**Think Research Patient Statements**

Many people want to talk about their rare disease condition, share stories or just need someone to listen. In particular, people want to reach out to medical practitioners and researchers to help change the way people with rare diseases are managed and suggest new ideas for rare disease research.

At the Rare Disease event in March this year, we’d like you to share your views

of what changes you would like to see with rare disease management and research. This could include ways your care could be improved, ideas to manage symptoms, questions you’d like to be asked when you present to a clinician at hospital or

with a GP, or a new research project for researchers.

We are collecting these statements from people with rare conditions to create a picture gallery that will be shown on the day.

We will also combine the statements and pass on to research funders and organisations involved in rare diseases research, in order to help shape rare disease research strategy.

Below are examples of the kind of story we are interested in:

I’d love to be asked how I have been feeling overall rather than how am I feeling today. I have good and bad days and that would help me and my doctor work out what causes my rare disease to flare up. It would be great to see a study about communicating better with people with a rare disease.

My granddaughter was diagnosed with CNO, but every time she sees a doctor, she has to repeat the same medical history. It would be great if people with a rare condition could carry a card, they could present which will alert the condition and main symptoms when having an episode. It would save time going over the same questions

My rare disease affects my immune system, I can feel fine one day and the next I’m in serious pain. I found reaching out to a support group for advice and sharing tips really helped. Our group would like to see the experience of being able to take part in research studies

improved at a local level.

I would like to see researchers investigate whether thyroid conditions can link to early arthritis. It would be useful to know if this can be found earlier though blood tests. Also, could research in this area improve diagnostics timescales

**What you need to do**

1. Complete one form on the next page
	1. If you would like to provide a statement as a **patient**, fill in **form 1**
	2. If you would like to provide a statement on behalf of an **organisation/ patient support group**, fill in **form 2**
2. Attach a picture of yourself in .jpeg format and any logos of your support group/ organisation if applicable – pictures/ logos should be a high resolution, aim for above 4MB in size for photos
3. Send it to Georgina via email: gan23@medschl.cam.ac.uk by 5pm, 3 March 2020

**Please note we may have to edit some stories in order to fit on the screen, but we will contact you in advance. If you do not wish to include an image of yourself, a group picture, logo, design motif can be used.**

**Statement form**

# Form 1

This form is for patients and carers

|  |  |
| --- | --- |
| Full name for event organiser |   |
| Name to be displayed on the statement |  First name only / Full name / Anonymous  (delete accordingly) |
| Contact telephone number and email address (only to be used by organisers if we need to contact you) |  |
| Rare disease condition |  |
| Please provide some details about your condition | 80 words max. |
| Statement | 80 words max. |
| Signature for ConsentI give the NIHR permission to use the following on the understanding that it will only be used in an appropriate manner to support promoting rare diseases and rare disease research | Date : XX/XX/2020 |

# Form 2

This form is if you are filling it in on behalf of an organisation/patient support group

|  |  |
| --- | --- |
| Full name for event organiser  |  |
| Name to be displayed on the statement |  First name only / Full name / Anonymous  (delete accordingly) |
| Title - if applicable e.g. Co-founder of X |  |
| Support group / organisations full name |  |
| Website address |  |
| Contact telephone number and email address (only to be used by organisers if we need to contact you) |  |
| Twitter address, if applicable |  |
| Please provide some details about the condition | 80 words max. |
| Statement | 80 words max. |
| Signature for ConsentI give the NIHR permission to use the following on the understanding that it will only be used in an appropriate manner to support promoting rare diseases and rare disease research | Date : XX/XX/2020 |