

The nutritional care of people living with dementia at home

Appendix A

PhD Project Proposal submitted as part of the RDC1 process
Plymouth University

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Student name: Louise Wilkinson, RD, BSc (Hons)^{3,4}

Student Number: 268821

Supervisory team: Mary Hickson, RD, BSc (Hons)^{3,4}, PhD, Bridie Kent, RN, BSc (Hons), PhD^{1, 2, 3}; Rebecca Abbott, BSc (Hons), PhD³

1. School of Nursing and Midwifery, Plymouth University
2. Centre for Health and Social Care Innovation, Plymouth University: an affiliated centre of the Joanna Briggs Institute
3. Collaboration for Leadership in Applied Health Research and Care, South West Peninsula (PenCLAHRC), The National Institute for Health Research (NIHR)
4. School of Health Professions, Plymouth University

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1.0 Background

There are an estimated 850,000 people living with dementia in the UK , and this figure is forecast to increase to over 1 million by 2025 (Prince et al., 2014). The behavioural and psychological symptoms of dementia may be caused by a number of progressive diseases, the two most common being Alzheimer's disease and vascular dementia. The many symptoms of dementia can be grouped as the following: affective (e.g. apathy, hallucinations, sleeping disorders), psychosis, hyperactivity (e.g. irritability, aggression and anxiety), and euphoria (van der Linde et al., 2014). There is little commonality between symptom presentation, rendering dementia a highly individualised disease. The average duration of the disease from diagnosis to mortality is ten years, however many people will live with dementia for years prior to diagnosis (Alzheimer's Society, 2016). Two thirds of people with dementia are thought to be living at home, with an estimated 670,000 family and friends taking the role of primary carer (Prince et al., 2014). This role includes meeting the individual's health, emotional and social needs, which become more complex and demanding as the dementia progresses, and can have profound impacts on the individual, their family, and their carers (Fauth and Gibbons, 2014).

The nutritional needs of an individual with dementia should be an integral consideration of the holistic care provided at all stages of the disease. Maintaining an individual's nutritional status includes preventing unintentional weight loss (fat and muscle), and meeting fluid and micronutrient requirements. The inter-dependant relationship between the decline in nutritional status and cognition has been explored (Lee et al., 2009, Spaccavento et al., 2009), and this decline can begin in the early stages of the disease (before formal diagnosis), which if not addressed can increase the rate of progression to mortality, as well as increasing the risk of clinical vulnerability e.g. risk of falls, infections and pressure sores. Across all care settings, the main symptoms of dementia that can affect nutritional status include: memory decline, loss of motor skills, visuospatial ability, taste changes, changes in appetite, swallowing problems, myoclonus (involuntary muscle movements), and restless behaviours (e.g. pacing). The management of these symptoms (and others) will vary dependant on the care setting, and previous systematic reviews have focused on Randomised Controlled Trials (RCT's) carried out across all care settings (residential homes, ward environments and own homes), but include minimal analysis of studies specific to a 'own home' setting (Bunn et al., 2016, Abdelhamid et al., 2016). Carer surveys have indicated that there is a need for increased primary care support relating to the nutritional needs and consequences associated with dementia in those living at home (Alzheimer's Society, 2012). The nutritional status of dementia caregivers and that of the person with

dementia has been shown to be associated (Rullier et al., 2013); this may be due to increasing stress and caregiver burden. Providing increased support regarding nutrition to caregivers could reduce feelings of burden, increase knowledge and improve nutritional outcomes for both patients and caregivers. To further reduce the burden experienced by family caregivers, domiciliary care support may be used, and can contribute to helping someone with dementia maintain an adequate nutritional status whilst living at home. Best practice guidelines have been published to support managers of domiciliary care agencies (Skills for Care, 2014), however there is limited literature that evaluates the nutritional care that these agencies provide, as well as capturing the views and experiences of domiciliary carers.

