Supplementary material: X-linked retinitis pigmentosa (XLRP): An investigation of the impact of XLRP on health-related quality of life of carers in Great Britain

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1 Table S1 Eligibility criteria

The vignette development in Phase 1 was discussed with N = 6 informal carers and N = 1 ophthalmologist. All recruited participants for Phase 2 were from the general population.

Study phase	Eligibility criteria
Phase 1: Vignette development – Interviews with informal carers (N=6)	• adult residents in GB • informal carers (i.e., carer) of a person with XLRP • able to read and speak English • willing and able to comprehend and provide informed consent prior to study entry
Phase 1: Vignette validation – Interview with Ophthalmologist (N=1)	• ophthalmologist who had seen at least 10 people with XLRP in the past 12 months • started their profession at least 5 years ago • was able to read and speak English • was willing and able to comprehend and provide informed consent prior to study entry
Phase 2: Feasibility interviews with general public (N=10)	• adult residents in GB • able to read and speak English • willing and able to comprehend and provide informed consent prior to study entry
Phase 2: Pre-testing interviews with general public (N=10)	
Phase 2: Final survey with general public (N=220 including the pre-test participants)	

GB: Great Britain

Summary of Informal Carers in the Study

Among the six informal carers included in the study:

- Two carers provide care for their spouse or partner, who has severely limited vision and may require substantial assistance with daily activities (severe symptoms).
    - One of these carers provides 7 or more hours of care per day.
    - The other provides between 3 and 7 hours of care per day.
- Four carers support their child, whose vision is moderately impaired, requiring some help with daily activities (moderate symptoms).
    - Three of these carers provide care for 3 to 7 hours per day.
    - The fourth previously provided care within that range but now provides less than 3 hours per day.

Follow-up Engagement

The final results of the study were presented to three of the six informal carers who had previously contributed to the vignette development. The selection aimed to reflect two levels of caregiving involvement:

- Those providing care for at least 3 but less than 7 hours per day, and
- Those providing care for 7 hours or more per day.

Additionally, the selected carers represented both types of caregiving relationships included in the study: spouse/partner and child.

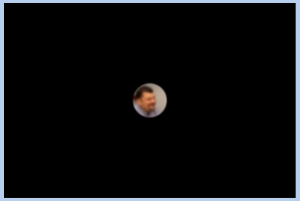
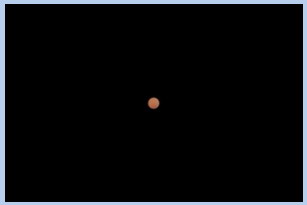
2 Table S2 Soft quotas

Soft quotas were established for recruiting participants for the pre-testing interviews and the final survey. These quotas were designed to enhance the representativeness of the sample relative to the general adult population of GB. However, due to the inherent limitations with recruitment from general population panels, full adherence to these quotas was not consistently achievable.

Sample Characteristic	**Group (Target Quota)**
Age	• 18-25 years (~10%) • 26-45 years (~40%) • 46-65 years (~40%) • >65 years (~10%)
Sex	• Men (~50%) • Women (~50%)
Country	• England (~87%) • Wales (~5%) • Scotland (~8%)
Income*	• Low (~33.3%) • Medium (~33.3%) • High (~33.3%)
Current caregiving experience	• Yes, I am a non-professional / unpaid carer (~20%) • No (~80%)

* Note for the purposes of screening, the income question was based on self-reported perception of low, medium and high income rather than specific numeric income brackets.

