RNIB Scotland welcomes the opportunity to respond to the consultation on the CSO draft Research Strategy.

RNIB Scotland is the leading charity in Scotland helping blind and partially sighted people. We deliver services our members need and campaign for their civil and welfare rights. We support children, young people and adults with sight loss to live full and independent lives, and work with others to help minimise preventable sight loss.

RNIB Scotland is not a Medical Research Charity and therefore much of the CSO draft Research strategy is not necessarily relevant. However, chapter two on 'Partnership with Scottish Patient and Public' is something that we feel we can feed back on.

* We welcome the recommendations to change the CSO Public Involvement Group to the Public Engagement Group. This is in-line with many other health based public partnership groups and will be a language that our service users and most others will understand. RNIB Scotland would be interested in more detail on how the representation will be broadened. It would be useful to know how people can engage with the Public Involvement Group or become involved directly and what this may entail.

We believe it is critical that there is lay representation when producing clinical information for the public. We work consistently with partners in the Health, Social Care and wider public sectors to ensure that our service users both understand the information being relayed, but also that it is accessible in a format that people can read or understand. This often involves simple adaptations of a document into a larger print or making information available in an audio format.

* Question 8: Would a trial register be of benefit to patients seeking trials? Would it be an effective way to partner patients with researchers? Is there a danger that expectations of taking part could be unfairly raised?

We believe that a trial register would be of benefit to patients. It will provide a simple route through which patients can engage with clinical trials and will allow them easier access to information regarding individual trials. It will also enable greater choice and control for individuals.

Access to the website and the provision of information in relation to each trial would need to be accessible in its language and format to ensure that those who choose to engage, are able to do so with ease. This is a major concern with regard to health services and health information in relation to our service users. People need to be able to understand what they are consenting to and to be able to make a fully informed decision; without accessible information, this cannot occur.

We also believe that the provision of information accessibly will help to limit any unfairly raised expectations with regard to taking part in a particular study. Lay summaries will be an important first step in helping patients understand more about clinical trials and what will be involved in taking part.