The purpose of this investigation is to provide new insights into what is known about meeting the nutritional needs of people living in their own homes with dementia, and to determine the experiences of those involved. The outcomes from these investigations will inform a second phase of the investigations; the design of an intervention (using the MRC Complex Interventions Framework) which will aim to improve the nutritional care of people with dementia who live at home. The intervention will be piloted and its feasibility evaluated. This project is based on James Lind Alliance research priorities for dementia six and seven ('what are the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake, and what are the most effective ways of supporting carers of people with dementia living at home?'). It is funded by The National Institute of Health Research (NIHR) Research Capacity in Dementia Care Programme (RCDCP) which aims to develop and evaluate interventions in dementia care. The care setting chosen as the focus of this research project, the patient's own home, aligns with government policy to provide seamless integrated care that focuses on keeping people in their own homes for longer, and therefore prevents unnecessary hospital admissions (The National Collaboration for Integrated Care and Support, 2013).

2.0 Research Design/Methodology

2.1 Research Questions

The research questions this project will answer are:

- i. What is known about managing the nutritional status of people with dementia living at home from the perspectives of people with dementia, their carer's, and other healthcare professionals involved in nutritional care?

- ii. How can the nutritional care provided by primary healthcare professionals and family carers of people living at home with dementia be improved?
- iii. What is the design of an intervention (incorporating the improvements identified in ii) that will potentially lead to improved nutritional care for people with dementia living in their own home?
- iv. Is the intervention designed in iii) feasible for implementation in a complex primary healthcare system, as measured by nutritional outcomes and feedback on experience from people with dementia, their carer's and other healthcare professionals involved?

The long term goal of this programme of work is that by improving the nutritional care provided to people living with dementia at home the following will occur:

- A reduction in the number of people with dementia presenting to a primary healthcare professional as malnourished or at risk of malnutrition in the early to middle stages of dementia.
- A reduction in the clinical consequences of malnutrition including dehydration, pressure sores, infections, and rapid cognitive decline (above that expected from dementia progression).
- People living with dementia who wish to remain living at home longer (prior to requiring residential nursing care) are able to do so.
- Caregiver burden relating to providing adequate nutrition will reduce.
- Hospital admissions as a result of malnutrition will reduce for people living at home with dementia.

2.2 Methodology

The phases of this project are as follows:

- Phase 1: To conduct a scoping review to establish the current evidence base regarding the nutritional care of people living with dementia at home.
- Phase 2: To explore the views and experiences of those involved in providing nutritional care to people living with dementia at home through qualitative methods.
- Phase 3: To understand the lived experiences of how people living with dementia at home attempt to meet their nutritional needs through ethnographic methods.

Phase 4: To use the outcomes of the above to inform the design and feasibility testing of a complex intervention.

The following sections provide detail regarding the research approaches that will be used to answer the questions highlighted in Section 2.1.

2.2.1 What is known about managing the nutritional status of people with dementia living at home from the perspectives of people with dementia, their carer's, and other healthcare professionals involved in nutritional care?

The following are proposed to answer this research question: 1) a scoping review to establish the current evidence base, and 2) a qualitative approach (including focus groups, interviews and observations) to explore the views and lived experiences of people living with dementia at home, their carer's, and healthcare professionals involved.

A scoping review approach was selected due to the benefits of mapping a wide range of evidence in order to convey the breadth and depth of a relatively unexplored topic, whilst still providing an analytical reinterpretation of the literature (but without assessing quality as in a systematic review) (Levac et al., 2010). The scoping review will use the Arksey and O'malley (2005) staged framework which includes identifying the research question, searching for relevant studies, selecting studies, charting the data, and collating, and summarising and reporting the results (Levac et al., 2010). Preliminary findings from the literature search stage of the scoping review will be shared with a stakeholder group including patients, informal carers, domiciliary carers and healthcare professionals. The outcomes of this patient and public involvement (PPI) activity will be integrated with the outcomes of the literature search. Following this, a further stakeholder engagement session will be held with the intention of sharing the integrated themes from the overall scoping study, and promoting opportunities for knowledge transfer and exchange. The positive impacts of PPI in health and social care research have been identified as enhancing the quality and appropriateness of research (Brett et al., 2014). Levac et al. (2010) state that stakeholder consultation should be a required component of scoping studies as it adds 'methodological rigour'. There are complexities of involving focus group participants with dementia, therefore 'study partners' (often carers) will be included, who can act as informants and provide comfort and reassurance to participants (Black et al., 2014).

