Supplementary Table 2: Categories, codes and quotes from question: Is there anything else that you would like to share with us?

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| **CATEGORIES** | **CODES** | **QUOTES** |
| Quality of Life | Health-related QoL | *“I'm looking for insights on the subject of women or pregnancy”* (*Adult*)  “*How to manage pain related to samaladia”* (Adult) |
| Psychological status | *“Yes, the psychological part.... feelings and fears!!!”* (PGC) |
| Social relationships | “*Meetings with patients to exchange and play down”* (Adult)  “*Promote encounters only among young people with osteogenesis imperfecta”* (Child) |
| Socio-economic status | “*The case of an adult unable to work”* (Adult) |
| Patient engagement | *“my experience, my background, our association”* (Adult) |
| Data collection | Data management | **“***I am concerned about the whole idea of a 'registry' in and of itself. This is an easily abused database potentially especially in the age of cyber-crimes”* (Adult)  *“how can I access the data collection/registry/etc […]”* (Child) |
| Survey data collection | “*There is a lack of better understanding to be able to better answer”* (PGC)  “*Are you anti-Apple? Can't answer on iPad. It's not easy”* (Adult)  *“Question 29 needs to be rethought”* (Adult) |
| Publications | Guidelines/Best practices | *“There are no physiotherapy best practice treatments for older patients […]”* (Adult) |
| Dissemination | *“Information and treatment results”* (Adult) |
| Survey’ results | *“I would like to have a feedback about the follow up of this project!”* (Adult)  *“Will the survey results be shared with the participants”* (PGC) |
| Other |  | *“Back to an earlier question, I am not only an adult with a rare disease […]”* (Adult) |
| No additional suggestions | No | *“At the moment that's all”* (Adult) |
| Appreciation | *“Thank you for helping us”* (Adult)  *“I appreciate this kind of initiatives very much”* (PGC)  *“yes, thank you for everything you do”* (Adult) |