

Are you, or have you been, the caregiver for a person who was diagnosed with an inherited retinal disorder (IRD)?

Are you interested in helping me understand how being a caregiver has impacted you?

The interview can be conducted **from your home** via a video interview using a computer or you can attend a research visit in Sydney?

I am a PhD student undertaking a research project at the University of Technology Sydney. The study aims to explore how caring for a person diagnosed with an IRD as a child impacts the carers' life and if the impact changes as the person being cared for gets older.

I am interested to understand the social, emotional, physical and financial impact of being an unpaid caregiver (you might be the parent, child, spouse, family member for example).

So, if you

- Are or have been a caregiver (unpaid), who speaks English and resides in Australia,
- Prior to turning 18 years of age, is or was the person you care for or cared for diagnosed with an inherited retinal disease (IRD) such as Leber congenital amaurosis (LCA), severe early childhood-onset retinal dystrophy (SECORD), early-onset severe retinal dystrophy (EOSRD), or retinitis pigmentosa (RP) for example, that they were diagnosed with prior to turning 18 years of age, and
- The main reason that you are caregiver to the person with IRD is because of their visual impairment due to the inherited retinal disease, then

I would appreciate it if you could share your experience with me,

Please email me at Maria.H.Kokoszka@alumni.uts.edu.au if you are interested in participating

I plan to conduct individual interviews or focus group interviews with up to 5 caregivers. The interviews can be either be face to face in Sydney or via videoconferencing (virtually) using MS Teams. The interview will take between 1 to 2 hours of your time. You will be offered compensation for your time (\$60 for one hour, research visits may take up to 2 hours) and also compensation for parking if the interview is face to face.

UTS Centre for Health Economic Research and Evaluation (CHERE)

UTS Ethics approval number UTS HREC REF NO. ETH23-8979 (approved March 2024)