Qualitative research will be used to develop a deeper understanding of the views and experiences of key stakeholders involved in providing nutritional care to people with dementia living at home and what they feel could be improved. The approach to be used for the qualitative research is yet to be defined, and will be based on reviewing previous

qualitative research involving people with dementia (a grounded theory and/or phenomenological approach is tentatively proposed at this stage). These stakeholders may include (but are not limited to): GP's, community dietitians, social workers, 'formal' domiciliary care workers, dementia support groups, and 'informal' family carers. It is anticipated that this approach will utilise interviews and focus groups to collect data, which will be analysed and a series of common themes produced. To gain a more in-depth and richer understanding of someone living with dementia's experience in this setting, an ethnographic approach is proposed for observation studies. This approach will enable a better understanding of the patient's perspective, the level of care provided and delivery methods used to promote adequate nutrition in an own home setting.

2.2.2 How can the nutritional care provided by primary healthcare professionals and family carers of people living at home with dementia be improved?

This question will be answered by data collected using the same qualitative research approach outlined in section 2.2.1. As part of the interview and focus group structure, questions that elicit patient and stakeholder views on what could be done to improve current nutritional care will be included. Local clinical commissioning groups and dementia charity organisations will also be consulted and invited to provide input into how nutritional care for people living with dementia at home can be improved within a complex primary healthcare system.

2.2.3 What is the design of an intervention that will potentially lead to improved nutritional care for people with dementia living in their own home?

An intervention will be developed to answer this research question, using the outputs of the scoping review, the qualitative research outlined in phases 1,2 and 3, and further PPI involvement to ratify the intervention design. This will align with the complex intervention development approach outlined in Medical Research Council (2006). The dimensions of complexity associated with the progressive symptomology of dementia as an illness, coupled with the requirement for multi-layered care provision warrants this methodology to ensure that the intervention developed addresses causal mechanisms and can improve outcomes for many people, with an individualised approach.

Developing knowledge for practice is a cyclical process, and the key issues need to be examined from several perspectives before embarking upon complex intervention design (*Complex interventions in health : an overview of research methods*, 2015). This is reflected in the research design outlined previously, in which the evidence base is established via a

scoping review, and theoretical understanding is developed via a qualitative approach. Following consultation with a PPI group, an intervention will then be developed.

2.2.4 Is the intervention feasible for implementation in a complex primary healthcare system, as measured by nutritional outcomes and feedback on experience from people with dementia, their carer's and other healthcare professionals involved?

The intervention will be piloted, with the intention of measuring the feasibility for implementation. A mixture of qualitative and quantitative methods are likely to be needed for the pilot, in order to understand factors such as participant experience as well as changes to measured outcomes (such as weight changes). A pilot study will provide insight into future barriers for implementation, such as policy or commissioning changes that may be required if the complex intervention was to be implemented on a larger scale.

3.0 Approvals

Conducting research involving vulnerable adults is subject to rigorous ethical approval, which will include Health Research Authority ethical approval, the academic institution ethical approval and healthcare organisation approvals. This project will be reliant on existing healthcare services to recruit participants and as such may require a range of organisation's approvals.

4.0 Timeline

The project is estimated to be completed by 31/03/2019. Please see *Appendix B* for a project Gantt chart.

