

Nocturnal Caregiving for Juveniles with Type 1 Diabetes

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01 Caregiving and UN SDGs for Health and Wellbeing

- Healthcare delivery relies on the provision of supplementary care by family members
- Over half a million unpaid family caregivers currently in Ireland, saving the Irish state up to 20bn¹
- Family caregiving can result in considerable economic, personal, social and emotional burdens for the carer²
- Unmet support needs underexplored in the literature and given low priority in clinical care settings³
- Sustainable health and wellbeing must recognise and support caregiver contribution

02 Research + Industry = Sustainable Society

Operationalising the goals of sustainable society requires a strong partnership between research and industry

Achieving the tightest fit between real-world experience of a problem and potential solutions from industry



This research: **PPI driven**, utilising **Human Factors frameworks** to achieve this aim

03 Nocturnal caregiving for juveniles with Type 1 Diabetes

- Irish survey reports that **62% of caregivers regularly got up during the night** to provide care⁴
- This research: Type 1 Diabetes (T1D) as exemplar caregiver population



- T1D is typically diagnosed in childhood, patients highly **dependent on parent caregivers for intensive, round-the-clock care**
- Over 22,000 people in Ireland are currently living with T1D⁵

04 Stage 1 - Systematic Review

Research Questions

Extent of nocturnal caregiving practice

Describing the lived experience

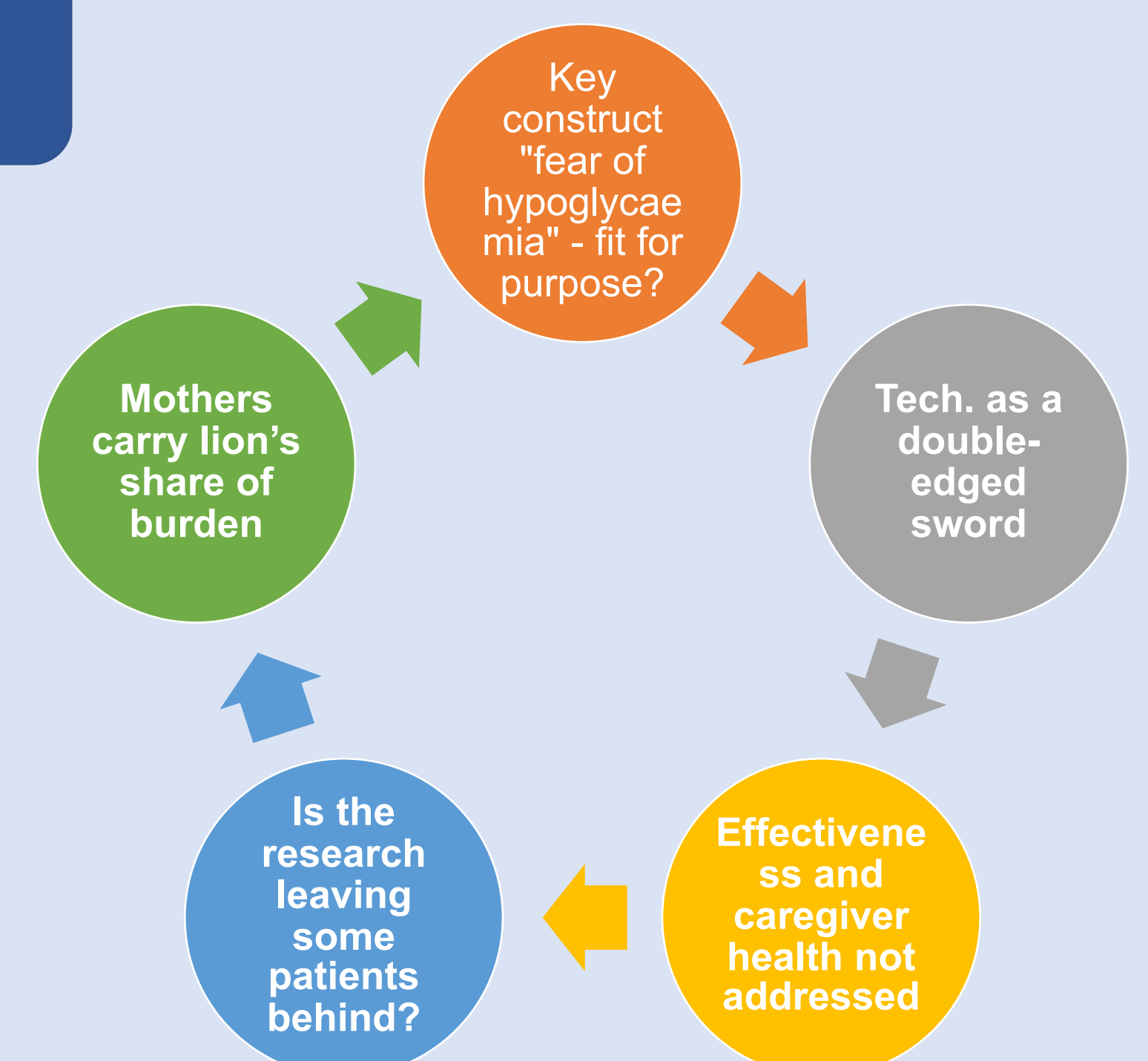
Perceived value of technological innovations for reducing burden

Impacts on diabetes related health outcomes

Impacts on caregiver health and wellbeing

Preliminary Findings

High-Level Themes



05 Stage 2 - Mixed-Methods Study

- **Extent of NC in Irish context**
- **Effectiveness** on glycaemic control
- **Unmet caregiver needs for NC support**
- **Potential solutions and innovations explored in collaboration with caregivers, using co-design principles**



Methods

Phase 1: Survey - quantitative self-report measures such as WHO-5, HFS and PSQI; open-ended qualitative questions
Phase 2: Semi-structured interviews; stakeholder FGs

06 Impact on Sustainable Health and Wellbeing

Envisaged that **adaptations** of solutions will be developed from further cross-discipline collaboration and ongoing **co-design** with other patient groups and will be applicable in **other caregiving contexts and caregiver populations.**

1. Hughes, Z. Care Alliance Ireland position paper on vaccine prioritisation for family carers. 2. McGarrigle, C. and R.A. Kenny (2020). Receipt of care and caring in community-dwelling adults aged 50 years and over in Ireland. The Irish Longitudinal Study on Ageing. 10.38018/TildaRe.2020-09 3. Kulski, K., Peckham, A., Gill, A., Arneja, J., Morton-Chang, F., Parsons, J., ... & Sheridan, N. (2018). "You've got to look after yourself, to be able to look after them" a qualitative study of the unmet needs of caregivers of community based primary health care patients. *BMC geriatrics*, 18(1), 1-11. 4. Family Carers Ireland, College of Psychiatrists Ireland, University College Dublin. Paying the Price: The Hidden Impacts of Caring. Dublin; 2019. 5. Mobasser, M., Shirmohammadi, M., Amiri, T., Vahed, N., Fard, H. H., & Ghojzadeh, M. (2020). Prevalence and incidence of type 1 diabetes in the world: a systematic review and meta-analysis. *Health promotion perspectives*, 10(2), 98