Literatur zum Cartoon:

Babac, A., von Friedrichs, V., Litzkendorf, S., Zeidler, J., Damm, K., & Graf von der Schulenburg, J. M. (2019). Integrating patient perspectives in medical decision-making: a qualitative interview study examining potentials within the rare disease information exchange process in practice. BMC Medical Informatics and Decision Making, 19(1), 188.

Blöß, S., Klemann, C., Rother, A. K., Mehmecke, S., Schumacher, U., Mücke, U., ... & Grigull, L. (2017). Diagnostic needs for rare diseases and shared prediagnostic phenomena: Results of a German-wide expert Delphi survey. PLoS One, 12(2), e0172532.

Bolz-Johnson, M., Kenny, T., Le Cam, Y., & Hernando, I. (2021). Our greatest untapped resource: our patients. Journal of Community Genetics, 12(2), 241-246.

Bonner, N., Hall, R., Tritton, T., Grimes, R., Trennery, C., Spencer, H., & Bennett, B. (2017). Rare diseases, are caregivers just as affected as patients?. Value in Health, 20(9), A562.

Litzkendorf, S., Frank, M., Babac, A., Rosenfeldt, D., Schauer, F., Hartz, T., & Graf von der Schulenburg, J. M. (2020). Use and importance of different information sources among patients with rare diseases and their relatives over time: a qualitative study. BMC public health, 20(1), 860.

Morris, S., Hudson, E., Bloom, L., Chitty, L. S., Fulop, N. J., Hunter, A., ... & Walton, H. (2022). Co-ordinated care for people affected by rare diseases: the CONCORD mixed-methods study. Health and Social Care Delivery Research, 10(5), 1-220.

Stanarević Katavić, S. (2019). Health information behaviour of rare disease patients: seeking, finding and sharing health information. Health Information & Libraries Journal, 36(4), 341-356.

Vázquez, E., Kim, M., & Santaella, M. E. (2023). Lived experience experts: a name created by us for us. Expert Review of Hematology, 16(sup1), 7-11.