Additional file 4

Top purposes of social media platforms and most popular information offered on websites.

Raising public awareness of rare Sharing information about your specific rare diseases disease 94% 94% Promoting fundraising campaigns Sharing information about upcoming events 81% 88% Posting information about clinical trials Sharing recent news 75% 75% Most popular information offered on the group websites FOR HEALTHCARE PROFESSONALS FOR YOUNGER PATIENTS FOR ADULTS PATIENTS FOR CARERS Current research and Information pack at key stages. Current research and Current treatment options. discoveries. discoveries. Training / educational events. Flver for individual Current treatment options. Current treatment options. disease(s). Current research discoveries. Flyer for individual Flyer for individual Inheritance facts. Current treatment options. disease(s). disease(s). Inheritance facts. Flyer for individual disease(s). Research funding links. Training / educational events.

Top purposes of the group's social media platforms