database.
- Review and discussion of core model assumptions.

All decisions regarding model structure, events, and parameter estimates were made by consensus through unanimity, ensuring that no objections remained.

Following these updates, a second online meeting was held with the broader research team (n = 9), which included clinicians, health economists, and health services researchers. This session focused on confirming the final model structure. Minor refinements, such as rephrasing of terms within event labels, were suggested. All changes were reviewed and confirmed by the panel, with final decisions again reached by consensus.

Expert Panel Discussion 2: Scenario Development

The second expert consultation focused on the development of hypothetical scenarios to test the model's sensitivity to changes in service delivery. This session was held online with six experts, including clinicians, health economists, and health service researchers.

The aim was to identify model parameters that could be adjusted to explore how changes in service delivery might influence care pathway engagement. Experts reviewed each parameter

and selected those they believed would benefit from sensitivity testing. Again, decisions were made by consensus via unanimity.

The selected parameters (provided in the main manuscript, Table 2) were adjusted as follows:

- Most were increased by 20-30%.
- A few were also tested with increases of 50% and 100%, depending on their relevance and potential policy significance.

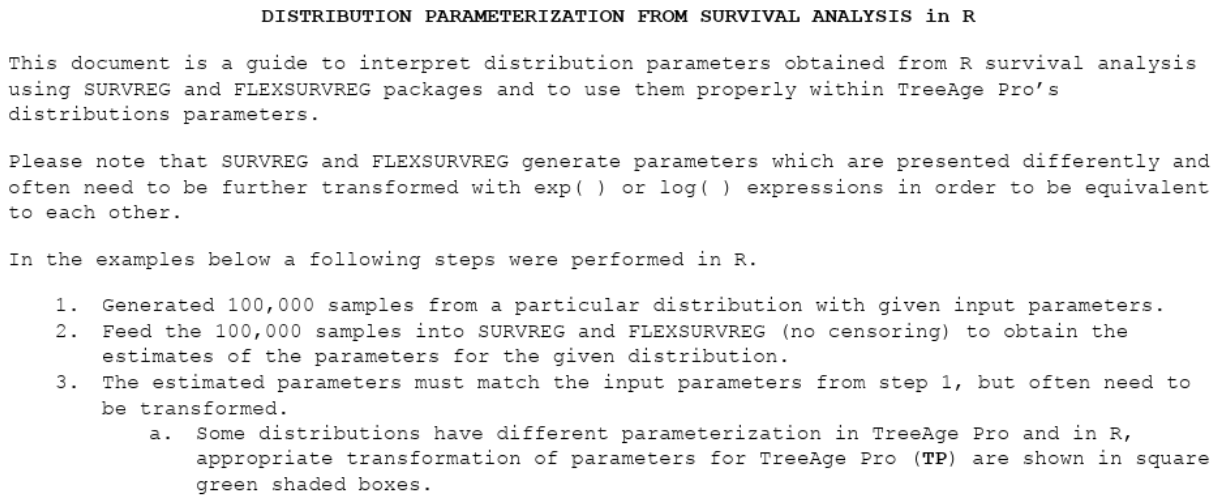
To ensure changes were clinically plausible and policy-relevant, experts considered the magnitude of variation that could realistically occur through changes in practice (e.g., increased screening uptake, improved referral processes). Most parameters were increased by 20-30%, reflecting incremental improvements which may be achieved through enhanced implementation strategies. For parameters with greater potential for system-level intervention (e.g., workforce capacity or resource allocation), larger increases of 50% and 100% were tested to represent ambitious policy shifts. This approach aligns with common practice in sensitivity analysis, where parameters are typically varied by 20-30% to assess robustness, and more optimistic scenarios (e.g., 50% or 100% changes) are explored to capture best-case or ideal scenarios (1-3).

Time varying estimates using Weibull distribution

To estimate time-varying transition probabilities using the Weibull distribution in TreeAge, survival analysis was first conducted in R using the 'survreg' function from the survival package. The resulting intercept (shape) and scale parameters were then used to parameterise the Weibull distribution in TreeAge. This approach is outlined in the table below.

