

# Session 2: European Reference Networks for Rare Diseases: Consolidation, Future and Integration into EU Health Systems

**Integrating the ERNs into the EU's health  
systems: joint action under the EU4HEALTH  
health programme (“JARDIN”)**

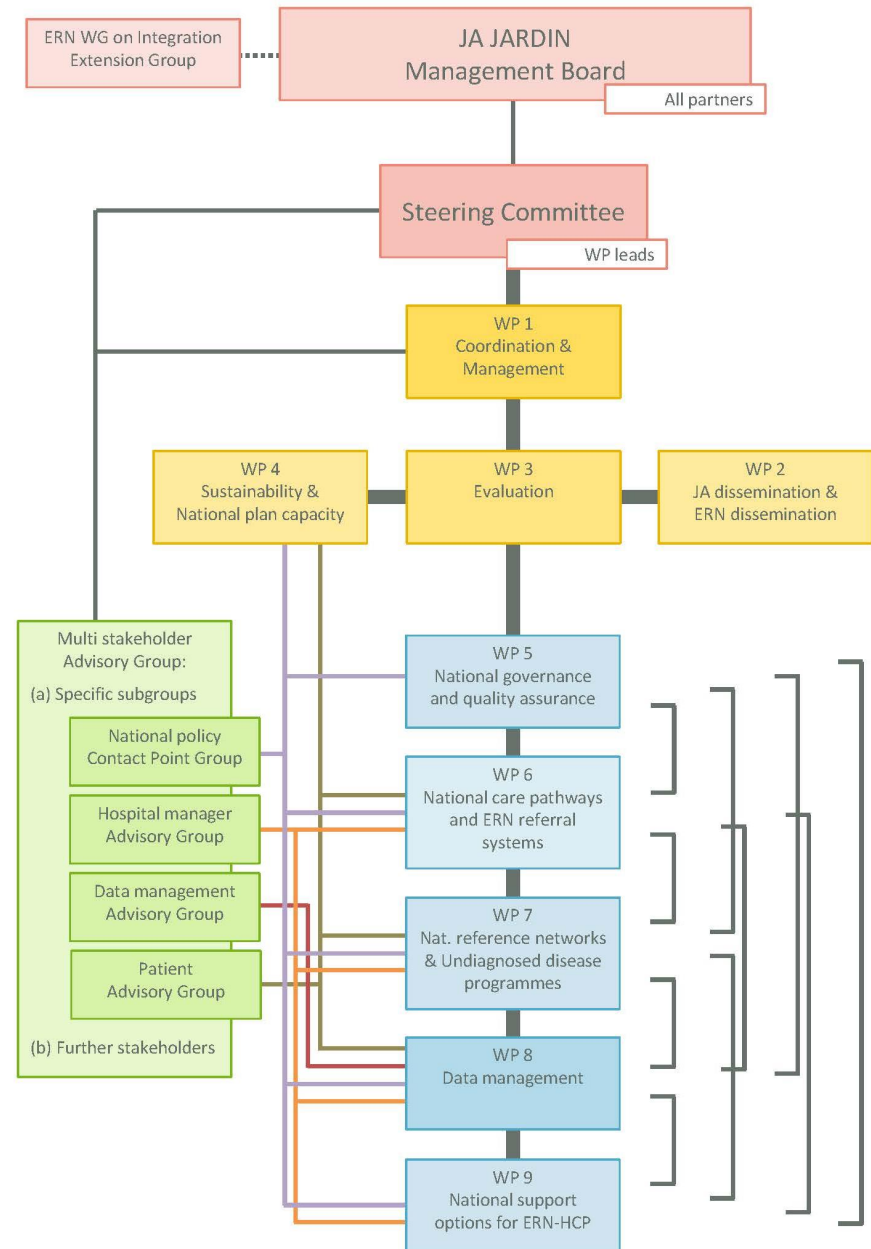
Till Voigtländer

EESC Conference “Rare diseases and European Reference Networks”,  
Euskalduna Palace, Bilbao, Spain, 10–11 October 2023

# Joint Action JARDIN






























## Basic figures:

- » 60 partner institutions
  - » 29 Member States
    - » 28 Competent authorities (CA)
    - » 31 Affiliated Entities (AE)
    - » 1 Associated partner
- » Funding
  - » Exceptional utility rule
    - » EU: 15.000.000,00
    - » MS: 3.750.000,00
    - » Total: 18.750.000,00
    - » (DK): 266.000,00
- » Timeline: 03/2024–02/2027

