

## Interview Guide

|    | MAIN QUESTIONS                                                                                                                                                                                | PROBING QUESTIONS                                                                                                                                                                                                   |
|----|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1  | How does EB affect your life?                                                                                                                                                                 | <i>How does EB affect your leisure time?</i><br><i>How does EB affect your work?</i><br><i>How does EB affect your partnership?</i>                                                                                 |
| 2  | How did your experience of EB change over time?                                                                                                                                               |                                                                                                                                                                                                                     |
| 3  | How do people around you deal with your EB?                                                                                                                                                   | <i>How does your family deal with EB?</i><br><i>How do your friends deal with EB?</i><br><i>How do other people around you deal with EB?</i>                                                                        |
| 4  | What is especially difficult in dealing with EB?                                                                                                                                              | <div> <div> <i>Medical aspects</i><br/> <i>Psychological aspects</i><br/> <i>Social aspects</i><br/> <i>Financial aspects</i> </div> <div> </div> <div> <i>How do you deal with that?</i> </div> </div>             |
| 5  | What do you experience as helpful in dealing with EB?                                                                                                                                         | <i>What helps you when you are not feeling well?</i>                                                                                                                                                                |
| 6  | There is quite a wide range of support for EB, e.g., medical, social, and psychological support. Where do you turn to in which matter?<br><br>Are there any other persons you are turning to? | <i>Where do you turn to for medical support?</i><br><i>Where do you turn to for psychological support?</i><br><i>Where do you turn to for social support?</i><br><i>Where do you turn to for financial support?</i> |
| 7  | What do you experience as especially helpful in this case?                                                                                                                                    | <i>Medical support</i><br><i>Psychological support</i><br><i>Social support (Personal network and „EB Community“)</i>                                                                                               |
| 8  | What do you think makes a treatment successful?                                                                                                                                               |                                                                                                                                                                                                                     |
| 9  | What sort of support would you wish to have that, until now, is not or not sufficiently available?                                                                                            |                                                                                                                                                                                                                     |
| 10 | Would you like to add something?                                                                                                                                                              |                                                                                                                                                                                                                     |

**Thank you very much for your precious time and your answers.**