**DRAFT EMAIL TO SEND OUT WITH SURVEY**

**(Date)**

Dear ….

[Add here the name of your ERN] is currently working on a project to develop a model care pathway for [add here the name of the condition].

The goal is to provide an easy to follow map to guide diagnosis and care suitable for people living with this conditions, carers, primary care health professionals, physiotherapists, occupational therapists, speech & language therapists, psychologists, social workers, hospital specialists and health service managers.

The model care pathway also aims to help mapping out where the care is best provided, be it in a specialist hospital setting or in primary and community care or a mixture of both. We are hoping that this pathway will be useful for planning care.

The ERN is working with the experts in the network to detail each of the medical aspects of the pathway. In parallel, we need to collect lived experience of people living with the condition to help in the design of this pathway.

The ERN will host the final care pathway on its website for easy access. The pathways will be regularly reviewed to make sure that new evidence about management and treatment of the condition is updated.

The [add here the name of the condition] pathway will cover the following stages: [add here the stages as described in the detailed scope of the care pathway] in [add here population]. The care pathway refers to the services provided in [add here the setting(s)].

Please use this survey to provide your feedback.

Please do get in touch if you have any questions. We look forward to hearing from you.

Yours sincerely,

(Signature)

**(Name)**

# **Needs Assessment Questionnaire Template**

*Please note that this template needs to be adapted. The patient lead will need to adapt this questionnaire to the stages included in the outline scope of the care pathway and may also further adapt some of the questions based on his/her own experience.*

*The questionnaire has been developed to survey:*

* *Patient representatives: people actively involved in national and/or European patient organisations have a good understanding of their community needs and priorities.*
* *Individual patients to share their own personal experience and views.*

*Administration: the questionnaire can be delivered either through an online survey tool (please contact your ERN care pathway project manager for support if needed). It may also be used in focus groups or as an interview guide to perform in-depth interviews.*

# **Needs Assessment Questionnaire for [add name of condition]**

1. **Please indicate in what capacity you are responding to this survey: (mandatory field – must be responded)**
   1. I am responding as an individual patient
   2. I am responding as a representative of my patient community

**Follow-up question ONLY if they select b:**

Please indicate the name of your patient organisation **(mandatory field – must be responded)**

1. **Highlight what are in your view the main priorities for people living with this condition and their families:**

1.1 Physical concerns (i.e. specific symptoms that need to be managed, walking, diet, pain, speech problems, etc.):

1.2 Emotional concerns, including family/relationship priorities:

1.3 Practical/Lifestyle concerns (caring, work, education, housing, transport or parking, etc.)

1. **First Symptoms to Diagnosis**

Please share any specific needs that people and families experience from first symptoms until diagnosis.

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| --- |
|  |

1. **Diagnosis**

Please share any specific needs that people and families experience at the time of diagnosis.

|  |
| --- |
|  |

1. **Access to Care** 
   1. What were the main needs that people and families have to access specialised healthcare services
   2. What were specific needs that people and families have to access social services?
2. **Treatment**

What were the main needs that people and families have [when the treatment was initiated] [when surgical procedure was performed?]

1. **Follow-up care**

What are the main needs that people and families have when receiving follow-up care?

1. **Transition**

What are the main needs that people and families experience when transitioning from pediatric-adult care and/or from adult-elderly care

1. **Guidelines and references**

Are there other guidelines or references that you feel would be helpful to include?

1. **Have you other general comments on any aspect of your care pathway?**