



# Care pathways for diagnosis of RD patients

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# Learning objectives

1. Understand what a care pathway is
2. Understand what the challenges are with establishing a care pathway for RD patients
3. Delineate what main components a care pathway for diagnosis of RD patients has
4. Understand what the challenges are regarding establishing a care pathway for diagnosis of RD patients

# Definition of Care Pathway

Methodology for mutual decision making and organisation of care for a group of patients during a well-defined period

In health and social care systems, a 'care pathway' is a **tool to enhance the coordination and quality of care** across this continuum by **improving patient outcomes**, promoting patient safety, increasing patient satisfaction, optimising the use of resources and reducing unnecessary variation in **best practice and evidence-based care**.


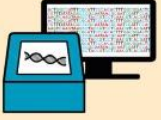











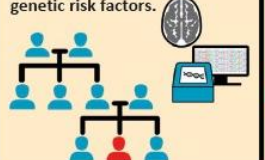


'Care pathways' resemble a **detailed care plan**, charting each step for a specific patient population to make sure they safely and efficiently reach the best outcomes and quality of life. Care pathways gather in one place all the guidelines and clinical protocols that provide instructions to treating clinicians and relevant professionals across health and social care for delivering optimal care and treatment to patients with specific conditions.

# Definition of Care Pathway





# Patient Journey

	First Symptoms	Diagnosis	Treatment	Monitoring
Disease	<p>91% neurological symptoms. 9% non-neurological symptoms: scoliosis and heart trouble.</p> 	<p>Genetic testing is available, but gene changes in FA are not recognized using standard NGS.</p> 	<p>One disease-specific therapy in Europe and USA approved, several clinical trials ongoing.</p> 	<p>Referral to expert center. Multidisciplinary team for heart condition and diabetes.</p> 
Clinic	<p>Assessment of symptoms and referral to relevant specialists.</p> 	<p>Genetic counselling for parents regarding future pregnancies and siblings above 18.</p> 	<p>Mental health support, neurological and scoliosis assessment.</p> 	<p>Annual review of mobility, ability to do daily activities, heart, diabetic risk etc.</p> 
Challenges	<p>Confusion and complexity of symptoms leads to frequent misdiagnosis.</p> 	<p>Consider diagnosis in all age groups, since 1% of all presentations are in those 60+ years.</p> 	<p>Maintaining personal autonomy and ability to walk, access to currently available treatments.</p> 	<p>Children may isolate themselves. Parents are often unsure how to treat their child with FA.</p> 
Goals	<p>Take patients with multi-system complaints seriously, i.e. clumsiness, fatigue, back pain.</p> 	<p>Genetic counselling and testing for extended family, including cousins, to inform about genetic risk factors.</p> 	<p>Care guidelines should be shared with person with FA. Worldwide access to therapy.</p> 	<p>Maximize the potential to live a life as normal as possible, e.g. driving and part-time work.</p> 

Patient Journeys map the common needs of a specific patient community along the different stages of their journey, from first symptoms and diagnosis to treatment and follow-up.

These needs are identified and described through the eyes of the patients or caregivers

They can be used to map the procedures and treatments documented in a Care Pathway against the needs captured in a Patient Journey, and to identify whether this mapping reveals any gaps in the delivery of care.

In this sense, Patient Journeys are a tool to enable patient partnership in the design of care pathways to prioritise activities and resources in the organisation of care services.