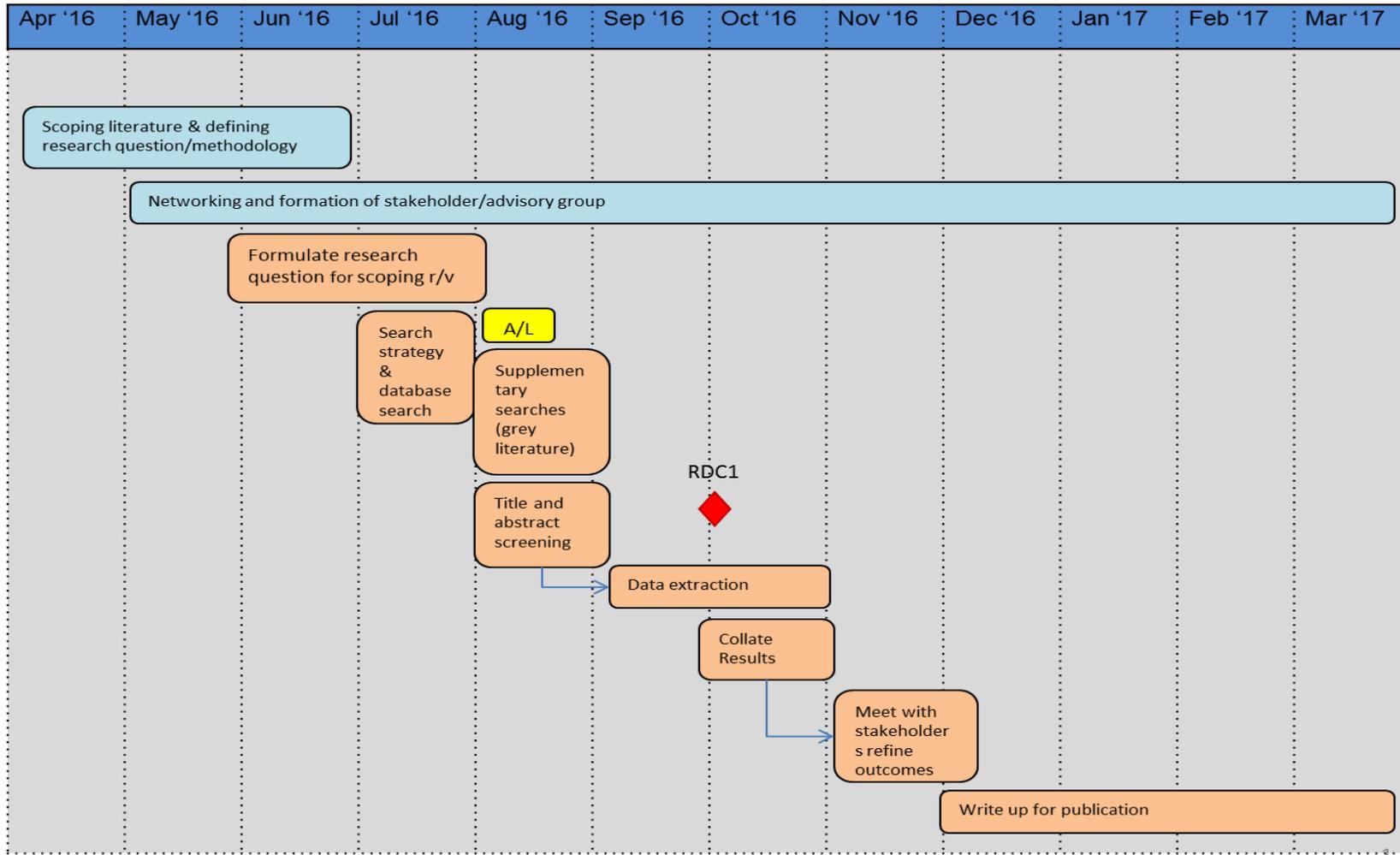
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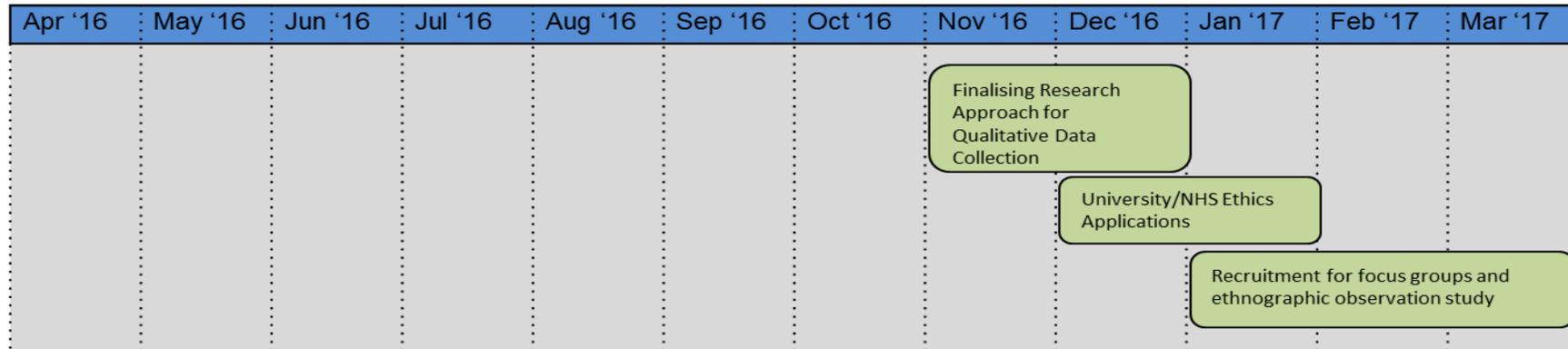
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Appendix B – Project Gantt chart

