

## EPCOG study

## Compliance reporting form

Patient ID:

Date:

|  |  |  |  |  |  |
|--|--|--|--|--|--|
|  |  |  |  |  |  |
|--|--|--|--|--|--|

|   |   |  |   |   |  |   |   |   |   |
|---|---|--|---|---|--|---|---|---|---|
|   |   |  |   |   |  |   |   |   |   |
| D | D |  | M | M |  | Y | Y | Y | Y |

| number of study visit | 1<br>(Base<br>-line)     | 5                        | 9                        | 13                       | 17                       | 19                       | 21                       | 23                       | 25                       |
|-----------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| please tick           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## Characterization of assessments

yes no

|  |   |                       |   |   |  |   |   |   |   |  |  |  |   |   |  |   |   |  |   |   |   |   |
|--|---|-----------------------|---|---|--|---|---|---|---|--|--|--|---|---|--|---|---|--|---|---|---|---|
| I. Patient answered questionnaires by him-/herself. ( <i>self assessment</i> )   | <input type="radio"/>   | <input type="radio"/> |   |   |  |   |   |   |   |  |  |  |   |   |  |   |   |  |   |   |   |   |
| if yes, date:  | <table border="1"> <tr> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td>D</td><td>D</td><td></td><td>M</td><td>M</td><td></td><td>Y</td><td>Y</td><td>Y</td><td>Y</td> </tr> </table> |                       |   |   |  |   |   |   |   |  |  |  | D | D |  | M | M |  | Y | Y | Y | Y |
|  |   |                       |   |   |  |   |   |   |   |  |  |  |   |   |  |   |   |  |   |   |   |   |
| D  | D   |                       | M | M |  | Y | Y | Y | Y |  |  |  |   |   |  |   |   |  |   |   |   |   |
| if (I.) no   |   |                       |   |   |  |   |   |   |   |  |  |  |   |   |  |   |   |  |   |   |   |   |
| II. Patient and another person (e.g. formal / informal caregiver) answered questionnaires jointly. ( <i>joint assessment</i> )         | <input type="radio"/>   | <input type="radio"/> |   |   |  |   |   |   |   |  |  |  |   |   |  |   |   |  |   |   |   |   |
| if yes, date:  | <table border="1"> <tr> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td>D</td><td>D</td><td></td><td>M</td><td>M</td><td></td><td>Y</td><td>Y</td><td>Y</td><td>Y</td> </tr> </table> |                       |   |   |  |   |   |   |   |  |  |  | D | D |  | M | M |  | Y | Y | Y | Y |
|  |   |                       |   |   |  |   |   |   |   |  |  |  |   |   |  |   |   |  |   |   |   |   |
| D  | D   |                       | M | M |  | Y | Y | Y | Y |  |  |  |   |   |  |   |   |  |   |   |   |   |
| if (I. an II.) no  |   |                       |   |   |  |   |   |   |   |  |  |  |   |   |  |   |   |  |   |   |   |   |
| III. Another person answered patient questionnaires instead of patient (e.g. formal / informal caregiver. ( <i>proxy assessment</i> )) | <input type="radio"/>   | <input type="radio"/> |   |   |  |   |   |   |   |  |  |  |   |   |  |   |   |  |   |   |   |   |
| if yes, date:  | <table border="1"> <tr> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td>D</td><td>D</td><td></td><td>M</td><td>M</td><td></td><td>Y</td><td>Y</td><td>Y</td><td>Y</td> </tr> </table> |                       |   |   |  |   |   |   |   |  |  |  | D | D |  | M | M |  | Y | Y | Y | Y |
|  |   |                       |   |   |  |   |   |   |   |  |  |  |   |   |  |   |   |  |   |   |   |   |
| D  | D   |                       | M | M |  | Y | Y | Y | Y |  |  |  |   |   |  |   |   |  |   |   |   |   |

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Please answer the following questions (1-5) only if the patient could not answer the questions (either alone or with help of another person). *(Neither self assessment (I.) nor joint assessment (II.), but only proxy assessment (III.) possible.)*

