

# Bedtime Story - nocturnal caregiving for juveniles with Type 1 Diabetes

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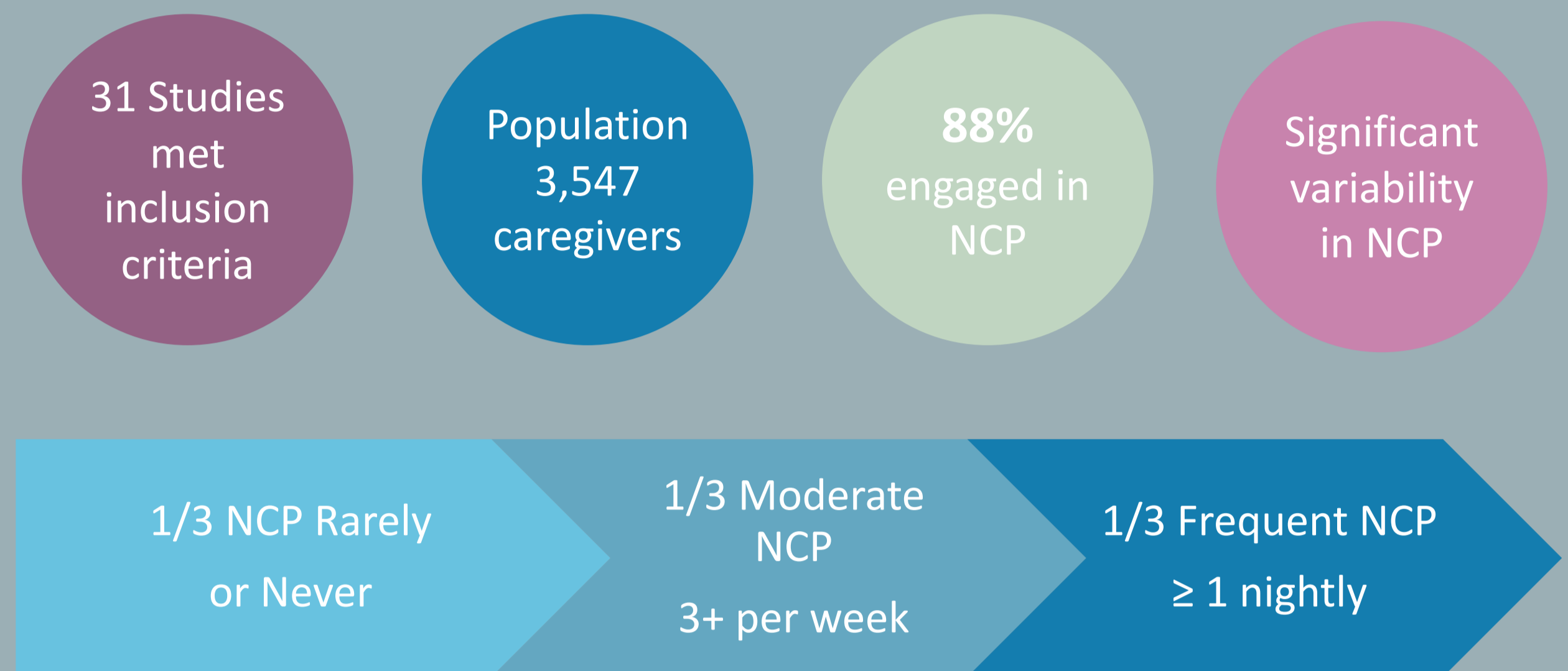
## Background

- Type 1 Diabetes (T1D) is an autoimmune disease typically diagnosed in childhood
- One in 4-600 juveniles diagnosed annually, Ireland is at the higher end of diagnoses<sup>1</sup>
- Diagnoses have been increasing at an alarming rate, particularly among the under 5s<sup>2</sup>
- Nocturnal illness management plays a crucial role in health outcomes for juveniles with T1D<sup>3</sup>
- Nocturnal caregiving practice (NCP) receives minimal attention in research and treatment guidelines<sup>4</sup>
- Consequently, very little is on offer to support this highly burdened population

