

## BEAMS Trial

## Patients' and caregivers' sub-study

**Topic Guide***(Patients)*

Participant's Screening Number \_\_ / \_\_ / \_\_

Date \_\_ / \_\_ / \_\_

Drop Out Conclusion 

Study Stage \_\_\_\_\_

**You have been asked to participate in this study because you have emphysema and feel shortness of breath...**

**1. What did you know about morphine before participating in the BEAMS study?**

- What is it used for?
- Effects (positive and negative)

**2. What was your source of information about morphine?**

- General Practitioner, other clinician, other health professionals, TV, radio, social media, family, friends

**3. Had you heard about using morphine for shortness of breath?****• What are your thoughts on this?**

(If the person mentioned other settings drug abuse, substitution therapy, pain, etc...)

Do you believe there are differences between the morphine given in other settings (drug abuse, substitution therapy, pain...) and morphine given for shortness of breath (route, dose, formulations)?

**4. What results were you expecting?**

- Breathlessness, Other symptoms
- Emotional status
- Function
- Other

**5. Did you have any fears or concerns about this medication?**

- Effect on sleep
- Effect on concentration
- Effects on driving
- Addiction, tolerance, side-effects
- Other

**6. Did you discuss this medication with anyone before?**

- [Caregiver], General Practitioner, other health professionals, family, friends...

**Now that you have completed the study:****7. Have your views on this medication changed over the study? In what way?**

- Overall effects, concerns, other (positives and negatives)...
- Describe by study stage in possible (differences between weeks 1, 2, 3, extension phase)

**8. How easy it is taking this medication?**

**9. Has this medication changed your daily life? In what way?**

- Breathlessness, other symptoms
- Emotional well-being
- Function
- Relationships
- Feelings about the disease (concerns, hopes)
- Overall quality of life

**10. Do you think this medication would benefit you enough to be on it long term?**

- Why / Why not?

**11. Do you have any advice to other people with emphysema and breathlessness?**

## BEAMS Study

## Patients' and caregivers' sub-study

**Topic Guide***(Caregivers)*

Participant's Screening Number \_\_ / \_\_ / \_\_\_\_

Date \_\_ / \_\_ / \_\_\_\_

Drop Out Conclusion 

Study Stage \_\_\_\_\_

You have been asked to participate in this study because [participant] has emphysema and feels shortness of breath, and has identified you as the person that knows him/her best...

**1. What did you know about morphine before participating in the BEAMS study?**

- What is it used for?
- Effects (positive and negative)

**2. What was your source of information about morphine?**

- General Practitioner, other clinician, other health professionals, TV, radio, social media, family, friends...

**3. Had you heard about using morphine for shortness of breath?**

- What are your thoughts on this?
- If the person mentioned other settings (drug abuse, substitution therapy, pain, etc) → Do you believe there are differences between the morphine given in other settings (drug abuse, substitution therapy, pain...) and morphine prescribed by a doctor or nurse for pain or breathlessness (route, dose, formulations)?

**4. What results were you expecting?**

- Breathlessness, Other symptoms
- Emotional status
- Function
- Other

**5. Did you have any fears or concerns about this medication?**

- Effect on sleep
- Effect on concentration
- Effects on driving
- Addiction, tolerance, side-effects
- Other

**6. Did you discuss this medication with anyone?**

- [Participant], General Practitioner, other health professionals, family, friends...

**Now that [participant] has completed the study:****7. Did your views on this medication changed over the study? In what way?**

- Overall effects, concerns, other (positives and negatives)...
- Describe by study stage in possible (differences between weeks 1, 2, 3, extension phase)

**8. How easy it is taking this medication?**

**9. Has this medication changed your daily life?**

- Things you could not do
  - Emotional well-being
  - Relationships
  - Feelings about the disease (concerns, hopes)
  - Overall quality of life

**10. Do you think this medication would benefit [participant] enough to be on it long term?**

- Why / Why not?

**11. Do you have any advice for other people providing care or support for people with emphysema and shortness of breath?**