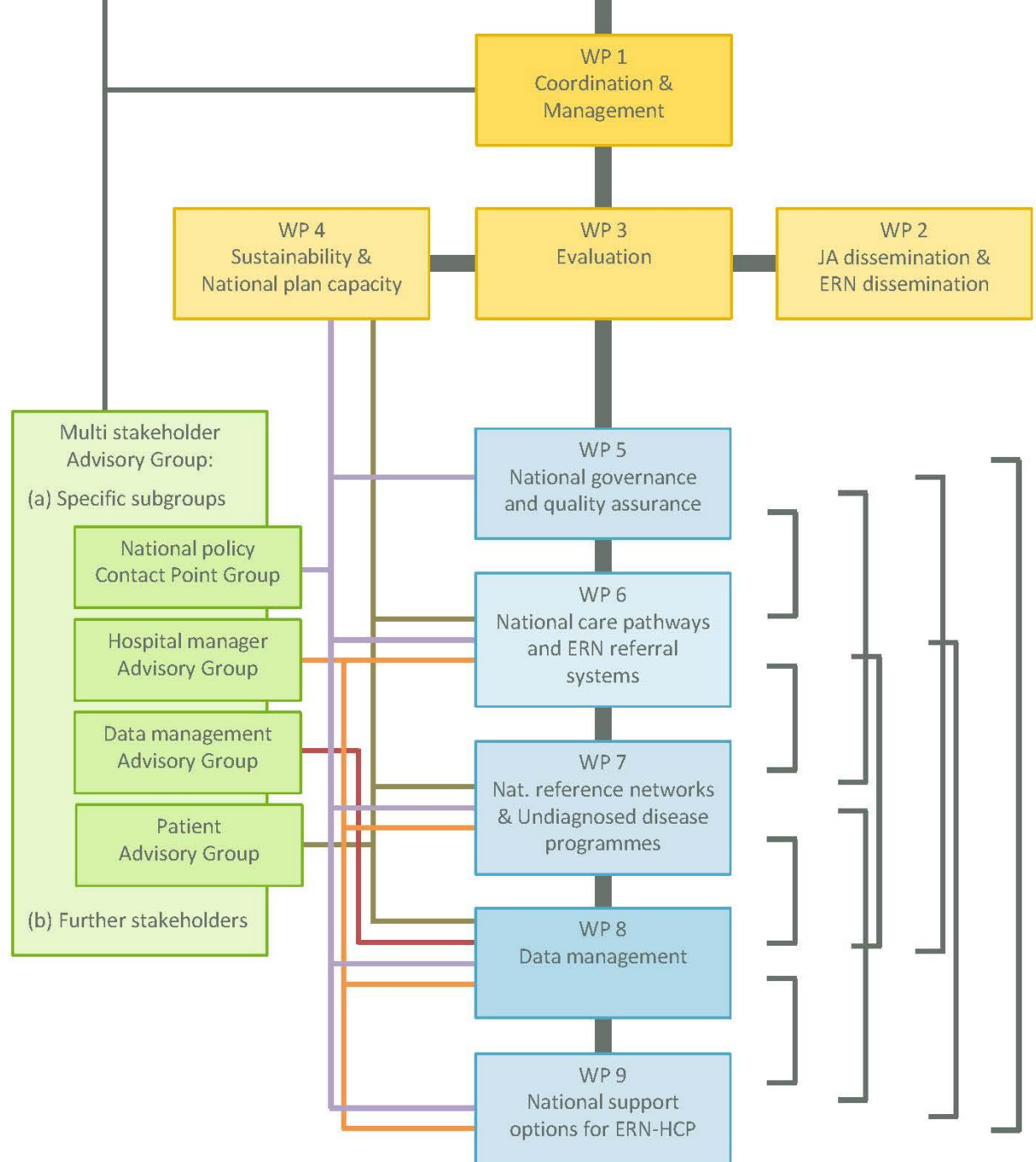


# JARDIN – Participating countries

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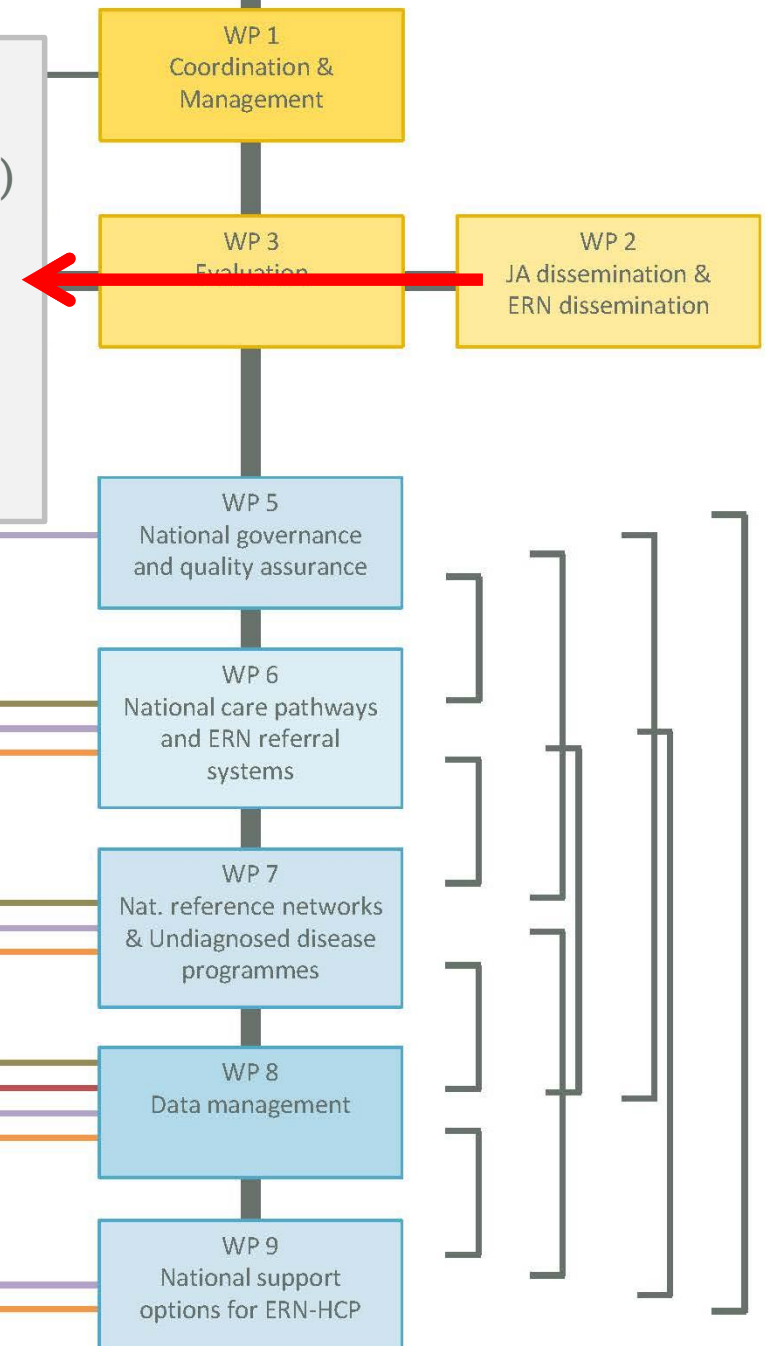
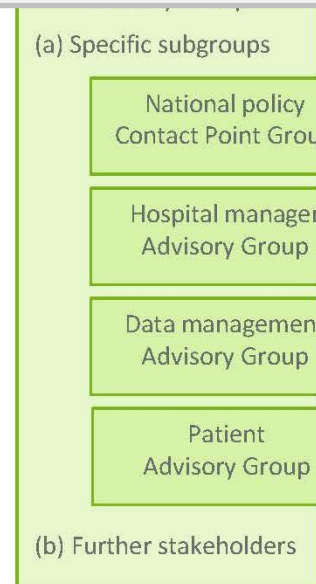
	Austria (1 CA)		Latvia (1 CA)
	Belgium (1 CA, 1 AE)		Lithuania (1 CA)
	Bulgaria (1 CA)		Luxembourg (1 CA)
	Croatia (1 CA, 1 AE)		Malta (1 CA)
	Cyprus (1 CA)		Netherlands (1 CA, 4 AE)
	Czech Republic (1 CA)		Norway (1 CA, 2 AE)