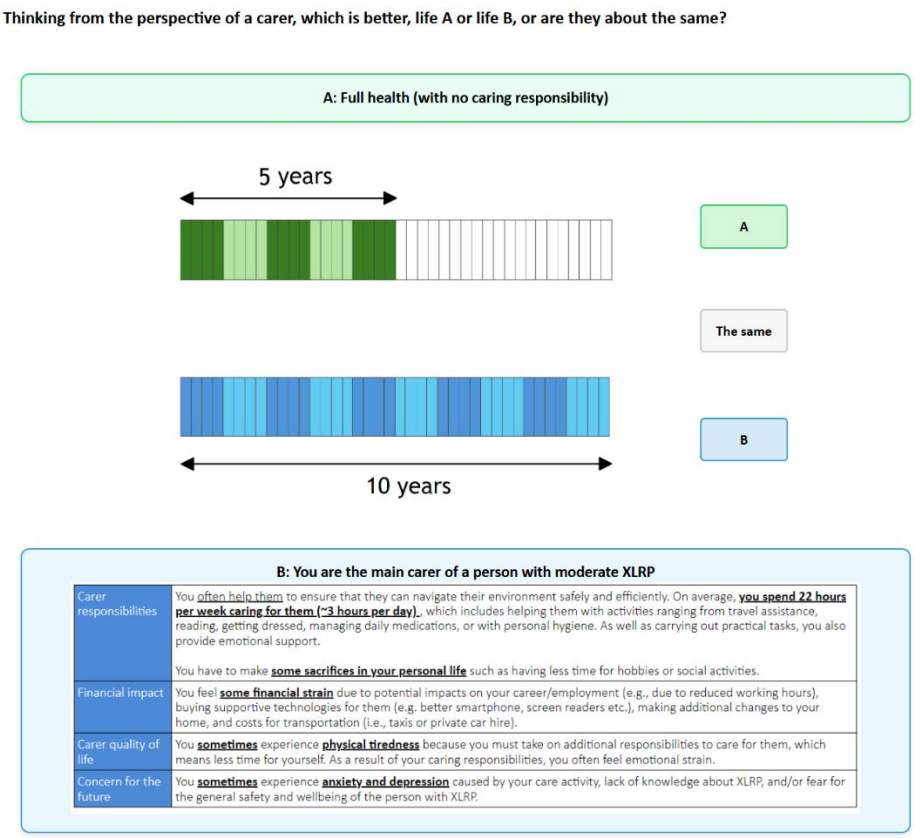
3 Table S3 – Health State vignettes

Scenarios	**Scenario 1** Imagine you are the main carer of a person with **Mild XLRP** 	**Scenario 2** Imagine you are the main carer of a person with **Moderate XLRP** 	**Scenario 3** Imagine you are the main carer of a person with **Severe XLRP** 	**Scenario 4** Imagine you are the main carer of a person who is Blind 
Carer responsibilities	Their vision makes completing tasks like reading and getting dressed challenging, so you **lend a helping hand** when needed. On average, **you spend 22 hours per week (~3 hours per day) caring for them**, which includes helping with some of their daily tasks, such as travel assistance or other activities that they are unable to conduct independently. As well as carrying out practical tasks, you also provide emotional support. You have to adjust your bedtime and personal routines but beyond this you **do not have to make sacrifices** in your personal life.	You often help them to ensure that they can navigate their environment safely and efficiently. On average, **you spend 22 hours per week caring for them (~3 hours per day),** which includes helping them with activities ranging from travel assistance, reading, getting dressed, managing daily medications, or with personal hygiene. As well as carrying out practical tasks, you also provide emotional support. You have to make **some sacrifices in your personal life** such as having less time for hobbies or social activities.	Your responsibilities as a carer are now **very demanding.** On average, **you spend 38 hours per week (~5 hours per day) caring** for them as they often need help and support with their daily activities such as cooking meals, managing finances, reading, getting dressed, person8al hygiene or pursuing any activity outside of home. As well as carrying out practical tasks, you also provide emotional support. You **often have to make sacrifices in your personal life** such as having less time for hobbies or social activities.	As they become blind, your responsibilities as a carer require you to **take charge of almost every situation**. On average, **you spend 38 or more hours per week (~5 hours or more per day) caring** for them as they often need help and support with their daily activities such as cooking meals, managing finances, reading, getting dressed, personal hygiene or pursuing any activity outside of home including travel assistance, shopping, socialising, and help with new technology. As well as these practical tasks, you also provide emotional support. You **often have to make sacrifices in your personal life** such as having less time for hobbies or social activities.
Financial impact	You feel **some financial strain** due to potential impacts on your career/employment (e.g., due to reduced working hours), buying supportive technologies for them (e.g., better smartphone, screen readers etc.), and making some changes to your home (e.g., better lighting).	You feel **some financial strain** due to potential impacts on your career/employment (e.g., due to reduced working hours), buying supportive technologies for them (e.g. better smartphone, screen readers etc.), making additional changes to your home, and costs for transportation (i.e., taxis or private car hire).	You have a **significant financial strain** due to potential impacts on your career/employment (e.g., due to reduced working hours), buying supportive technologies for them and costs for transportation (i.e., taxis or private car hire). There may be costs for ongoing home modifications. You receive a Carer's allowance that only partially supports with this financial impact.	You have a **significant financial strain** due to potential impacts on your career/employment (e.g., due to reduced working hours), buying supportive technologies for them and costs for transportation (i.e., taxis or private car hire). There may be costs for ongoing home modifications. You receive a Carer's allowance that only partially supports with this financial impact.
Carer quality of life	You **sometimes** experience physical tiredness because you must take on additional responsibilities to care for them, which means less time for yourself. As a result of your caring responsibilities, you often feel emotional strain.	You **sometimes** experience physical tiredness because you must take on additional responsibilities to care for them, which means less time for yourself. As a result of your caring responsibilities, you often feel emotional strain.	You **sometimes experience physical tiredness or fatigue** due to extended hours of caring and the difficulties of taking care of another person. As a result of your caring responsibilities, you often feel emotional strain.	You **sometimes are physically and mentally exhausted** due to extended hours of caring and the difficulties of taking care of another person. As a result of your caring responsibilities, you often feel emotional strain.
Concern for the future	You **sometimes** experience **mild anxiety and depressive symptoms** due to your prolonged involvement in caring and worrying about their future.	You **sometimes** experience **anxiety and depression** caused by your care activity, lack of knowledge about XLRP, and/or fear for the general safety and wellbeing of the person with XLRP.	You **sometimes** experience **anxiety and depression** caused by your care activity, how XLRP has impacted and will impact your lives, and/or fear for the general safety and wellbeing of the person with XLRP.	You **often** experience **anxiety and depression** caused by your care activity, how XLRP has impacted and will impact your lives, and/or fear for the general safety and wellbeing of the person with XLRP.

