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PATIENT PATHWAY TOOLKIT

Interview guide mapping patient pathways

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Interview guide mapping patient pathways:

Purpose:

- We will look at different types of diseases and create a general patient pathway based on the experiences of various patients at different stages. This includes prevention and screening, diagnosis, treatment, and supportive care, as well as quality of life. We want to understand how patients go through this journey.
 - Your perspectives on how these navigations occurs are going to be key to establish a general pathway that patient organisations could base their patients' pathway could potentially follow.
1. Do the terms prevention and screening apply to your disease? What measures are currently in place? Could you explain this in the context of your disease?
 2. For a patient, what are the first signals (symptoms) that prompt them to seek medical advice? (We know the list can be long and diverse, we aim at finding some illustrative examples here)
 3. Within your healthcare system, what are the first steps for patients after the onset of their first symptoms? – i.e. can you give a general overview of how the patient typically moves through the healthcare system? *Another way of asking this, is "If we think of the pathway of a typical patient through the system, what are the main stops on that pathway?"* This aims to get a general idea of how patients move through their healthcare journey, either based on their community experiences or their personal knowledge. We want to confirm that our draft of the pathway is accurate.
 4. Let's break this down and look **in detail at some of those main stops** on the pathway:
 - a) Prevention and screening
 - From your perspective, in terms of the pathway that patients follow, what are the main prevention measures?
 - What are the main screening tests?
 - What is working well with prevention and screening?
 - What is working less well, and why?
 - b) Diagnosis
 - From your perspective, in terms of the pathway that patients follow, what are the main diagnosis steps?
 - Who is involved in the diagnosis?
 - What is working well with diagnosis?
 - What is working not so well, and why?
 - c) Optimise treatment
 - From your perspective, in terms of the pathway that patients follow, what are the main treatment and care steps?
 - Who is involved in the treatment and care?
 - What is working well with treatment, management and care?

- What is working not so well, and why?
- d) **Supportive care**
 - From your perspective, in terms of the pathway that patients follow, what are the main diagnosis steps?
 - Which stakeholders are involved in the supportive care?
 - What is working well with survival? (either when patients are in remission or in maintenance mode)
 - What is working not so well, and why?
 - For those patients who unfortunately will not survive, what works well in terms of the palliative support and care provided?
 - What works not so well for these patients and why?

These two questions pursue to deepen in the strengths and weaknesses of the patient pathway experienced.

- a) **Screening:** Describe how you think the ideal pathway for preventing and screening illnesses should work.
 - Who (which stakeholders) do we need to persuade to make these changes happen?
 - What evidence (kind of proof or information) would we need to show to convince these stakeholders?
 - b) **Diagnosis:** Describe how you think an ideal pathway to diagnosis should be.
 - Who (which stakeholders) would we need to persuade to implement the changes leading to the pathway you describe?
 - What evidence would we need to show to convince these stakeholders?
 - c) **Treatment:** Describe how you think the ideal pathway through treating illnesses should work.
 - Who (which stakeholders) would you need to persuade to change the pathway to what you describe?
 - What evidence do you think we could provide to convince these stakeholders?
 - d) **Supportive care:** Describe how you envision the ideal pathway to provide supportive care.
 - Who (which stakeholders) would we need to persuade to make these changes happen?
 - What kind of proof or information would we need to provide to convince these stakeholders?
 - e) **Palliative care:** Describe how you think the ideal pathway for providing palliative care should be
 - Who (which stakeholders) would we need to convince to implement the pathway you describe?
 - What evidence do you think we need to convince these stakeholders?
5. Considering the idealised steps in the pathway you have outlined and the stakeholders that you need to convince, can you consider the tools and evidence you will need?
 6. As we are getting to the end of the interview, from all the topics we discussed is there anything else you would like to add? Any subject that from your perspective we have not touched on?

Thank you for your time. Here's what we will do next:

- Generate a general outline of the patient pathway through healthcare.
- Provide a toolkit to help map out patient pathways and identify any challenges they face compared to the “general patient pathway”.
- Use these tools in a specific disease area, working together with a patient organisation.