Summary factsheet on patient involvement in ERN care pathway development

This document is part of the
Care Pathways Toolkit for **Healthcare Professionals** & **Patient Representatives**

WP6 TASK 6.2

JARDIN

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SUMMARY FACTSHEET: PATIENT INVOLVEMENT IN ERN CARE PATHWAY DEVELOPMENT

PHASE 1: PREPARATION PHASE

The preparation phase aims to identify potential topic areas (for example, conditions and target populations) for a care pathway to be developed. Once a condition or thematic group of conditions has been selected, the outline scope of the pathway and key disciplinary representation is decided. Experts and key stakeholders are identified and invited to take part in either the 'core writing group' and/or the extended 'pathway development group'. A clinical lead is selected to oversee and lead the care pathway development, and a pathway project manager is appointed to plan and co-ordinate the care pathway development process. The governance structure is established and the planning for the development of the project is completed.

STEP 1: SELECT TOPICS & DEFINE SCOPE

WHAT TO DO

Patient Advocates active in the ERNs (ePAG Leads) should **take part in the Network discussions on identification of possible topic areas** that can be considered for the development of care pathways under JARDIN. Patient Advocates active in the ERNs (ePAG Leads) should also **be consulted to define the outline pathway scope and target population.**

TIPS

Patient Advocates active in the ERNs should discuss in the ePAG potential topic areas and engage the ERN Coordination Team to suggest possible care pathway topics.

For multi-system conditions, experts from other ERNs should be engaged to inform the development of the outline pathway scope. For example, experts from ERKNet, ERN ITHACA and ERN eUROGEN should collaborate to define the outline pathway scope for the spina bifida care pathway.

STEP 2: IDENTIFICATION OF EXPERTS & KEY STAKEHOLDERS

WHAT TO DO

Patient Advocates active in the ERN, in collaboration with Clinical Leads, should **identify patient representatives for the respective condition to be active in the development of a care pathway**. Patient representatives can be from inside or outside the Network or from other ERNs where relevant.

In addition, Patient Advocates can also **identify and propose key experts and stakeholder groups** to be engaged throughout the scoping and development phases.

TIPS

The selection of possible patient representatives to be engaged and take part in the development process should reflect the target population of the care pathway and be from different EU Member States, providing a balanced geographical representative.

STEP 3: GOVERNANCE & PLANNING

WHAT TO DO

Patient Representatives identified by the Patient Advocates and Clinical Lead should **be invited to take part in the Core Writing Group (CWG), Pathway Development Group (PDG) and Stakeholder Network**[1] . **A minimum of 2 Patient Representatives will be members of the Core Writing Group.** Patient Representatives who agree to take part in the CWG & PDG should be involved as equal partners and included in the planning, scoping and development phases.

Patient representatives may use the Engagement Planner Workbook included in this Patient Partnership Planning Toolkit to plan how they will engage with their community in Phase 2 Scoping (2) and Phase 3 Development.

TIPS

Make sure that during the planning and setting up of the CWG & PDG, the care pathway project manager takes into account that patient representatives are volunteers and s/he is flexible with the timings of meetings.

For multi-systemic conditions, the care pathway governance structure should cover multiple ERNs. All key disciplines should be represented in the CWG.

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[1] The Core Writing Group (CWG) will conduct the research and coordinate the development of the care pathways from the outline pathway scope. It will consist of clinical expert leads and patient representative, a sub-group of the Pathway Development Group.
The Pathway Development Group will be engaged by the CWG to develop the outline pathway scope into a 'detailed pathway scope'; will be engaged in the key activities, will provide feedback on the ideal care pathway and will take part in building a consensus where there is a gap in the evidence.
The Stakeholder Network will be established from representatives from the wider key stakeholder community, who can be engaged with throughout the pathway development process including policy makers, hospital managers and patient groups.

PHASE 2: SCOPING PHASE

The Core Writing Group will further detail the pathway scope by including pathway parameters and key outcome measures.

During the scoping phase the CWG will:

- review existing guidelines and evidence.
- map the existing clinical practices is summarised to form a ‘baseline pathway’.
- capture the shared experiences and needs from the target patient population are used to form a ‘patient journey’.

The existing guidelines/evidence, baseline pathway and patient journey are triangulated together to identify key bottlenecks and sticking points in the pathway. Feedback is secured from the Pathway Development Group and Key Stakeholders on the findings from the comparison exercise.

STEP 4: DEFINE PATHWAY PARAMETERS

WHAT TO DO

Patient representatives should **take part in the co-creation of the detailed pathway scope, pathway parameters and key outcome measures**.

TIPS

Patient Representatives are best placed to shape the detailed scope and ensure the pathway will address the holistic needs for this target population. In addition, they can identify meaningful outcome measures and key performance indicators such as patient reported outcome measures (PROMs) and patient reported experience measures (PREMs).

STEP 5: GATHER & APPRAISE GUIDELINES & EVIDENCE

WHAT TO DO

Patient Representatives should **take part in identifying and appraising guidelines and existing evidence-based tools**.

