

DEVELOPING PATIENT JOURNEYS

ITHACA

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Activity	Developing Patient Journeys
Area	healthcare
Duration	3 months, on going
Contact	Matt Johnson, Sue Routledge, Ammi Sundqvist Andersson

1. SUMMARY

i The ePAG group in ITHACA separately developed their own disease specific “Patient Journey” from the perspective of patients and parents, as a reference point for ERN Pathways, Guidelines and information sharing. The Patient journeys are personal testimonies from people with first-hand experience of living with a rare syndrome. They map the natural history and needs of patients along their life journey, through the patients’ or parents’ eyes. The patients’ disorders are very complex and require a multi-disciplinary team to support the patient based on the needs identified in the journeys.

The approach was developed in ERN GENTURIS but is relevant to other rare diseases and Networks. ERN ITHACA covers a wide range of rare diseases and syndromes and patient advocates were unsure about representing other rare diseases other than their own. The advocates were given a table to map the specific needs and obstacles for the rare disease they represent along the different stages of the pathway, based on their experience and the experience of others living with the disease.

The information presented in the table was summarized into a visual “Patient Journey” or “route map” to support user-friendly communication. At a face to face workshop with the ERN coordinating team, each ePAG patient advocate presented their Patient Journey, the life journey from first symptom, diagnosis through to care, treatment and follow up. This was presented to the wider ePAG group to support better understanding of each other’s diagnosis. Between each presentation, the group were asked to highlight common needs that others had also experienced in their rare disease. The common needs for all the ERN ITHACA syndromes were captured through this workshop and summarized into one common Patient Journey.

The next step was to identify recommendations for each of the common need identified and for the ERN to address both at a strategic and operational level how the Network will address these common needs.

2. INITIAL SITUATION

i We are a small ePAG group who see each other at different conferences and we have tried to have small unofficial gatherings back-to-back to other meetings. One of the main concerns we had with this exercise was how to represent the journey of other diagnostic groups within ERN ITHACA. It was challenging to create a template that suited every disorder because some of us had struggled with getting a diagnosis, whereas others knew it from the beginning but had a problem of getting the right care. We brought up the concerns we had with Matt Bolz-Johnson and he created a template to describe a Patient Journey across the different diseases.

To summarise our needs, we wrote down how we think our own journey in the healthcare system should be by filling in the template. Some of the ePAGs patient advocates already had a clear vision on how a multidisciplinary healthcare pathway should be, but they had never described it in writing.

3. CONTRIBUTION TO PATIENT ENGAGEMENT AND/OR IMPROVEMENT OF CARE

i With this exercise, we now have a better understanding of each other's situation and have a better knowledge of the different diagnoses. In addition, the members of the ePAG are now more confident in their role as representatives of their own disease. We have gone in a systematic way through all the steps along the healthcare pathway, and responded to the question: what did I have and what did I need. This has given us a stronger voice in our role as patient advocates.

As new syndromes are being diagnosed/discovered, there is a great need for patient journeys. When similar symptoms are identified in other syndromes, possible solutions can be learnt from each other.

4. SUCCESS FACTORS

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- We were provided a common template in which we were asked to describe our experiences and desires by answering specific questions. That made it easier to compare the different disorders with each other. It provided us with a structured way to share our experiences and expertise in a common approach.
 - Doing the mapping exercise in your own home environment at your own pace, and not as a group exercise, made it easier to really reflect on the reality of the healthcare services that we could access and what was the gap with our real needs. It is easy to lose your thread when you are having group discussions.
 - Having a clear visual for each disease pathway made easier the comparison to identify the common situations and needs.
 - The journeys made it easier for us to engage with clinicians. At a face to face meeting with the ITHACA ePAG patient advocates and the ERN Coordinator Alain Verloes, we all presented our own syndrome's pathway in a more relaxed environment and we could all share our own expertise. After every session there was enough time for reflections and questions.

- The common needs of all ITHACA syndromes were described in a document and they are now being used to advocate for the needs of all patients represented and to inform the development of the ERN scope and structure.
- Having someone facilitating and collecting information is crucial for the success of this exercise.

5. LESSONS LEARNED



- There is a need for a facilitator to lead the work.
- The ePAG patient advocates need to be committed to the exercise and work together.
- We learnt more about each other's syndromes and found out that, even if the diagnoses are different, we do have similar needs.
- The exercise made us more united in the group, sharing brought us more together.
- We found out that the healthcare services for the same syndrome varies between countries.
- We learnt about the importance of getting other parents input for completeness to be sure everything was covered. This is particularly important if there is not a complete natural history for a syndrome.
- We learnt how similar some of the issues were.
- It was made clear that psychological support was much needed for parents getting a new diagnosis!
- We learnt that patient groups might need external help to describe their journey and fill in with the templates, particularly those where the children have developmental delay and need a lot of input from therapists.

ANNEX – Patient Journey Template

Stage of Journey	Timeline	Clinical Presentation/ Symptoms	Identify Patient Needs	What good care would ideally be / what support is needed
Pre-diagnosis		•	•	•
First symptom		•	•	•
Diagnosis		•	•	•
First treatment ...		•	•	•
Surgery		•	•	•
Follow up care		•	•	•
etc.		•	•	•

Further Information

- *Add FREE TEXT*