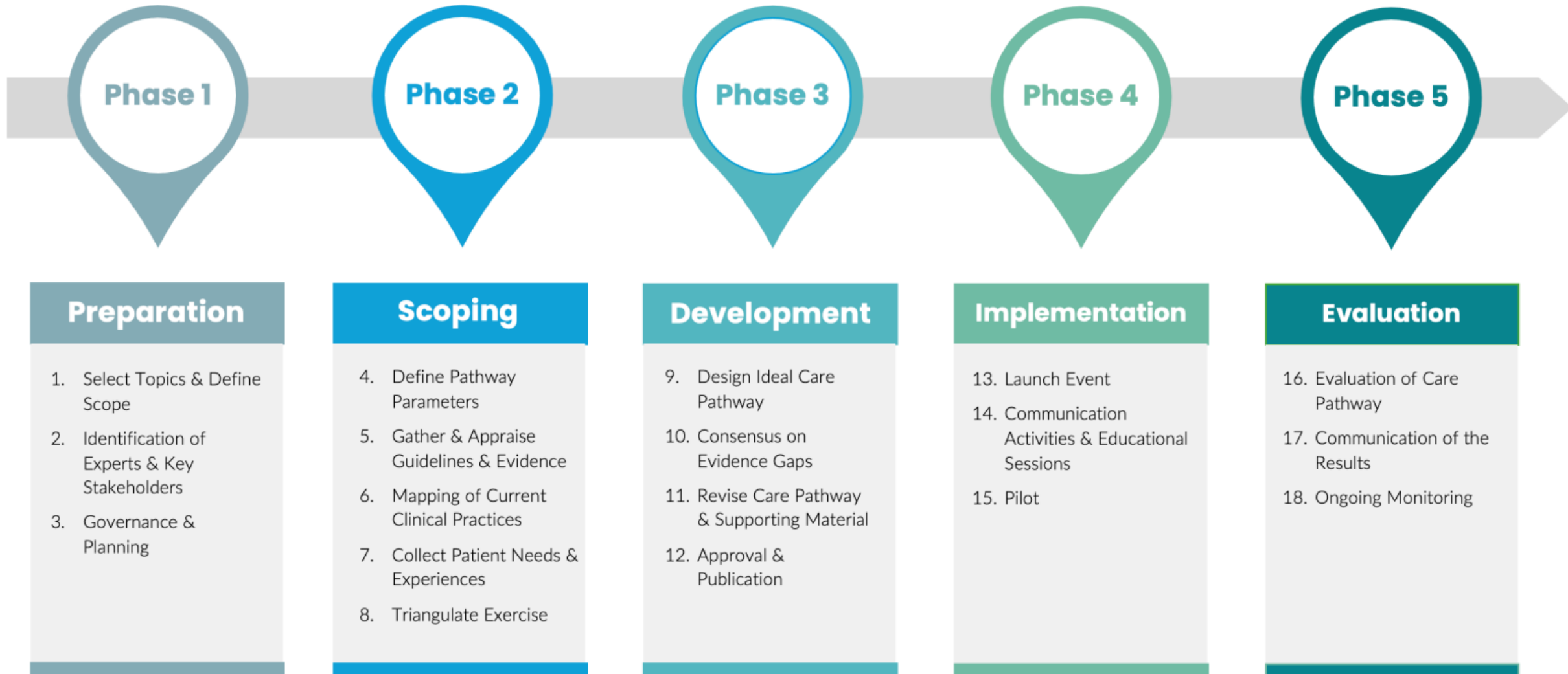
Care Pathways Toolkit for Healthcare Professionals & Patient Representatives,

<https://jardin-ern.eu/resource/care-pathways-toolkit/>

# Operationalising

How do you do it ?

# MODEL PROCESS IN 5 PHASES



# Care pathway for RD patients

What are the challenges with establishing a care pathway for RD patients ?