	Denmark (1 CA)		Poland (1 CA)
	Estonia (1 CA)		Portugal (1 CA, 1 AE)
	Finland (1 CA)		Romania (1 CA)
	France (1 CA, 4 AE)		Slovakia (1 CA, 1 AE)
	Germany (1 CA, 6 AE)		Slovenia (1 CA)
	Greece (1 CA, 1 AE)		Spain (1 CA, 1 AE)
	Hungary (1 CA, 2 AE)		Sweden (1 CA)
	Ireland (1 CA)		Ukraine (1 AP)
	Italy (1CA, 7 AE)		

# Joint Action J



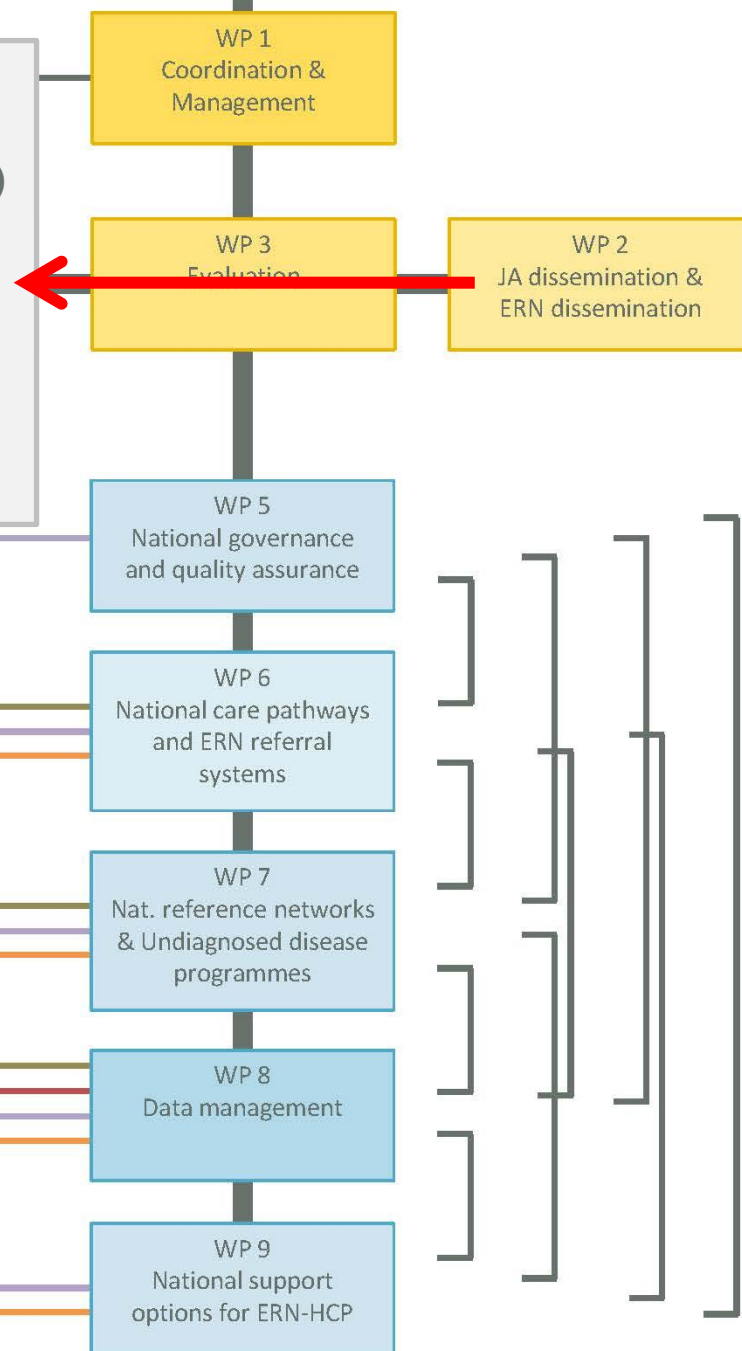
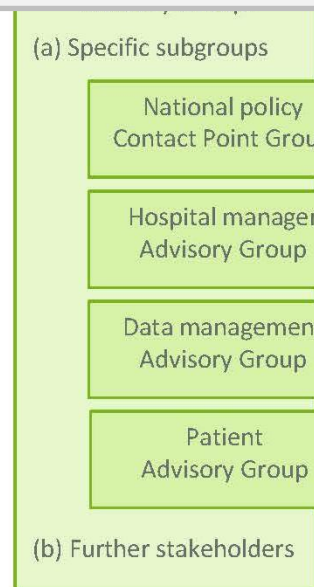
## Promoting ERN integration in NHS:

- » Development of full scale (professional) information campaigns on ERNs
- » Primary target groups:
  - » Patients
  - » Medical doctors and staff (primary care level)



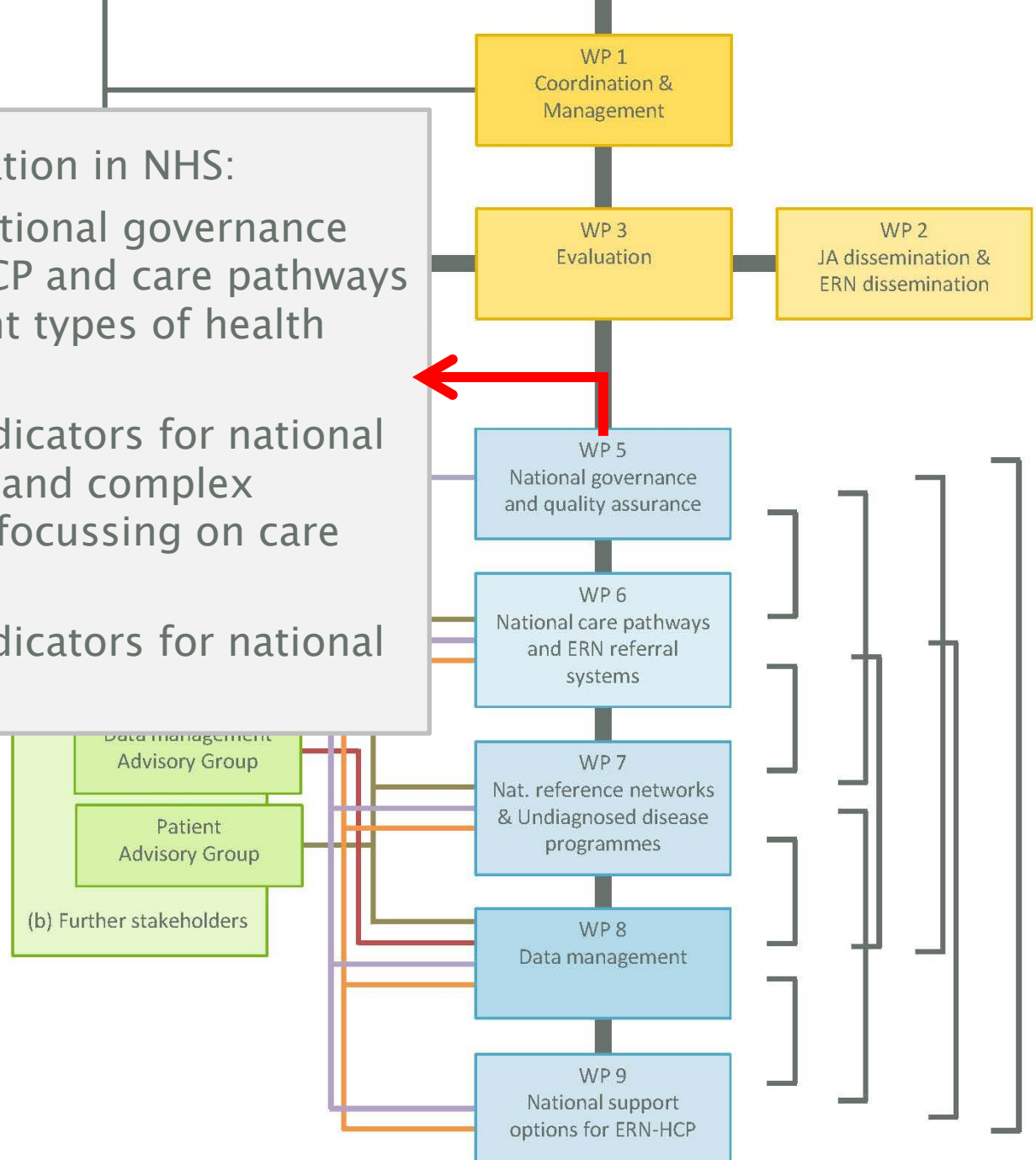
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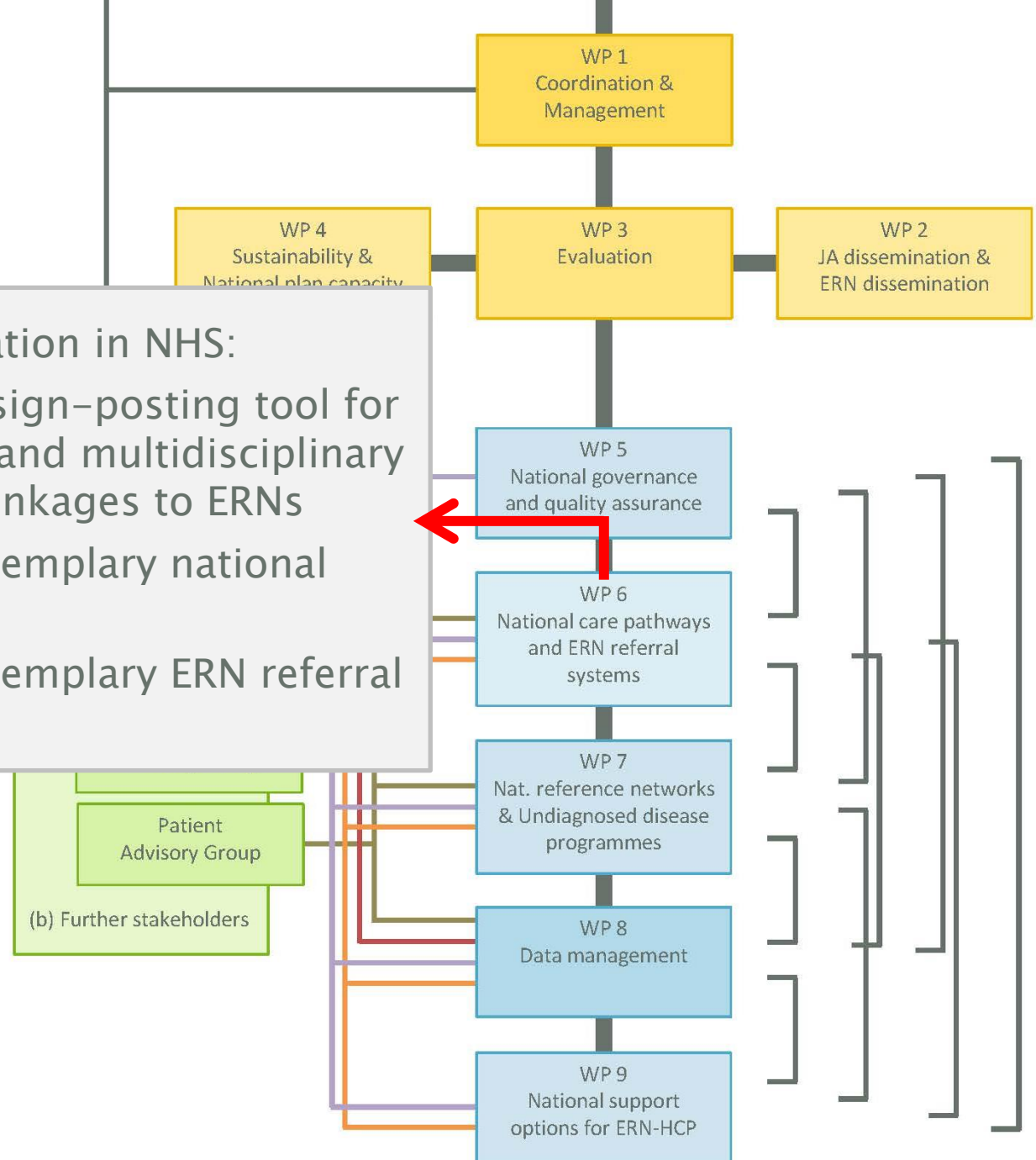
- » Development of national governance models for ERN-HCP and care pathways adapted to different types of health systems
- » Development of indicators for national monitoring of rare and complex diseases primarily focussing on care pathways
- » Development of indicators for national ERN integration



