ERN Clinician Checklist for Care Pathway Development

##### Phase 1: Preparation

Description

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, 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.

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| Step | Actions | Tick Box | Role / Responsibility |
| 1. Select Topics & Define Outline Scope
 | Identify care pathway topics |  | JARDIN WP6 Leads / ERN coordinators |
| Obtain commitment from ERN Networks Lead(s) |  | JARDIN WP6 Leads |
| Appoint pathway Clinical Lead(s)  |  | ERN co-ordinators |
| Appoint Pathway Project Manager |  | ERN co-ordinators / Clinical Lead |
| Approve care pathway topics list |  | JARDIN Task 6.2 WG |
| Define ‘outline pathway scope’ - condition, population(s), duration, care setting  |  | Clinical lead engages with ERN Network Members & Patient Advocates (selected via EPAGs) |
| **Outputs:** |  | 1. **List of Care Pathway Topics**
2. **Outline Pathway Scope**
 |
| 1. Identification of Experts & Key Stakeholders
 | Map clinical disciplines required based on outline pathway scope including care coordinators, medical and nursing staff, psychologists, allied health professionals, patients and their representatives  |  | Clinical Lead / Pathway Project Manager |
| Identify and invite expert leads from each relevant clinical discipline and expert patient leads to join a pathway development group (PDG) |  | Clinical Lead / Pathway Project Manager / ERN coordinator |
| Identify wider stakeholders who can be engaged with during pathway development process incl. policy makers, hospital managers and patient groups |  | Clinical Lead / Pathway Project Manager / ERN coordinator |
| **Output:** |  | **List of Disciplines, Experts & Key Stakeholders** |
| 1. Governance & Planning
 | Prepare work plan to co-ordinate activities to develop care pathways for Phase 2 & 3 |  | Pathway Project Manager |
| Set up the governance structure: * Pathway Development Group (PDG)
* Core Writing Group (CWG) - key experts from the PDG
 |  | Clinical Lead / Pathway Project Manager / ERN coordinator |
| **Output:** |  | **Governance Structure & Project Plan** |

##### Phase 2: Scoping

Description

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

* Review existing guidelines and evidence
* Map the existing clinical practices to form a ‘baseline pathway’
* Capture the shared experiences and needs of the target patient population - 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.

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| Step | Actions | ☑ | Role / Responsibility |
| 1. Define Detailed Pathway Scope & Parameters
 | Develop detailed pathway scope inc key parameters:* Patient population – demographics, age
* Rare condition(s) and sub-types, stage of disease(s)
* Test(s), procedure(s) and treatment(s)
* Stage and duration of the pathway
* Health and social care settings and entry and exit points
* Expected outcome measures including PROMS and PREMS
 |  | Core Writing Group (CWG) |
| **Output:** |  | **Detailed Pathway Scope including Parameters** |
| 5. Gather & Appraise Guidelines & Evidence | Gather and review existing guidelines and pathways & identify evidence relevant to the agreed scope |  | CWG supported by PDG |
| Existing guidelines already endorsed by the ERNs can be utilised. If no approved guideline exists, appraise new guidelines in line with international best practice, using AGREE II and a systematic review of the published evidence using GRADE if required.  |  | CWG supported by PDG |
| **Output:** |  | **Repository of Evidence & Existing Guidelines & Pathways** |
| 6. Mapping of Current Clinical Practices | Gather knowledge and experience from existing clinical practice / care pathways from ERN HCP members, including access to treatments via survey, workshop and / or interviews |  | CWG engage ERN HCP members  |
| **Output:** |  | **Baseline Pathway of Existing Care & Clinical Practice** |
| 7. Collect Patient Needs & Experiences | Collect patient experiences, needs, preferences, and bottlenecks and potential solutions |  | Patient Representatives in the CWG |
| Present in a patient journey |  | Patient Representatives |
| **Output:** |  | **Summary of patient needs and experiences eg. Patient Journey** |
| 8. Triangulate Patient Needs, Baseline Pathway & Published Evidence | Compare baseline pathway with the patient journey to identify gaps / sticking points in existing pathway |  | CWG |
| Map the published evidence, guidelines & recommendations to the baseline pathway |  | CWG |
| Consult key stakeholders on the results from the comparison of the baseline pathway & patient journey and provide feedback |  | CWG consult with PDG and wider stakeholders |
| **Output:** |  | **Summary of main research findings from the comparison exercise** |

##### Phase 3: Development

Description

**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 is completed where gaps exist in the evidence.** Key outcome measures set out in the detailed pathway scope will be used to audit and evaluate 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 ERN Network and then published and a communication plan is developed**

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| Step | Actions | ☑ | Role / Responsibility |
| 1. Design Ideal Care Pathway
 | Draft an ‘ideal care pathway’ based on the main findings of the triangulation of patient needs, baseline pathways and published evidence include:* proposed key solutions to address gaps in existing pathway
* include red flags (where relevant)
 |  | CWG  |
| Identify supporting material |  | CWG |
| **Output:** | **Ideal Care Pathway & Supporting Material** |
| 1. Consensus on Evidence Gaps
 | Form a consensus on any gaps in the evidence base |  | PDG engage with wider clinical leads and patient groups |
| **Output:** | **Consensus Statement (s)** |
| 1. Revise Care Pathway & Supporting Material
 | Update the ideal care pathway, and supporting material, based on the outcome of the consensus building process  |  | CWG |
| Review the format the care pathway - and decide on a graphical version of the care pathway  |  | CWG |
|  | Develop key performance indicators (KPIs) including PROMs and PREMs based on the outcome measures in the detailed pathway scope to evaluate the pathway |  | CWG including patient representatives |
| **Output:** | **Updated Care Pathway (Near-Final Draft), outcome measures / KPIs, graphical representation & Supporting Material** |

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| 1. Approval & Publication
 | Internal peer review of the Final Care Pathway  |  | PDG / ERN Network |
| Submit final Care Pathway for approval by the Network Board, or the relevant devolved management group e.g. Executive Committee |  | Clinical Lead / Pathway Project ManagerNetwork Board / Executive Committee or equivalent |
| Develop a publication presenting the final care pathway |  | CWG |
| Publish approved Care Pathway on the ERN website along with a peer review publication. |  | Clinical Lead / CWG / Pathway Project Manager |
| **Output: Care Pathway (Approved), Supporting Publication & Communication Plan** |