

## INTERVIEW PART TWO:

What affects carers choice for own versus healthcare professional (e.g. district nurse) administration of medications to seriously ill people in their own home?

### Background / Introduction:

People who are seriously ill and nearing the end of their life may want to be cared for in their own homes. As their illness gets worse they may find it difficult to take medications by mouth – either because they are experiencing nausea or vomiting or because they are becoming too weak to swallow. In the UK, when this happens, it is usual practice for a cannula to be put in – this is a small plastic tube placed under the skin. Once it is in place it can be used to give the person medication under the skin without using needles – this is sometimes called a subcutaneous injection. The healthcare team check the cannula most days and change it on a regular basis.

If a person is on regular medications, a syringe pump is often connected to the cannula to give these medications throughout the day and night to keep symptoms controlled. The person may experience some symptoms even when this is in place – these are called ‘breakthrough’ symptoms and the most common are pain, agitation, nausea and noisy breathing (rattle). When this happens, a friend/family member is advised to call a healthcare professional (HCP), usually a district nurse. The nurse will visit and give the patient an extra dose of medication using the cannula that is already in place. It can take a long time, often much more than an hour, for the nurse to arrive, prepare and give the medication. This wait can be distressing for patient and carer.

Giving injections through the cannula that is already in place is usually less painful than an injection into muscle and easier to give. We want to find out whether it is useful and practical for a friend/family member who is involved in the person’s care to learn to do this instead of having to wait for a nurse to attend. This person acting as a carer would be trained and educated by a healthcare professional to recognise breakthrough symptoms, and prepare and give these no-needle injections. This method of teaching carers to do this has been used successfully in parts of Australia for many years. We are working with the team from Brisbane who pioneered it. We cannot be sure that this approach would be welcomed in the UK, or if it will be useful and practical for UK patients and their carers. That is why we need to test it out and find out what you think.

## Attribute Selection STAGE 1: Ranking Exercise - Interview Schedule (Version 3)\*

Key: *Instructions for interviewer*

We are keen to find out what is likely to affect carers' choice for own versus healthcare professional (district nurse) administration of these injections.

Here are some factors\*\* that we think may affect a carer's decision ...

*Interviewer displays cards (Appendix 7.1) in a random order in front of the participant.*

Looking at these cards:

1. **Is there anything missing?** Are there any other factors what would affect your choice?

*Interviewer writes additional factors on blank cards and places them alongside the pre-defined cards in front of the participant. **Record any self-nominated factors on the interview record sheet (Appendix 7.2).***

2. **Which are the most important factors in your opinion?** Can you pick up all the cards that would most likely affect your decision?

*Explain that these factors can have been experienced, or not; and include any that were self-nominated in this exercise. Clear the remaining cards from the table.*

3. **Now, can you rank these in order of most important to least important?**

*Check the order the interviewer places the cards is i.e. So, you think 'X' at the top is the most important? Encourage the participant to "think aloud" and explain their ranking. If participants find it hard to rank certain factors, or align them side by side, explore why. **Record the rank scores on the interview record sheet.***

**\*to be completed with first SIX participants in each group.**

### **Waiting time for healthcare professional**

Length of time it would take for the healthcare professional (e.g. nurse, GP) to arrive at your home.

### **Time for medication to work**

This is the time from starting to prepare the injection until symptoms are reduced to an acceptable level.

### **Frequency of additional home visits by healthcare professional**

How often you would need to request a healthcare professional to visit and to administer the injection because the person you are caring for has breakthrough symptoms that require medication.

### **Potential for administration error**

Risk of making a mistake e.g. giving the wrong medication or the wrong dose.

### **Cost to the NHS**

Cost to the NHS of the associated healthcare.

### **Number of medications**

The number of different types of medication prescribed for you to administer.

### **Amount of training required**

Time it takes be trained and educated by the district nurses to recognise breakthrough symptoms, and prepare and give these no-needle injections.

### **Symptom severity**

The severity of breakthrough symptoms before medication. Rated on a scale of 0-10 by the person you are caring for or your experience.

### **Frequency of symptoms**

How often the person you are caring for has breakthrough symptoms e.g. pain, agitation, nausea and noisy breathing (rattle).

**Anything Else?** <write here>

**Anything Else?** <write here>

Participant ID: \_\_/\_\_/\_\_

Interviewer ID \_\_

<b>Factor*</b>	Rank Results (insert 1-10) 1 = most important 10 = least important X = not selected
Anything Else? <b>Write here:</b>	
Anything Else? <b>Write here:</b>	
Amount of training required	
Cost to the NHS	
Frequency of additional home visits	
Frequency of symptoms	
Number of medications	
Potential for administration error	
Symptom severity	
Waiting time for healthcare professional	
Time for medication to work	

## Attribute Selection Stage 2: Cognitive Interview Schedule (Version 2\*)

*\*to be completed with remaining participants in each group.*

Key: *Instructions for interviewer*

**We are keen to find out what affects carers' choice for own versus healthcare professional (district nurse) administration of these injections.**

We have previously asked carers' about what was important in their **decision**.

I am going to show you some cards that describe what they thought was most important - and some examples of the type of questions we want to use in our survey.

Then I would like you to describe to me **what YOU think the card is explaining**.

*Interviewer displays cards\* (Appendix 7.3) in front of the participant one at a time.*



Prompts for discussion:

- Can you describe what you see on this card? What does that mean to you?
- Can you describe in Option 1?
- Can you describe in Option 2?
- Is it clear how they differ?
- What is your understanding of <insert attribute label>, presented here?
- So, what do you think the card is describing?
- Do you understand the question?
- Do you think the information here <point to box below Option 1 or Option 2> explains this factor <point to attribute label>?
- Do you think we could present this information differently?

*\* list of attributes will be informed by the results of the ranking exercise of the first 6 participants in each group. Examples provided in Appendix 7.3 show descriptions of attribute, potential levels, and choice task format. Maximum of cards per participant.*







*\*To be informed the first 6 interviews in each group*

**Card A**

	Scenario 1	Scenario 2
<p><b>Waiting time</b> Length of time it would take for the healthcare professional (e.g. nurse, GP) to arrive at your home to administer the injection.</p>	 <b>1 hour</b>	 <b>15 minutes</b>

**Card B**

**In which scenario would you prefer to administer the no-needle injection?**

	Scenario 1	Scenario 2
<p><b>Waiting time</b> Length of time it would take for the healthcare professional (e.g. nurse, GP) to arrive at your home to administer the injection.</p>	 <b>1 hour</b>	 <b>15 minutes</b>
<p><b>Symptom severity</b> The severity of breakthrough symptoms before medication. Rated on a scale of 0-10 by the person you are caring for or your experience.</p>	 <b>3 out of 10</b>	 <b>8 out of 10</b>
<p><b>Time for medication to work</b> This is the time from starting to prepare the injection until the symptoms are reduced to an acceptable level.</p>	 <b>10 minutes</b>	 <b>1 hour</b>

Please tick ✓ one option

[ ]

[ ✓ ]