# Joint Action J

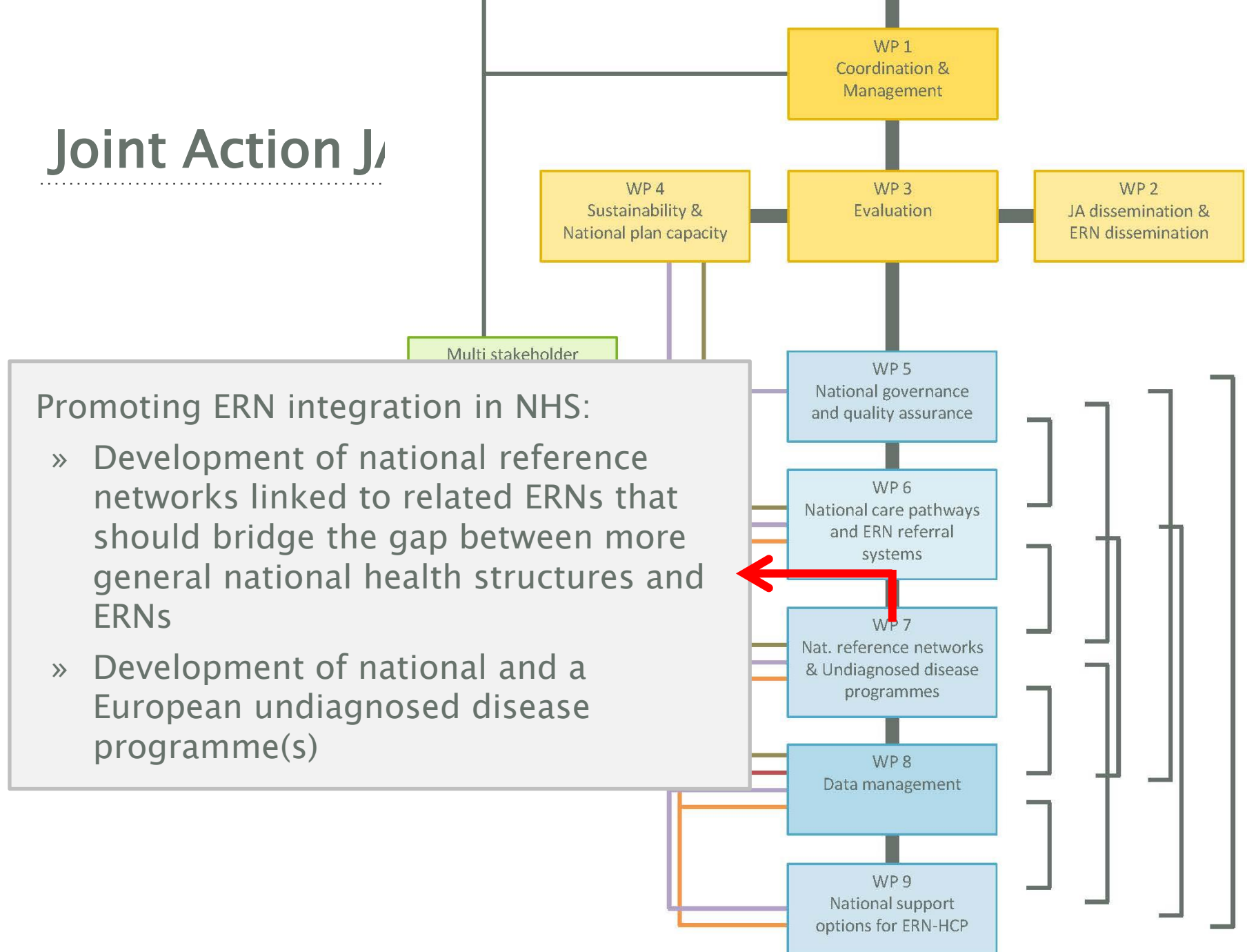
## Promoting ERN integration in NHS:

- » Development of a sign-posting tool for national expertise and multidisciplinary team access, and linkages to ERNs
- » Development of exemplary national care pathways
- » Development of exemplary ERN referral pathways