# Care pathway for RD patients

Disease related

Knowledge related

Healthcare related

# Main components/steps of a care pathway for diagnosis of RD patients

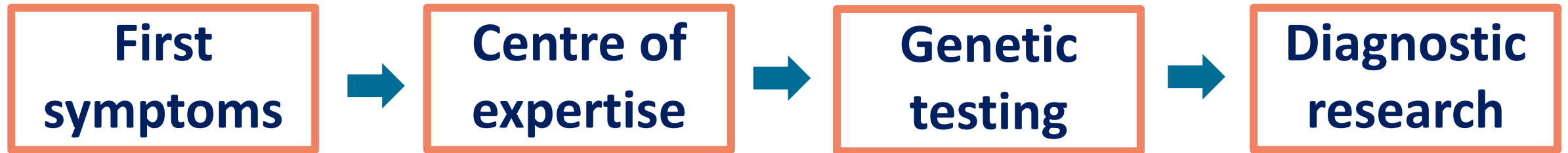
## Patient Journey through diagnosis



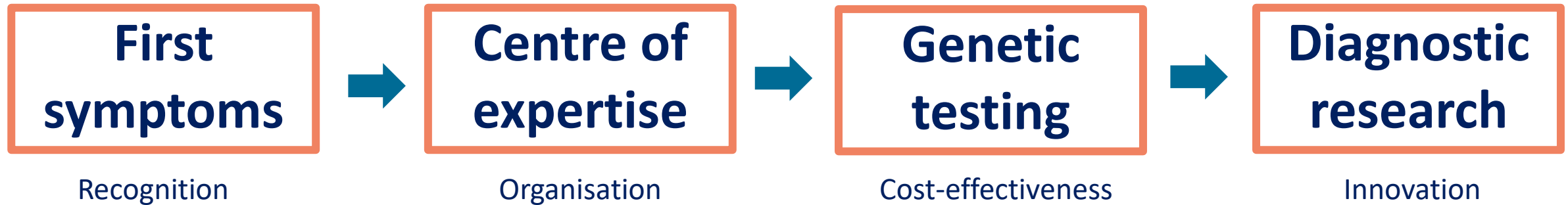
# Main components/steps of a care pathway for diagnosis of RD patients

What are the main components/steps of a care pathway for diagnosis of RD patients ?

# Main components/steps of a care pathway for diagnosis of RD patients

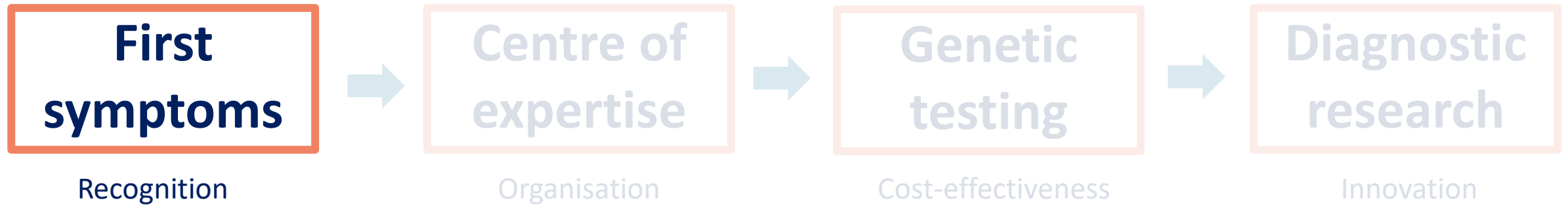


# Main components/steps of a care pathway for diagnosis of RD patients

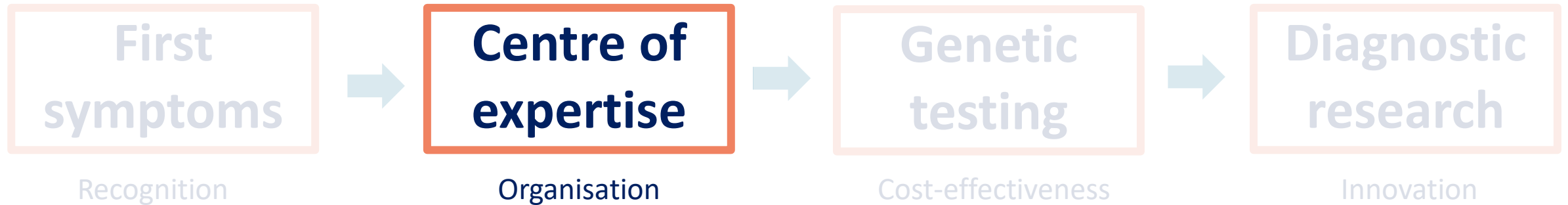




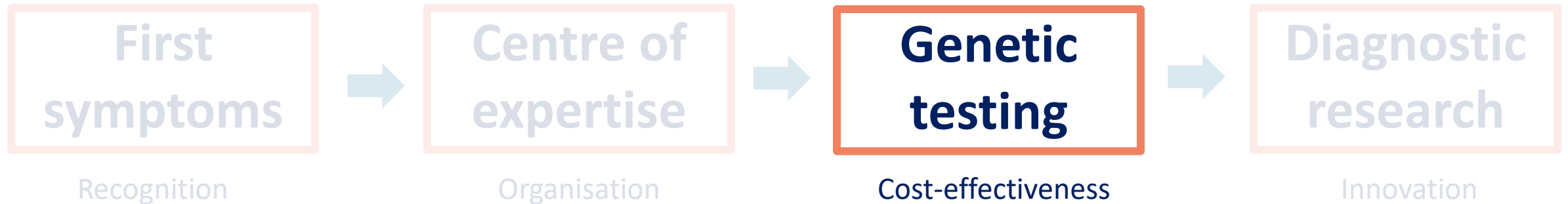
# Methodologies to standardize these steps?



