

TOP 10 RESEARCH PRIORITIES FOR INHERITED RETINAL DISEASE

Progressing research that matters most to individuals living with an inherited retinal disease, their families and health professionals.



Treatment /
cure











Psychosocial
wellbeing



Health
service
delivery



Symptoms /
disease
progression

Rank	Domain	Priorities
#1		What treatments can safely prevent, slow down or stop vision loss that occurs for someone with an IRD?
#2		What is the psychological impact of having an IRD, and what support is most effective?
#3		What treatments can safely restore vision for someone with an IRD?
#4		What are the information and psychosocial needs of individuals with an IRD and their families at diagnosis?
#5		What training and/or guidelines are needed for health professionals to provide optimal support for individuals with an IRD, from diagnosis and beyond?
#6		What are the most effective ways to support carers and family members of an individual with an IRD?
#7		How do environmental and lifestyle factors influence IRD symptoms and disease progression?
#8		What are the most effective ways to manage IRD symptoms?
#9		How can a program to detect IRDs as early in life as possible be implemented?
#10		What is the anticipated progression of vision loss for each IRD?

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“My one hope is that this Priority Setting Partnership carries significant merit in the research community and that future research projects are influenced by the outcomes of this exercise.”

- Individual living with an inherited retinal disease who participated in the final prioritisation workshops

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