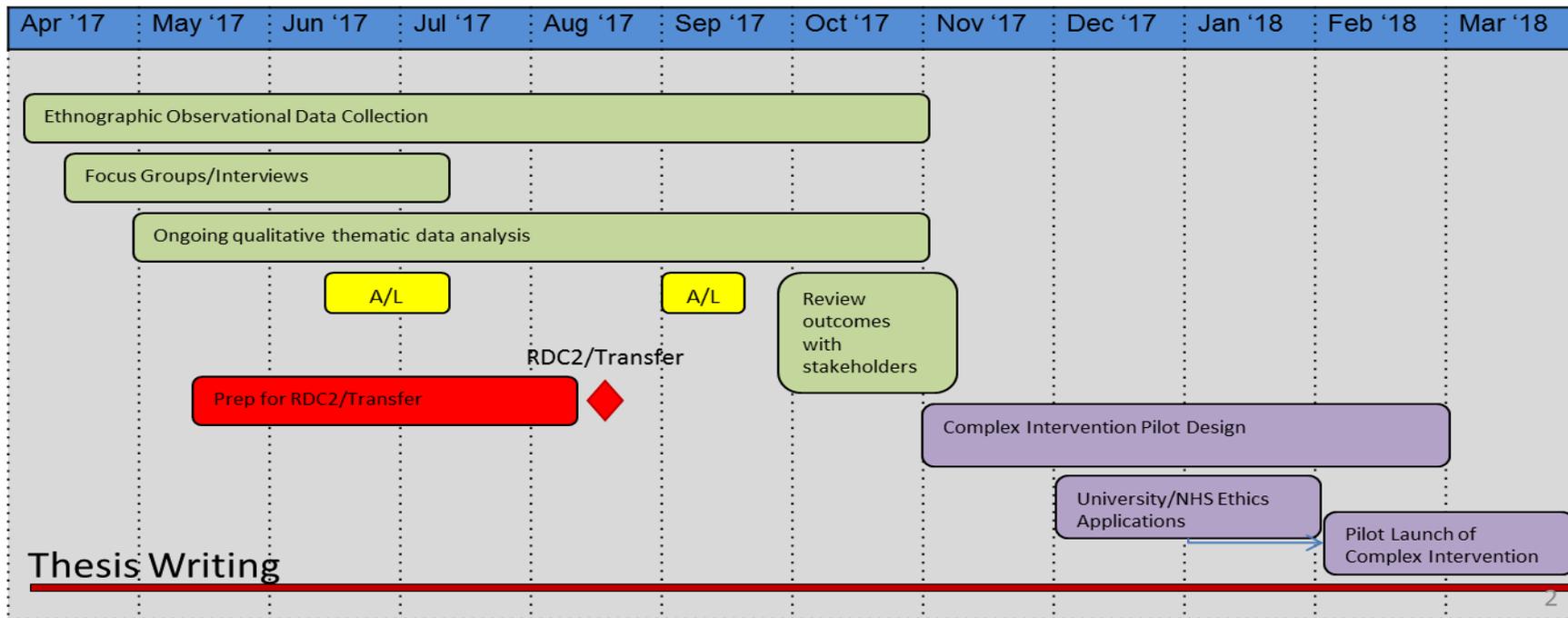
Year 1 2016-2017 *Nutritional care for people with dementia living at home*