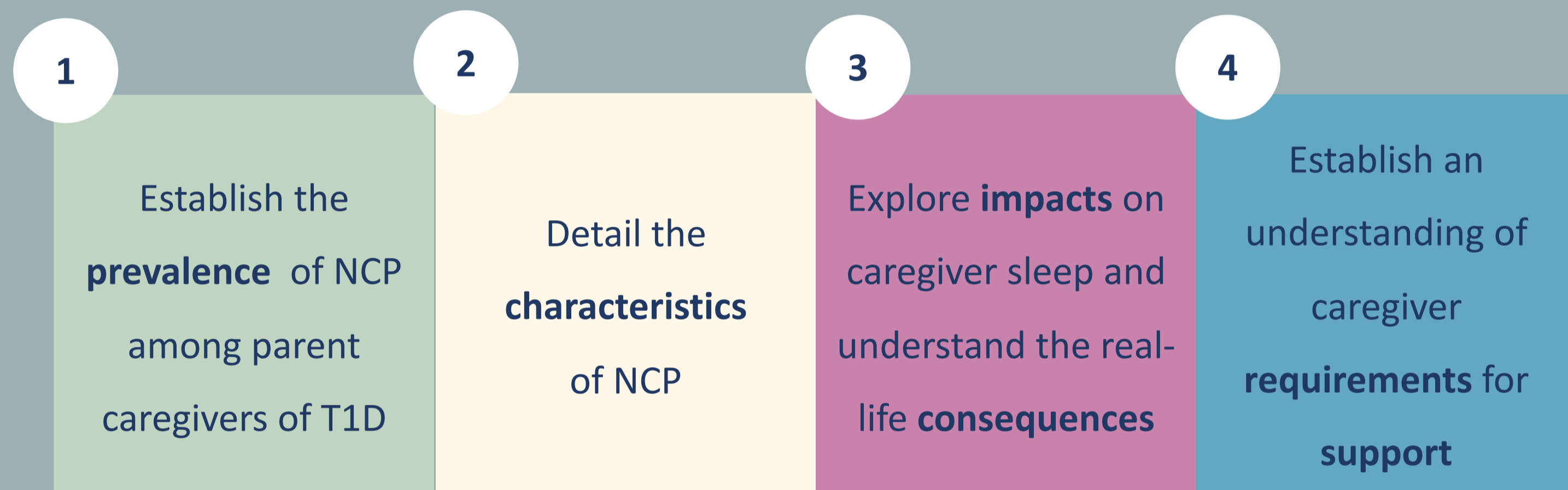
The 2AM check.  
Zombie moms unite!