Further details on this method can be found here: https://www.treeage.com/help/Content/88-Distributions-creating-editing-using/3-Distribution-parameter-options.htm

Moreover, the screenshot below is taken from a resource available within the TreeAge software that outlines the above estimation approach and serves as a useful reference.



DISTRIBUTION PARAMETERIZATION FROM SURVIVAL ANALYSIS in R

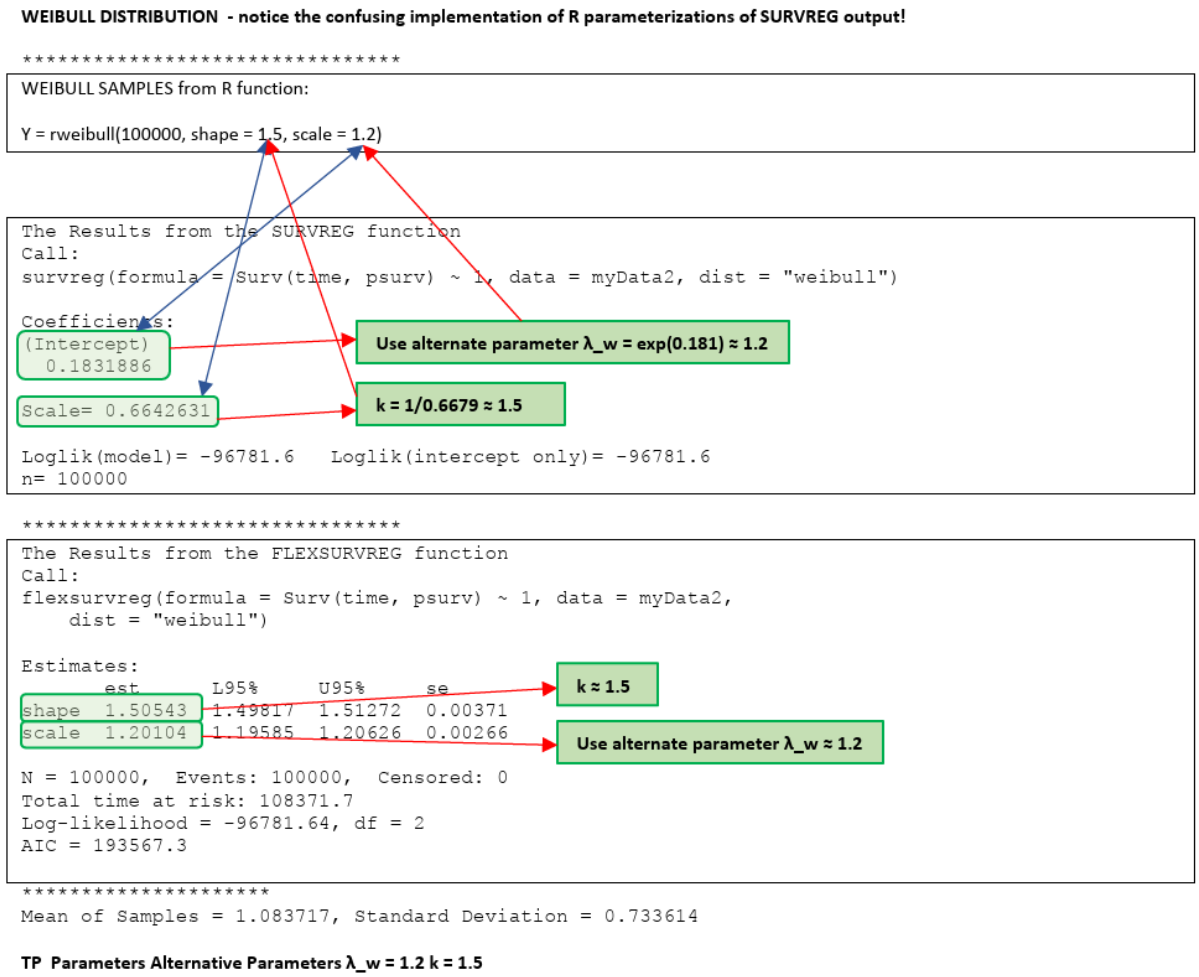
This document is a guide to interpret distribution parameters obtained from R survival analysis using SURVREG and FLEXSURVREG packages and to use them properly within TreeAge Pro's distributions parameters.

