THE IDEAL-2 STUDY

IDEAL STUDY PARTICIPANTS
As part of IDEAL assessed at T1 (baseline), T2 (12 month follow up) and T3 (24 month follow up) Participants who agreed to be re-contacted will be invited

NEW PARTICIPANTS
With mild-to-moderate dementia from at least one of the following groups: having diagnosis of frontotemporal dementia, dementia with Lewy bodies or Parkinson’s disease dementia OR being ≥90 years old OR under 65 years old

Recruited and consented by NHS research network staff

STUDY ONE
IDEAL-2 COHORT

STUDY TWO
DETERMINANTS OF SERVICE USE PATTERNS AND COSTS
The study will use data collected at T4, T5 and T6 from participants who took part in Study One.

QUALITATIVE IN-DEPTH INTERVIEWS AND OBSERVATIONS
Throughout the study with a small number of selected participants
Recruitment, consent and interviews conducted by researchers from IDEAL-2 team at participant’s home/care home

QUANTITATIVE ASSESSMENTS
At T4, T5 and T6 (each 12 months apart) Conducted by NHS research network staff at participant’s home/care home
T4 occurs 24 months after T3

STUDY THREE
CO-PRODUCTION OF NEW MEASURES OF LIVING WELL
Conducted by people with dementia (as co-creators/co-researchers) and researchers from IDEAL-2 team
Co-produced measures of living well will be used by NHS research network staff with IDEAL-2 cohort participants from T5 onwards

STUDY FOUR
PERSPECTIVES OF PEOPLE WITH ADVANCED DEMENTIA
Conducted by researchers from IDEAL-2 team/NHS research network staff in local care homes in South West England
The communication tool developed here will be used by NHS research network staff with IDEAL-2 cohort participants with advanced dementia living at home or in residential care from T5 onwards

STUDY FIVE
PERSPECTIVES OF PEOPLE WITH DEMENTIA FROM BLACK, ASIAN AND MINORITY ETHNIC GROUPS
Conducted by researchers from IDEAL-2 team
Based on questions used in IDEAL/IDEAL-2 we will develop a culturally acceptable survey

STUDY SIX
PERSPECTIVES OF PEOPLE LIVING WITH UNDIAGNOSED DEMENTIA
Conducted by researchers from the IDEAL-2 team
Based on data collected as part of CFAS-Wales
Conduct of in-depth interviews with CFAS-Wales participants to understand experiences of those with undiagnosed dementia