|  |                                | yes                   | no                    |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
|--|--------------------------------|-----------------------|-----------------------|---|---|---|--|--|---|---|---|---|---|--|--|--|---|---|--|--|--|---|---|--|--|--|---|---|---|---|--|--|--|
| 1. Patient died.   |                                | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
| if <u>yes</u> , date: <table border="1" style="display: inline-table; vertical-align: middle;"> <tr> <td></td><td></td><td></td><td></td> <td>-</td> <td></td><td></td><td></td><td></td> <td>-</td> <td></td><td></td><td></td><td></td> <td></td> </tr> <tr> <td>D</td><td>D</td><td></td><td></td> <td></td> <td>M</td><td>M</td><td></td><td></td> <td></td> <td>Y</td><td>Y</td><td>Y</td><td>Y</td> <td></td> </tr> </table> |                                |                       |                       |   |   | - |  |  |   |   | - |   |   |  |  |  | D | D |  |  |  | M | M |  |  |  | Y | Y | Y | Y |  |  |  |
|  |                                |                       |                       | - |   |   |  |  | - |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
| D  | D                              |                       |                       |   | M | M |  |  |   | Y | Y | Y | Y |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
|  | if <u>yes</u> , place of death |                       |                       |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
|  | A. clinic / hospital           | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
|  | B. patient's home              | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
|  | C. nursing home                | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
|  | D. hospice                     | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
|  | E. other, please specify:      | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
|  | _____                          |                       |                       |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
|  | _____                          |                       |                       |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
| 2. Consent to study was withdrawn.   |                                | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
| 3. Patient too ill (incapacity due to illness or illness related complications / restrictions).  |                                | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
| 4. It was not possible to make an appointment / meet the patient.  |                                | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
| 5. Patient declined.<br>Please specify reasons:  |                                | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |
|  | A. felt too ill                | <input type="radio"/> | <input type="radio"/> |   |   |   |  |  |   |   |   |   |   |  |  |  |   |   |  |  |  |   |   |  |  |  |   |   |   |   |  |  |  |

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|  |                                   |                       |                       |
|--|-----------------------------------|-----------------------|-----------------------|
|  | B. felt too burdened              | <input type="radio"/> | <input type="radio"/> |
|  | C. lack of time                   | <input type="radio"/> | <input type="radio"/> |
|  | D. lack of interest               | <input type="radio"/> | <input type="radio"/> |
|  | E. bothered by questions          | <input type="radio"/> | <input type="radio"/> |
|  | F. other reasons, please specify: | <input type="radio"/> | <input type="radio"/> |
|  |                                   |                       |                       |
|  |                                   |                       |                       |

Please answer the following questions (6-7) if patient questionnaires could also not be answered by another person instead of patient (e.g. formal/informal caregiver). (Also no proxy assessment (III.) possible.)

|  |  | yes                   | no                    |
|--|--|-----------------------|-----------------------|
| 6. No such person available.                   |  | <input type="radio"/> | <input type="radio"/> |
| 7. Person declined.<br>Please specify reasons: |  | <input type="radio"/> | <input type="radio"/> |
|  | A. felt not competent to answer questions instead of patient | <input type="radio"/> | <input type="radio"/> |
|  | B. felt too burdened   | <input type="radio"/> | <input type="radio"/> |
|  | C. lack of time  | <input type="radio"/> | <input type="radio"/> |
|  | D. lack of interest  | <input type="radio"/> | <input type="radio"/> |
|  | E. bothered by questions                                     | <input type="radio"/> | <input type="radio"/> |
|  | F. other reasons, please specify:                            | <input type="radio"/> | <input type="radio"/> |
|  |  |                       |                       |
|  |  |                       |                       |

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Please answer the following questions (8-16) in any case.

## Place of assessment

|  | yes                   | no                    |
|--|-----------------------|-----------------------|
| 8. Patient's home                            | <input type="radio"/> | <input type="radio"/> |
| 9. Caregiver's home                          | <input type="radio"/> | <input type="radio"/> |
| 10. Clinic / hospital                        | <input type="radio"/> | <input type="radio"/> |
| 11. Nursing home                             | <input type="radio"/> | <input type="radio"/> |
| 12. Hospice                                  | <input type="radio"/> | <input type="radio"/> |
| 13. Other, please specify:<br>_____<br>_____ | <input type="radio"/> | <input type="radio"/> |

## Time point of assessment

|  | yes                   | no                    |
|--|-----------------------|-----------------------|
| 14. Questionnaires were completed at the correct time.<br><u>if no</u> , please specify reasons:<br>_____<br>_____ | <input type="radio"/> | <input type="radio"/> |

## Completeness

|  | yes                   | no                    |
|--|-----------------------|-----------------------|
| 15. Were all questions answered?<br><u>if no</u> , please specify reasons:<br>_____<br>_____ | <input type="radio"/> | <input type="radio"/> |

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Blinding

|   | yes                   | no                    |
|---|-----------------------|-----------------------|
| 16. Blinding of the scientists persists.<br>if no, please specify reasons:<br><br><div></div> <div></div> | <input type="radio"/> | <input type="radio"/> |