**Information leaflet**

**Views of Patient and Informal Carer- Evaluation of**

**Palliative Care in Partnership Service**

You are being invited to take part in a questionnaire-based survey using the Palliative Care in Partnership Service questionnaire. Before you decide to participate, it is important that you understand why the survey is being done and what it will involve, as you may then choose not to take part. Please take time to read the following information carefully and feel free to ask if you would like more information or if there is anything that you do not understand (see contact details at the end of this information sheet). Please also feel free to discuss this with family or friends if you wish. Thank you for taking the time to read this. Your views are very important and will be used to help us to provide better care for patients and families in the future. We very much hope you will feel able to contribute. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

**What is the purpose of the survey?**

We know that when people are at the end of their life, having the right care and support is very important, both for the person who is ill but also for their families and friends too. The Palliative Care in Partnership is a new service that aims to provide patients who are approaching the end of their life with care and support in a place of their choosing, usually at home or in their normal place of residence. We need to find out if this way of working has benefits for people and those who care for them. This will help with improving this service in the future.

**Why have I been chosen to take part?**

You have been chosen to take part because you, your family or friend have received care from the Palliative Care in Partnership Service and we would like to know whether this helped you, your family or friend and how we can improve.

**What will happen if I take part?**

We would like you to fill in a short questionnaire. This will take around 10 minutes. It asks about the care and support both you and your family or friend received and whether your needs were fully met. Your experiences are very important, so please feel free to be completely open and honest. Most of the questions can be answered by simply ticking the most appropriate box. If you would prefer not to answer a question, please go on to the next one. We would be very grateful for any additional comments that you would like to make in the spaces provided or on the back page. You will not be identified personally on this document. Any information you share will be treated respectfully, confidentially and all identifiable details will be removed from information that is fed back to the service. All the information you provide is anonymous. We are more than happy to provide extra help and support in completing the questionnaire. If you would like help, or if you have any questions, please see contact details at the end of this information sheet.

**Do I have to take part?**

No, it is entirely voluntary. If you do agree to take part then change your mind and wish to withdraw that is fine. You can do so without giving any reason. This will not affect your care if you choose to use the service in the future.

**What are the benefits to taking part?**

By taking part, the information you provide will be used to decide on how the service continues and help us to improve our service.

**What if I am unhappy or there is a problem?**

If you are unhappy, or if there is a problem with the survey questionnaire, please feel free to let us know please see contact details at the end of this information sheet.

**Will my participation be kept confidential?**

The Palliative Care in Partnership service is committed to handling your information securely and in line with the Data Protection Act 2018 and General Data Protection Regulation (GDPR).All the information collected will be kept strictly confidential within the team and secured against unauthorised access. We would also like to make absolutely clear that no names, or other information that could identify you, will be used in any reports we write. You will not be asked to include your name on the questionnaire; instead an identification number will be assigned to ensure that you remain anonymous in any reports about the results. The information collected will be retained and securely stored for 10 years and will then be disposed of securely. The Palliative Care in Partnership service do not need any personal information about you for the purposes of this service evaluation.

**What will happen if I want to stop taking part or withdraw my information?**

You can decide to stop taking part at any time without giving a reason and without your future use of the new service being affected.

**What will happen to the results of the survey?**

Information obtained from the questionnaire will be entered into a database and analysed by the team. At the end of the project, the findings will be written up into a report, which will be submitted to xxx. The results will be available to the public. We cannot promise the project will help you but the information we get from this project will help improve the quality of end of life care provided locally. No identifying information about you will be included in the report or any articles about this survey. We are confident that this survey will make a difference to improving the way that care is delivered to people at the end of their lives.

**Who can I contact if I want further information about the evaluation?**

Tess Cleaver

East Cheshire Hospice @Home

East Cheshire Hospice

Millbank Drive

Macclesfield

SK103DR

Ecccg.echospiceathome@nhs.net

01625 664999

**This information is available in audio, Braille, large print and other languages. To request a copy, please telephone 01270 758120**

**Views of Patient and Informal Carers**

 **Evaluation of**

**the Palliative Care in Partnership Service**

This questionnaire is about the care and services received by you and your friend/relative. The information you give will help us improve care for people and for their family and friends. Your views are, therefore, important to us. If you feel upset or distressed, you do not have to continue with the questionnaire and can stop at any time.

We are interested in finding out the experiences of all people who have experienced the Palliative Care in Partnership Service. We also think it is important to find out about the care you and the family received at this time. Some of the questions may not be relevant to you. Please fill in as much of the questionnaire as you can. Your answers to these questions will be treated as strictly confidential. No names will be used in the reports we write.

Instructions:

As you go through the questionnaire, please answer the questions by **ticking** the most appropriate box. If you make a mistake or wish to change your answer, cross through the answer you do NOT want. If you would rather not answer one of the questions, please go on to the next one. We are very interested in what you have to say.

**Please state if you are:**

|  |  |
| --- | --- |
| **Patient** | **Yes / No** |
| **Carer / friend / family member** | **Yes / No** |

*If you are not the patient receiving care, please complete to the best of your knowledge on their behalf-thank you*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Strongly disagree** | **Disagree** | **Neither agree or disagree** | **Agree** | **Strongly agree** |
| 1. **Were you involved in decisions about your care as much as you would have wanted?**
 |  |  |  |  |  |
| 1. **Were you advised of who to contact and how if you needed help or advice?**
 |  |  |  |  |  |
| 1. **Do you feel you were treated like an individual by the care team ?**
 |  |  |  |  |  |
| 1. **Do you feel able to have an open and honest conversation with the team providing your care?**
 |  |  |  |  |  |
| 1. **Do people providing your care communicate with one another and you and other professionals involved in your care ?**
 |  |  |  |  |  |
| 1. **Do you have confidence that the team who were providing care were competent and skilled to support your needs?**
 |  |  |  |  |  |
| 1. Please use the space below if there is anything more you would like to say about the care provided:
 |

**Thank you for taking the time to complete this questionnaire.**