Round table I

State of play of the ERNs: setting up the system

From the design to the final product

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Conflict of interest disclosure

I have no actual or potential conflict of interest in relation to this program/presentation
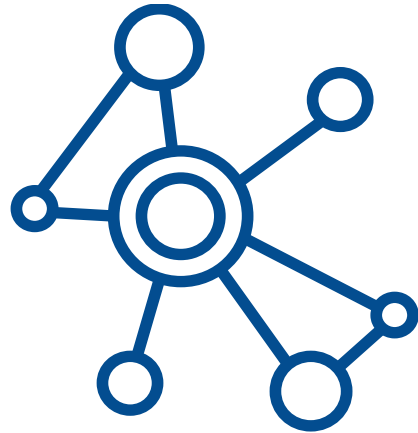
Outcome call 2016
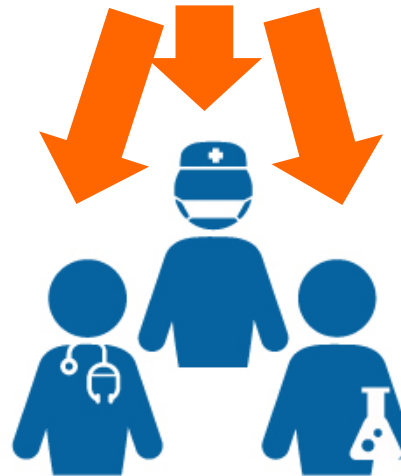
Phases of the ERN life cycle

European Commission

European Reference Networks

We are here

2011-14

Legislation and initial planning

Directive

Implementing decisions

Awareness and communication

2015-16

Implementation: (Approval stage)

Design and development Assessment tools

Call for ERN

Assessment of Network proposals

Approval of ERNs

2017-18

Implementation: (deployment stage)

Establishment

Initial organizational phase

Functioning (initial actions and services)

Partial service production

project cycle re-initiation

2021

Evaluation and update

2019-20

Consolidation

Full service production

Continuous monitoring

Performance indicators and initial outcome assessment

Health and Food Safety

Key achievements so far

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At ERN level:

- 24 Networks started their **clinical work** with patients

- Increasing numbers of **patient cases** discussed virtually

- Consolidation and implementation of **the governance structure and networking capacity**

- Development of **training, education and awareness** actions

- Implementation of **clinical patient guidelines (CPG)**

- Development of **research projects including registries**

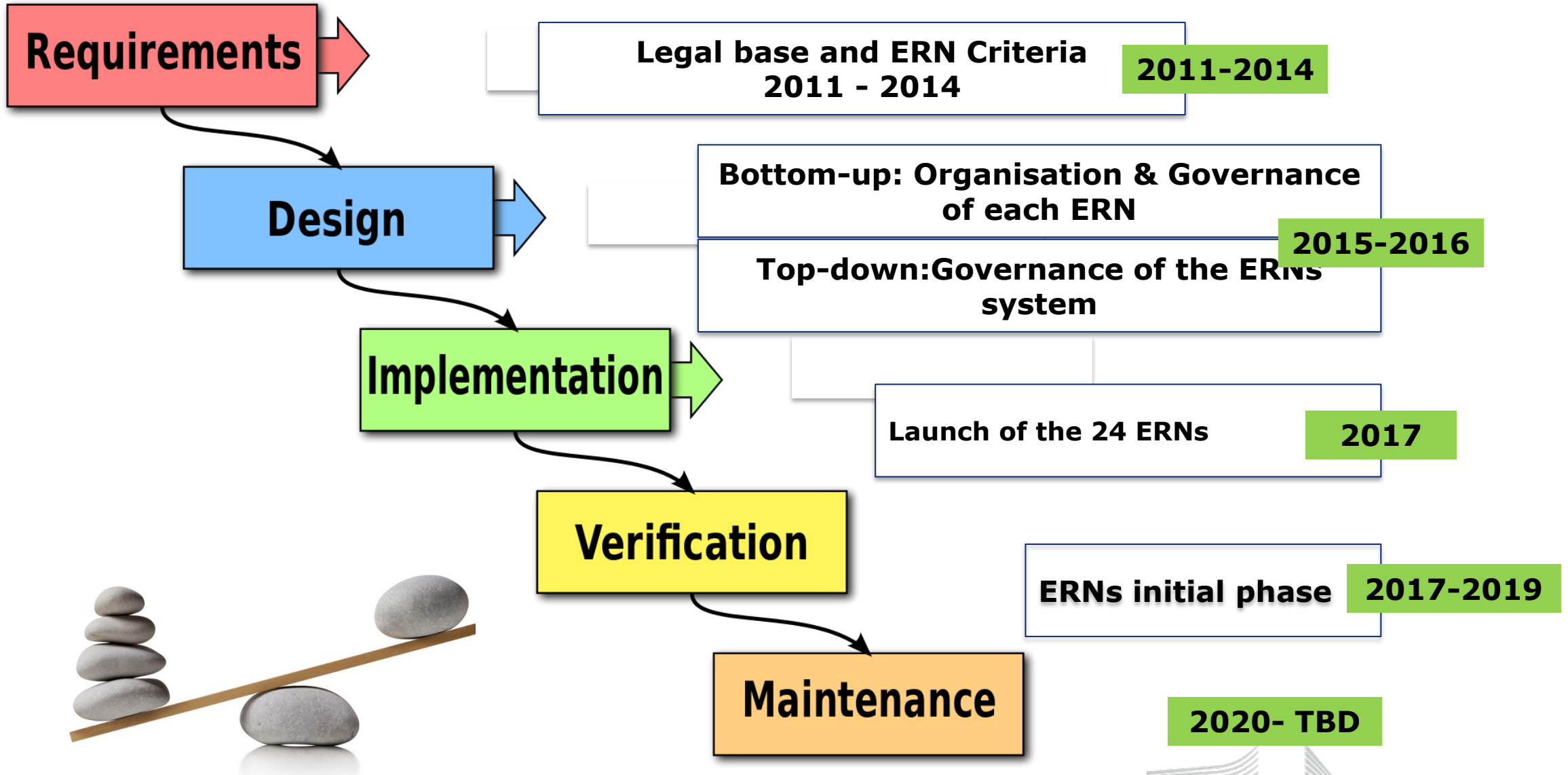- Collaboration with **patient organisations**