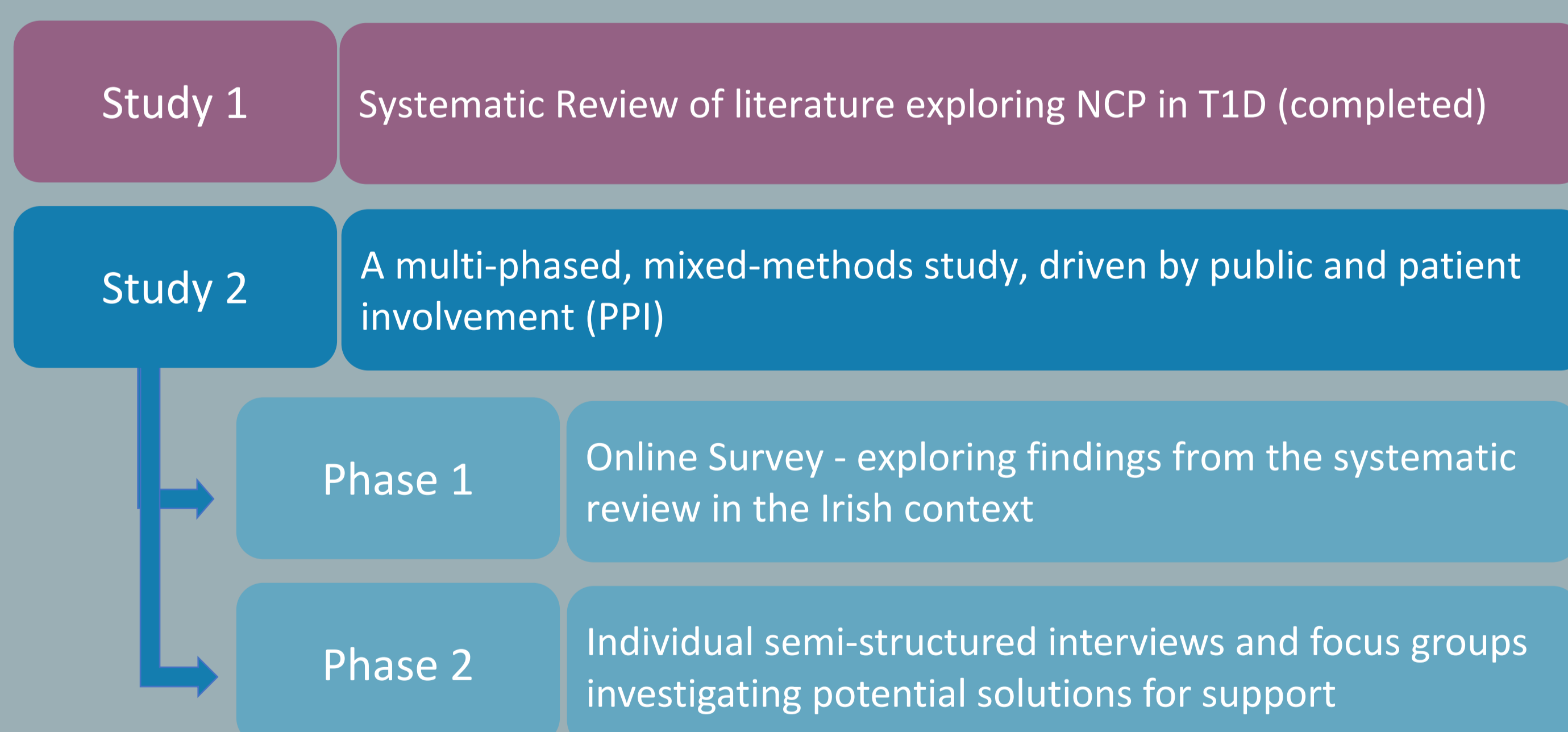
## Systematic Review - Findings



## Project Aims



## Methods



## Impacts on sleep



- Over 50% of caregivers (19-80%) below threshold for adequate sleep
- 54% scored for poor sleep quality on the PSQI<sup>5</sup>
- 60% reported significantly disrupted sleep

## Caregivers say...

"Some nights the exhaustion holds me like a straight jacket..."

"...every 2 hours waking up is hard. I mean, it makes me really cranky the next day"

"...it's hard to make good [illness management] decisions when you are exhausted"

"One of my friends said 'it has lost a part of me"



"I have this image of a ship going through a very narrow strait with very high sharp rocks on either side...at night-time you never really know what is going to hit"

"I can't even function and focus on what I need to be doing at work"

## Researchers say...

"diabetes care providers should ask about sleep as part of routine clinical practice..."



82% of Authors Agree

## Discussion

- Systematic Review (study 1) shows that NCP is pervasive, with significant negative impacts, highlighting urgent need for caregiver support
- Supporting the development of care guidelines to include protocols for acknowledging NCP within clinical settings
- Later studies will use co-design principles to explore a potential support solutions and explore their feasibility with stakeholder input
- Findings from this study will have applications for other cohorts burdened by nocturnal caregiving responsibilities, such as those caring for individuals living with dementia, physical disability or ASD.