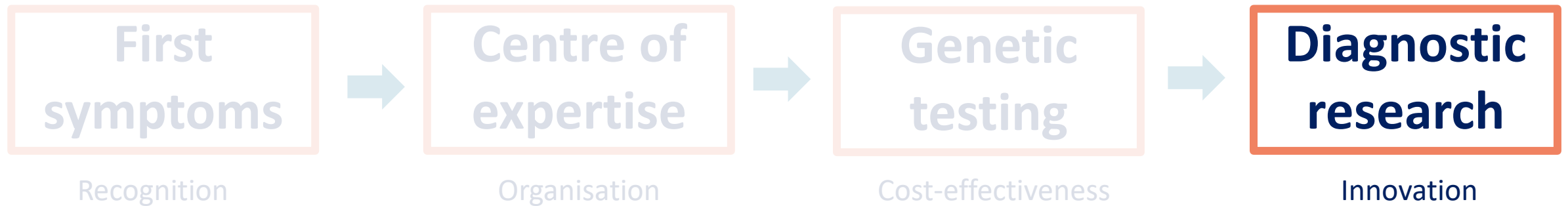
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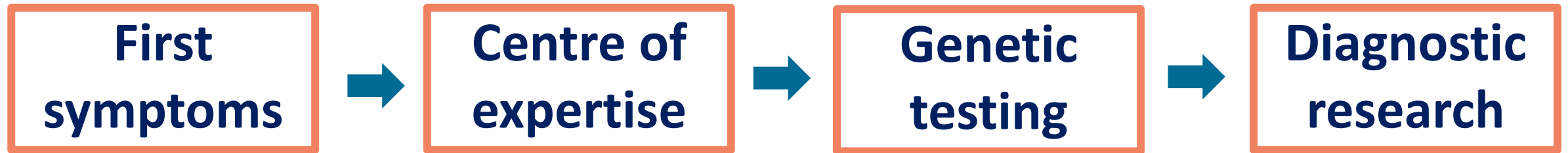


# Pitfalls

What can go wrong?

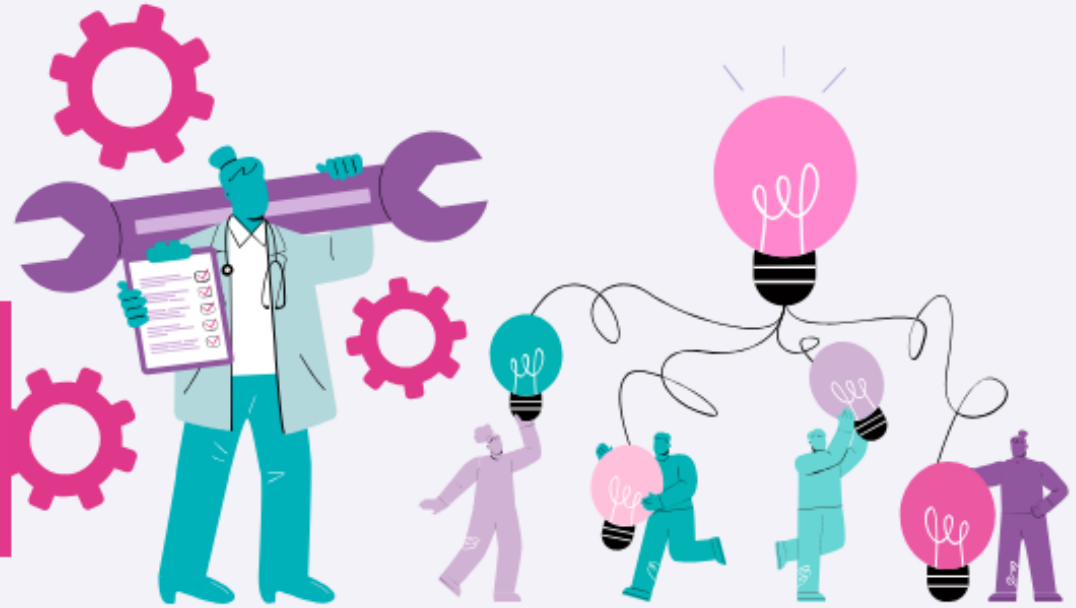


# Main components/steps of a care pathway for diagnosis of RD patients



 / Care Pathways Toolkit

# Care Pathways Toolkit



## Care Pathways **Toolkit** for Healthcare Professionals & Patient Representatives

**Thank you for your  
interaction !**

**Holm Graessner**

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