TIPS

Patient Representatives should be included in appraisal of any new guidelines using the AGREE II methodology. In the event that the ERN decides that a systematic review is needed then patient representatives should be involved especially in the ‘Evidence to Decision’ discussions (as recommended by GRADE) to share their preferences and opinions of possible recommendations, weighing the harm and benefits of any care and treatment.

STEP 6: MAPPING OF CURRENT CLINICAL PRACTICES

WHAT TO DO

Local & National Patient Groups can **contribute to map existing care and clinical practice**.

TIPS

Suggest questions for local patient groups to answer that can be included in the survey of existing care (state of the art) and clinical practice. Given the heterogeneity of national healthcare systems across member states where possible, a range of countries should be surveyed e.g.: small, medium & large to ensure good geographical balance across different EU Member States and the spectrum of different types of healthcare systems.

STEP 7: COLLECT PATIENT NEEDS & EXPERIENCES

WHAT TO DO

The Patient Representatives who are members of the CWG should **lead on engaging the relevant patient community identified in the care pathway scope to map their experiences and needs and identify the key bottlenecks and potential enablers to accessing timely care and treatment.**

Patient representatives can use different methods to collect the experiences and needs from their respective communities including questionnaires, surveys, interviews to collect stories, focus groups, workshops, or a mix of these methods.

TIPS

Patient representatives may correlate and visually present the shared experiences and common needs along the different stages of the care pathway, from first symptoms, diagnosis, to treatment and follow-up using this “Patient Journeys” template.

STEP 8: TRIANGULATE PATIENT NEEDS, BASELINE PATHWAY & PUBLISHED EVIDENCE

WHAT TO DO

Patient Representatives in the CWG & PDG should be **involved in the comparison exercise that identifies the gaps and sticking points** between the existing baseline pathways and the common needs highlighted in the patient journey.

Patient Representatives, supported by relevant Patient Groups, should **engage the wider patient community on the results from the comparison exercise** between the common patient needs (detailed in the patient journey) and existing care and clinical practice (detailed in the baseline pathway) and provide feedback on the main research findings.

TIPS

When involved in the comparison exercise, patient representatives can also identify ‘good practices’, ‘enablers’ and ‘potential solutions’ that can be used to inform the design of the ideal care pathway. Engagement with the wider patient and medical community can be undertaken through existing events, conferences and webinars. Engagement with the wider medical community can also be via existing network, MDTs, events and conferences.

PHASE 3: DEVELOPMENT PHASE

Following the triangulation of the evidence-base, baseline pathway and patient journey, the Core Writing Group designs an ideal care pathway. A consensus building exercise will be conducted where gaps exist in the evidence. Key outcome measures are chosen to audit and evaluate the implementation and effectiveness of the pathway.

Supporting material is developed in parallel. This may include a graphical representation. The final care pathway is peer reviewed and submitted for approval.

The final care pathway and supporting material is signed off by the Network and then published and a communication plan is developed.

STEP 9: DESIGN IDEAL CARE PATHWAY

WHAT TO DO

Patient Representatives should be involved in the co-creation of an ideal care pathway and recommendations based on sharing the main findings of the research and addressing patient needs and sticking points.

TIPS

All contributors including Patient Representatives, health and social care professionals, hospital managers etc. should be recognised as co-authors in any publication of the final care pathway.

STEP 10: CONSENSUS TO COVER EVIDENCE GAPS

WHAT TO DO

Patient Representatives who are members of the PDG & CWG should be **involved in a consensus building exercise.** They can provide the key insights and preferences that have been gathered through the collection of patient needs (Step 8).

TIPS

Ensure that a critical mass of clinical and patient representatives is included in the consensus building exercise to cover all aspects of the rare condition/thematic group and to provide a good geographical balance across different EU Member States and the spectrum of different types of healthcare systems.

STEP 11: REVISE CARE PATHWAY & SUPPORTING MATERIAL

WHAT TO DO

Patient Representatives should be **involved is discussions on the format of the final care pathway, specifically the graphical version and any supporting infographics**, to ensure they incorporate accessible language for non-specialists, for example family doctors, community teams, nurses, patients, caregivers and their families.

Patient Representatives can **co-create the supporting material and infographics** and include useful links and key information that should be available at the right point in time.

TIPS

Supporting material and infographics should be developed to support patients and their families to navigate healthcare systems and be empowered to access the care and treatment they need in a timely manner, as care pathways are more than clinical management tools.

How do we connect the ERN system, providing a bridge to local systems?

STEP 12: APPROVAL & PUBLICATION

WHAT TO DO

Patient Representatives who have not been directly involved in the process should be included in the internal peer review.

Patient Representatives should **contribute to identifying communication needs** and the development of a communication plan, as Patient Groups are key stakeholders to support the implementation of care pathways through their extended networks and communities.

TIPS

National Patient Groups can be engaged in any national quality review process.

Patient organisations can develop supportive materials relevant to their local systems, to facilitate the implementation of the care pathway.

This file is part of the

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Please refer to this document to access all resources:

https://jardin-ern.eu/?resource=care-pathways-toolkit

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