Please note that SURVREG and FLEXSURVREG generate parameters which are presented differently and often need to be further transformed with exp( ) or log( ) expressions in order to be equivalent to each other.

In the examples below a following steps were performed in R.

1. Generated 100,000 samples from a particular distribution with given input parameters.
2. Feed the 100,000 samples into SURVREG and FLEXSURVREG (no censoring) to obtain the estimates of the parameters for the given distribution.
3. The estimated parameters must match the input parameters from step 1, but often need to be transformed.
    a. Some distributions have different parameterization in TreeAge Pro and in R, appropriate transformation of parameters for TreeAge Pro (**TP**) are shown in square green shaded boxes.

Screenshot Image 1. Survival Analysis in R



Screenshot Image 2. Weibull distribution from R to TreeAge

Parameters	**From R**		**Parameterisation in TreeAge**	
	Intercept	**Scale**	**λ_w = exp(intercept)**	**k = 1/scale**
Probability of being lost to follow-up if no developmental concerns were identified	2.99	0.62	20.06	1.61
Probability of developmental concerns identified for the first time during a screening appointment via ASQ or PEDS screening tool	3.52	0.67	33.8	1.47
Probability of being lost to follow-up if developmental concerns were identified	0.53	0.67	1.71	1.49
Probability of getting seen by a health professional during an assessment appointment	2.07	0.72	7.98	1.37

The **probability of getting screened when in the routine surveillance and screening pathway** was estimated using five-year probabilities derived from the database, as shown below.

Month	Value	Month	Value
1	0	31	0.11
2	0	32	0.11
3	0	33	0.11
4	0	34	0.11
5	0.25	35	0.11
6	0.5	36	0.11
7	0.25	37	0.11
8	0	38	0.11
9	0	39	0.11
10	0	40	0.11
11	0.25	41	0.11
12	0.5	42	0.11
13	0.25	43	0
14	0	44	0
15	0	45	0
16	0	46	0
17	0.25	47	0
18	0.5	48	0.11
19	0.25	49	0.11
20	0	50	0.11
21	0	51	0.11
22	0	52	0.11
23	0	53	0.11
24	0	54	0.11
25	0	55	0.11
26	0	56	0.11
27	0	57	0.11
28	0	58	0.11
29	0	59	0.11
30	0.11	60	0.11

Detailed calculation of duration the cohort that remained in the recurring health states in the base scenario.

In TreeAge, outcomes or "rewards" can be modelled as payoffs, which may be defined either as transition payoffs or Markov state payoffs, depending on the objective of the analysis:

- **Transition payoffs** are applied once when a patient enters a particular health state (one-off states). These are typically used to model event counts or incidence rates, as they capture how many times a cohort enters a given state.
- **Markov state payoffs** are accrued during each cycle that a patient remains in a specific health state (recurring health states). These are appropriate when the aim is to understand the average duration (in cycles) that the cohort spends in a particular state.

The method used to assign payoffs will directly influence how the results are interpreted. For example, if the goal is to quantify the number of times an event (e.g., a screening appointment) occurs, a transition payoff should be used. Conversely, if the goal is to measure the duration cohort remains in a state (e.g., in intervention state), a Markov payoff is more appropriate.

To track multiple, distinct events separately (e.g., pre-discharge pathway, screening and assessment events), multiple payoffs must be defined (e.g., Payoff 1 for pre-discharge pathway, Payoff 2 for screening, etc.). Failing to separate them would result in overlapping counts, making it difficult to isolate specific event types.

More details on this are available here: https://www.treeage.com/help/Content/70-Markov-Model-Tools/27-Extra-Rewards.htm

References

1. Taylor M. What is sensitivity analysis. Consortium YHE: University of York. 2009:1-8.
2. Picot J, Cooper K, Bryant J, Clegg A. The clinical effectiveness and cost-effectiveness of bortezomib and thalidomide in combination regimens with an alkylating agent and a corticosteroid for the first-line treatment of multiple myeloma: a systematic review and economic evaluation. Health technology assessment (Winchester, England). 2011;15(41):1.
3. Hamby D. A comparison of sensitivity analysis techniques. Health physics. 1995;68(2):195-204.