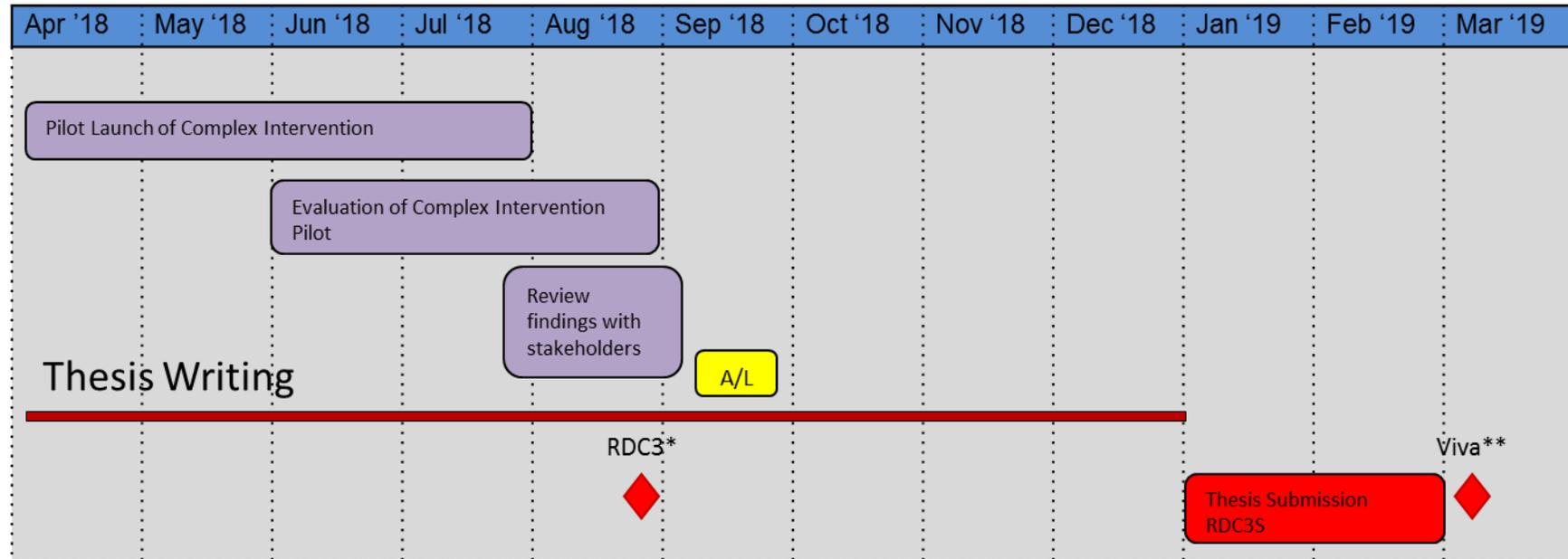
Year 1 2016-2017 Continued



Year 2 2017-2018



Year 3 2018-2019



* 6 months before submission

** Viva – one month following thesis submission

Note: This 3 year project plan is a draft, and it is acknowledged that this will need to be reviewed throughout the project. It is also acknowledged that submission dates for thesis and Viva are subject to change.