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PATIENT PATHWAY TOOLKIT

How to Map a Patient Pathway

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How to Map a Patient Pathway

Contents

1. Introduction

1.1. What is the aim of this document?

This document aims to provide the steps needed to use the supplied toolkit to map the pathway patients and caregivers may experience. By following this guide, you or your organisation should be able to map the patients' pathway, identifying steps and challenges along the way, while also considering all the people who are affected by the disease (called "stakeholders") and research gaps. Mapping patient pathways can be a very useful tool for a patient organisation, both to help prioritise their activities, as well as to advocate for changes where the pathway identifies obstacles.

1.2. How was the methodology created?

Already existing patient pathway methodologies were modified and developed, together with the tools in the toolkit, to be more useful from the patients' perspective. *Why is it needed?*

It is important to determine why patient pathways need to be mapped before you start. Nailing down challenges experienced by your particular patient community to find appropriate solutions is a great starting point. To carry out the mapping, the initial phase is to understand and comprehend the steps and challenges yourself as a patient or a loved one experience.

Some reasons why mapping a patient pathway might be useful include:

- Understand the reality of patients and the associated challenges and burdens they encounter, including when those obstacles are experienced in the pathway
- Compare the reality of the patient-generated pathway with those developed by Health Care Providers (HPCs) or the health system, to highlight discrepancies of perception
- Feed disease-specific local patient experience data in order to leverage other stakeholders by showing where blockages/pain points exist in reality and across health systems
- Pinpoint blockages or pain points in the patient and/or caregiver pathway, which may be indirectly associated with the healthcare pathway (eg financial, anxiety, etc)
- Provide a framework for patient experience data to support impact measurement of novel interventions

- Structure qualitative evidence obtained from interviews for application in local/national/international advocacy efforts.

Being able to conceptualise the benefits of mapping the patient pathway can provide granular evidence to the patient community, for example, to lobby for inequality or challenge the healthcare sector as well as identifying research gaps, advocacy needs, or system personnel issues.

2. Preparation

When planning to map the pathway the patients from your organisation undergo, it is important to initially discuss collectively and agree on the reasons why the mapping should be carried out and what the expected/hoped action points resulting from mapping the patient pathway. An example of an action point would be to improve the pathway and combat the challenges the patient encounters throughout their pathway. From this starting point, more concrete goals can be identified. In addition, there may very well be action points that are very specific to the condition you are mapping, for example, campaigning for audio information to be made available for patients with visual disturbances. The process of mapping the pathway will inventorise all of the problems typically encountered, and will allow the organisation to document changes over time, and can also be adapted to include new treatments or specialties, as needed.

3. Implementation

To map the pathway it is most important to establish the ideal patient pathway. This can seem fairly easy, yet patients from different countries or health systems can have a variety of expectations or even pathways. Hence, gathering the narrative of the ideal pathway from patients and caregivers is essential.

The toolkit contains a tool that can be used as questions in an interview-style or focus group style with targeted questions that will provide the necessary answers to identify and establish the steps and challenges patients encounter. Through the questions, the ideal pathway can be established, and the challenges patients encounter arise almost in parallel.

The visual tool provided in this toolbox can be used as a canvas to note the established steps in the ideal pathway and the challenges. Although many rounds of rough drafting of the pathway are recommended, patient organisations that have gone through this process tend to use their annual general meetings to brainstorm and note down either on paper or using brainstorming platforms such as Miro or MindMap. The visual tool provided should be utilised to note down the final draft of the pathway, where then the challenges and actions to be taken can be associated and correlated.

Most certainly, desk research will be needed to complement the patient input on the ideal pathway. The research may include going through scientific publications, guidelines, white papers, etc. Certain points may be overlooked as they are standard or a given in the health system but still important to be considered in the ideal patient pathway. The desk research can also provide a more general perspective outside the country and disease-specific data gathered, potentially considering another step or a challenge.

With the information from the interviews or focus groups, the objective is to add the data gathered into the visual tool. This provides a visual representation of the steps and challenges and can used in a workshop organised within your patient organisation, and should be periodically reviewed and adapted as an ongoing task. Organising such a workshop is very valuable in capturing patients' and caregivers’ perspectives on the steps and challenges.

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2

The visual tool was designed to be used in workshops in which patients and caregivers provide their input through Post-it notes. The challenges are identified as well as the stakeholders involved in each stage of the pathway. Participants of the workshop should connect each challenge to the stakeholders involved. This guide provides colour codes for each stakeholder.

By the end of the activity, you should have a visual canvas with the identified steps in the patient pathway and the challenges the patient encounters in each step.

4. Analysis

Once the steps and challenges have been established, the following step is to define actions that will address the steps and challenges. It is very important to analyse the challenges and collectively brainstorm and agree on the actions to be taken to reduce or remove that challenge.

In this toolkit, you can find a bank of questions targeting each “column” within the pathway. The questions will help you to drive the brainstorming of actions to be taken by the patient organisation to advocate for better access, care, or other aspects.

Once again, the visual tool is useful for brainstorming ideas for each action to be carried out by the patient organisation. IMPORTANT: Your patient organisation may need to consider extending the volunteers and/or staff available to carry out the actions defined, to ensure successful implementation of the mapping exercise. Each action will need to be assigned an “owner” responsible to reporting progress against a pre-defined timeline and resource allocation. It is important to celebrate the completion of each predefined action, and consider reporting the process in your organisation’s newsletters, social media, etc.

The implementation step for this toolkit is also supported by the “Guidance Document for Planning Advocacy Projects”, which guides how to take challenges into action. We recommend using the guide to prioritise actions as usually resources are limited and require effective use.

5. Prioritisation

Once a list of steps and challenges has been coupled to actions intended to address them, the next really important step is prioritisation. Your organisation will not be able to do all of the actions at the same time, so the actions need to be categorised into what is urgent and important, and what is important but can wait. Some of the actions may be sequential in nature and that can be planned out too. Then you will want to estimate the resources in human work and in financial support that will be needed for each action. You will possibly need to write proposals or grants to fund some of these actions, and keep in mind that that may take at least a year, so also plan in time to write those proposals. It is important to make feasible plans that will incrementally improve the patient pathway, and a common mistake for organisations at this step is to take on more than they can handle. Most organisations find more success when 1-2 individuals “own” a single action, and can work within a budget and timeline accordingly.

6. Knowledge translation

Dissemination and publication of findings is also a very important step to consider since other patient organisations can benefit from the information as well as the development of guidelines within the disease area. Your organisation might consider how to optimise and share the learnings gathered from the patient pathway mapping exercise.