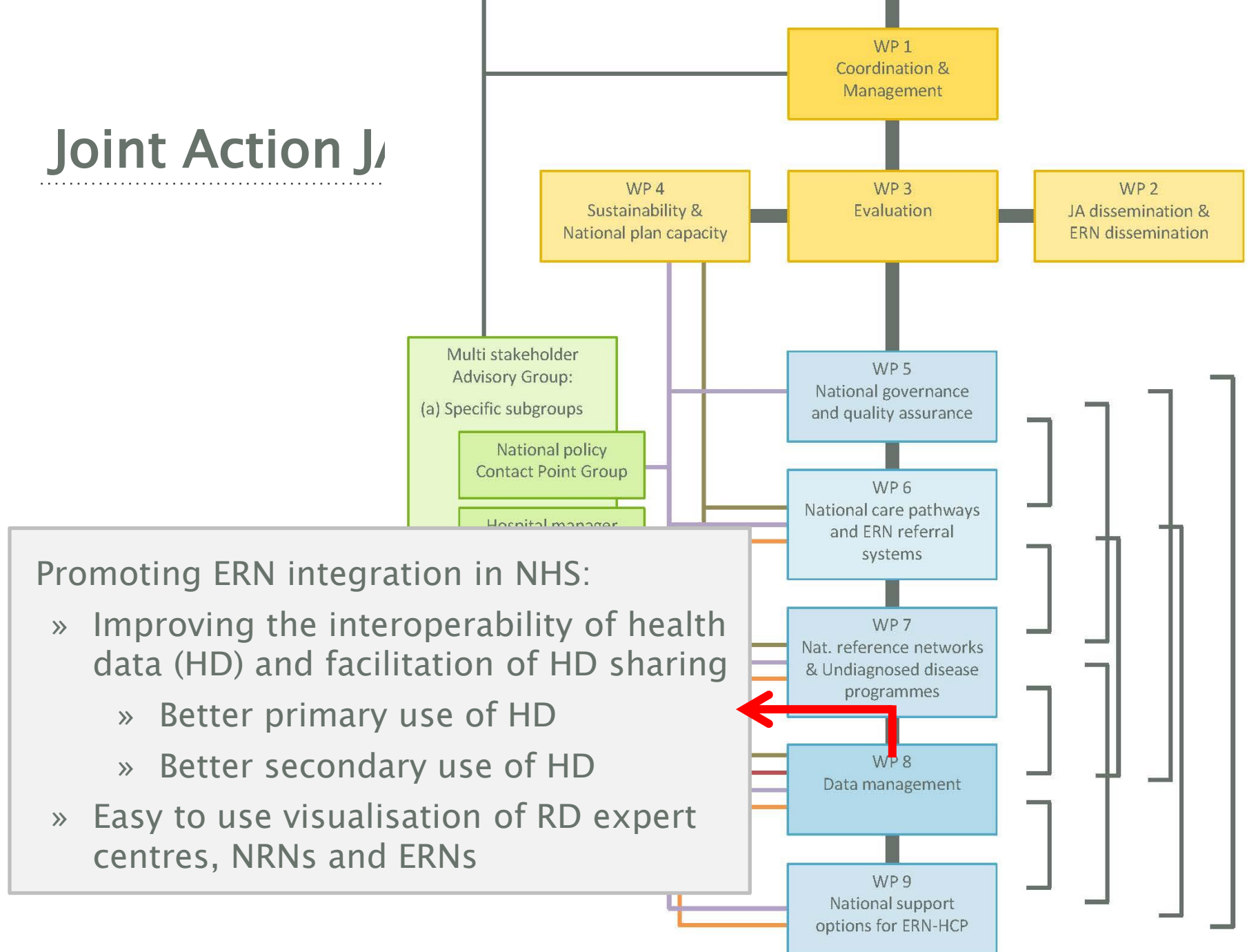




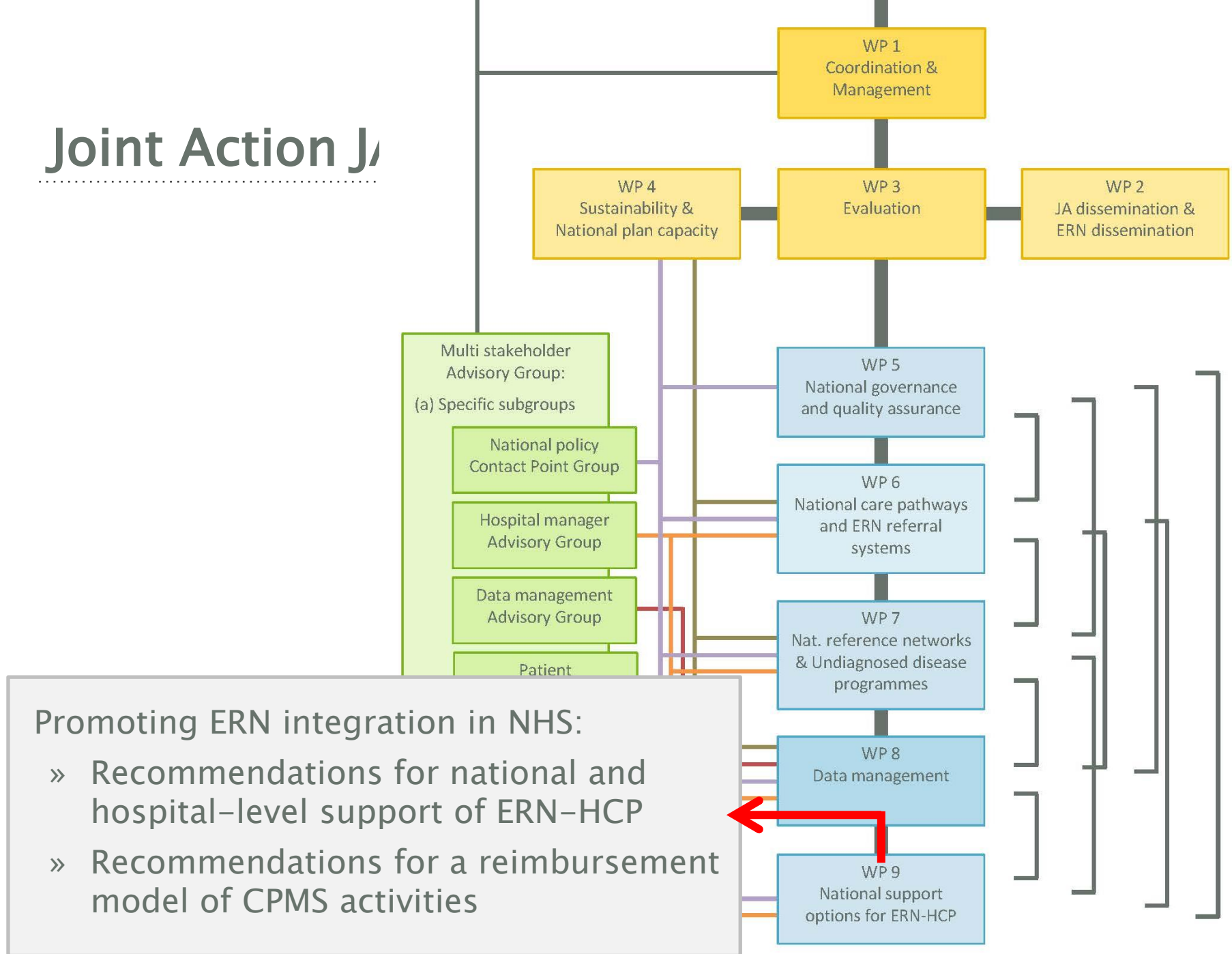
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