XLRP: X-linked retinitis pigmentosa

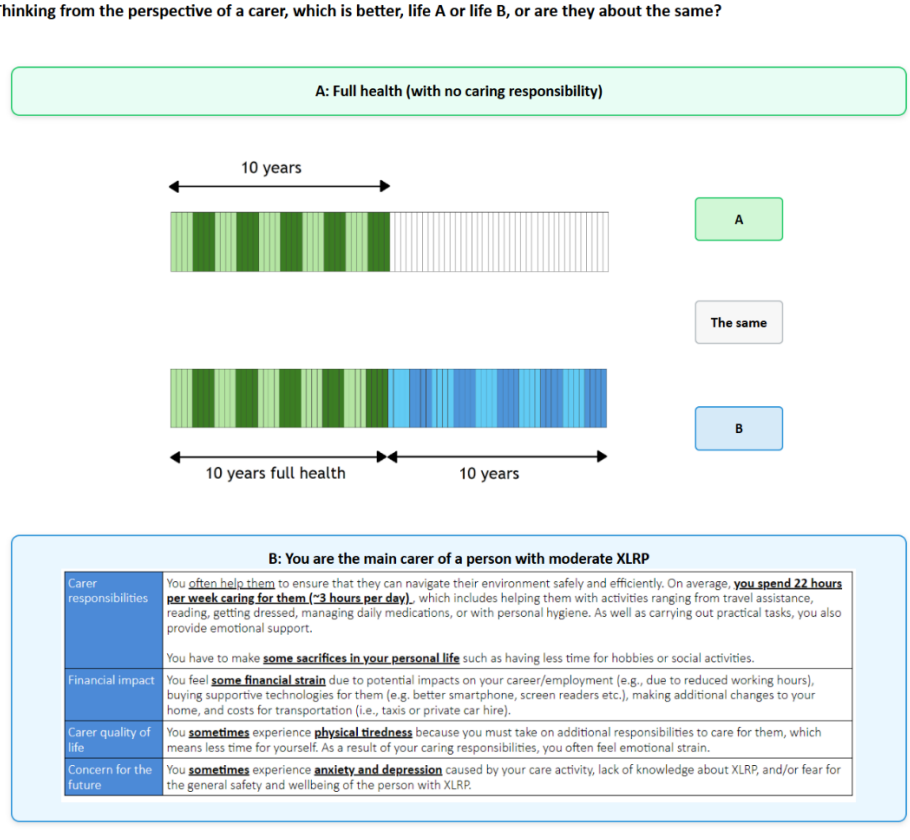
4 Example TTO tasks

Figure S1. Better than dead TTO task



XLRP: X-linked retinitis pigmentosa, TTO: Time trade-off

Figure S2. Worse than dead TTO task



XLRP: X-linked retinitis pigmentosa, TTO: Time trade-off