Definitions for Follow-up Studies

Term	Definition	Explanation	Calculation
Eligible	Meets the criteria for this study phase, and has not died or withdrawn before this study phase.		Eligible = Awaiting Follow-Up + Active Follow-Up
Awaiting Follow-Up	Participant is eligible but has not yet reached the minimum age for active follow-up		
Active Follow-Up	Participant is eligible and has reached the minimum age for active follow-up for this study phase.	Minimum age for active follow-up may be earlier than the minimum assessment age window eg if the planned assessment window is 23-25 months, active follow-up might start from 20 months.	Active Follow-Up = Withdrawn + Declined + In Progress + Lost + Not Assessed + Assessment Completed
Reached Minimum Assessment Age	Participant is eligible and has reached the minimum assessment age	Defined for each study as the start of the planned assessment window eg 23 months for assessment window of 23-25 months.	Subset of Active Follow-Up
Withdrawn	Participant has made an informed decision they do not want any further involvement in the study.	Participant should not be contacted again in the future. They should be asked whether they wish to be informed of the results at the end of the study.	Can have withdrawn before this study phase (thus not eligible) or after contact for this study phase
Died			Can have died before this study phase (thus not eligible) or after the minimum age for active follow-up
Declined	Participant has stated they do not want to take part in this phase of the study.	Participant is eligible to be contacted for future follow up.	
In Progress	Actively being traced or assessed		In Progress = Tracking + Booked + Incomplete + Overseas
Tracking	Participant is being traced and consent is being sought		Subset of In Progress
Booked	Participant has consented and an appointment has been made.		Subset of In Progress
Incomplete	Participant has completed part of this phase of the study, but further data are expected.	E.g. Questionnaires still coming or waiting for a further appointment.	Subset of In Progress
Overseas	Participant is overseas but has not declined and may still be assessed		Subset of In Progress
Lost	After all attempts, there are no positive leads regarding the participant's whereabouts.	Unlikely to acquire data, although a further attempt may be made in the future.	
Not Assessed	Data are not going to be available for this study phase	Eg past time window	
Assessment Completed	All data that are expected for that participant have been collected.	Some elements of the data may still be missing, but they are not expected, and reasons for this will be recorded. May or may not have the minimum dataset.	
Some Data Available	Some data is available for this participant.	Participant has consented and some elements of the data have been collected eg questionnaires. Some may still be coming. May or may not include the minimum dataset.	Percentage calculated as Some Data Available / Reached minimum assessment age
Minimum Data Available	Minimum dataset as defined for this study is available for this participant.	Additional data may still be coming, or may already be collected . Minimum data will usually be what is needed to assess the primary outcome.	Percentage calculated as Minimum Data Available / Reached minimum assessment age

Follow-Up Coordinator Report

Participants		Progress Status (In Progress)					Assessment Status						Data Status	
Active Follow-Up	Reached Minimum Assessment Age	Total	Tracking	Booked	Incomplete	Overseas	Withdrawn	Died	Declined	Lost	Not Assessed	Assessment Completed	Some Data Available N (%)	Minimum Data Available N (%)