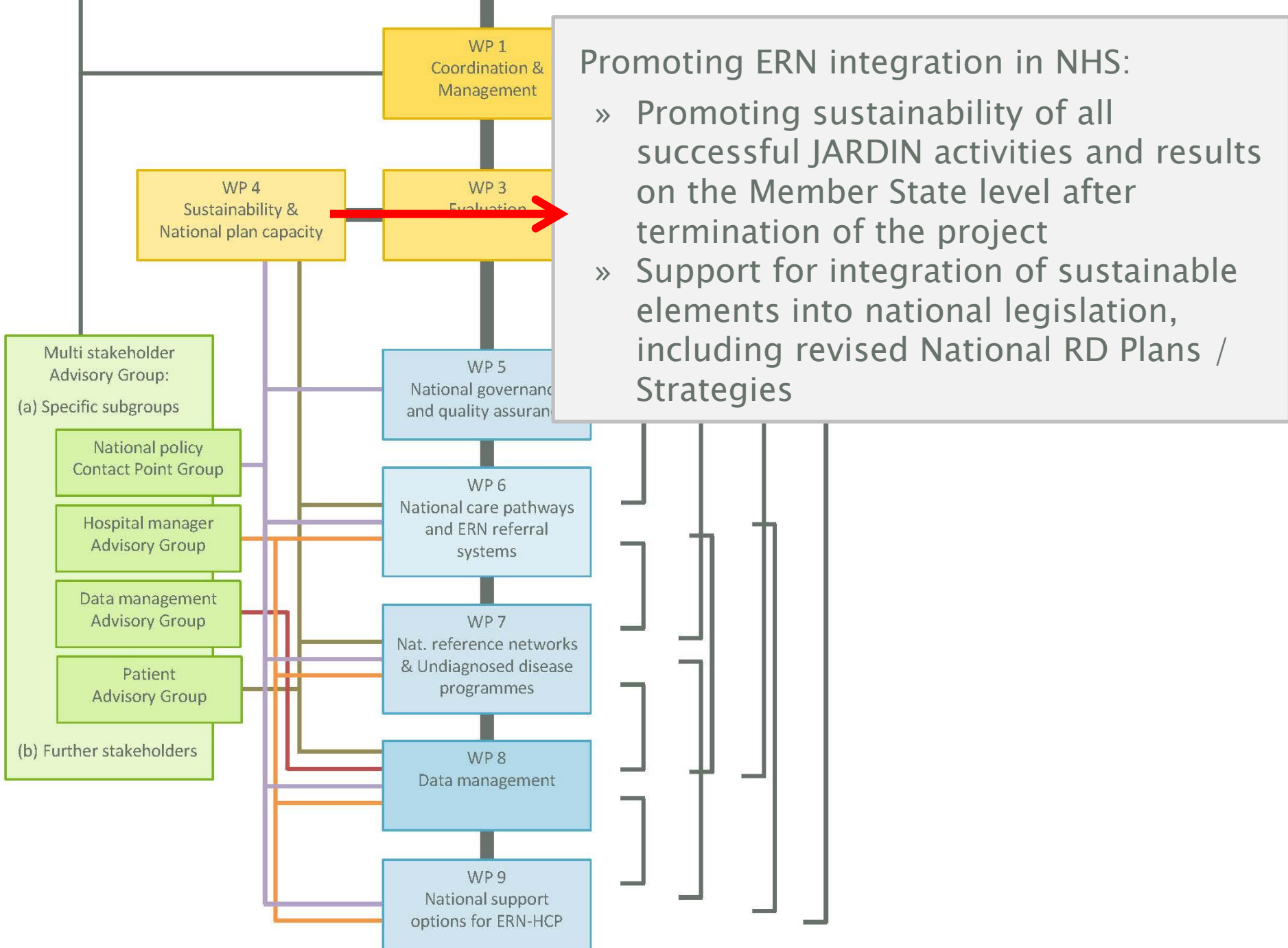


# Joint Action J



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**Thank you for your  
attention**