Key achievements

ERN System

- ✓ **Consolidation of the governance bodies** *(Board of MS & Coordinators Group)*
- ✓ **Cooperation between the MS and the ERNs** *coordinators*
- ✓ *Board of MS & ERN Coordinators Group developing* **common administrative and clinical strategies, guidelines and procedures**
- ✓ **Communication with Hospital Management**
- ✓ **Integrated** *working groups on:*

  - ➢ **Knowledge Generation**
  - ➢ **Research**
  - ➢ **ERN Integration into the National Healthcare Systems**
  - ➢ **Continuous monitoring and quality improvement**
  - ➢ **Ethics and code of conduct**
  - ➢ **Business continuity**
  - ➢ **IT platforms**
  - ➢ **Monitoring**

ERNs : from design to final product

Requirements

| Legal base and ERN Criteria 2011 - 2014 | 2011-2014 |

Design

| Bottom-up: Organisation & Governance of each ERN | 2015-2016 |
| Top-down:Governance of the ERNs system | |

Implementation

| Launch of the 24 ERNs | 2017 |

Verification

| ERNs initial phase | 2017-2019 |

Maintenance

2020- TBD

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ERN Requirement Analysis

Goals

General Criteria

Specific Criteria

Operational Criteria

Assessment

Requirements Analysis: common ERN requirements

To ensure that ERNs are operational

To improve access to clinical advise, diagnosis, treatment and follow-up of patients

To optimise patient outcomes by combining expertise

To promote education and training

To reinforce clinical research

To ensure access to high quality healthcare services

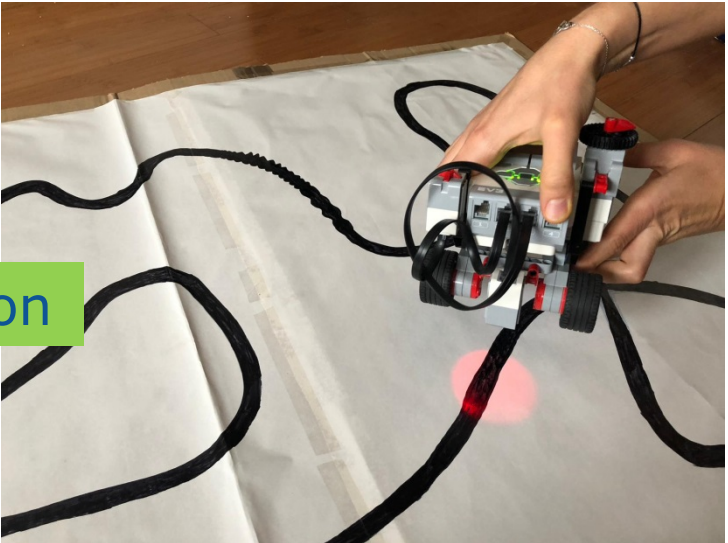**To guarantee that knowledge is spread outside the ERN**

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System Design and Prototyping

ERN

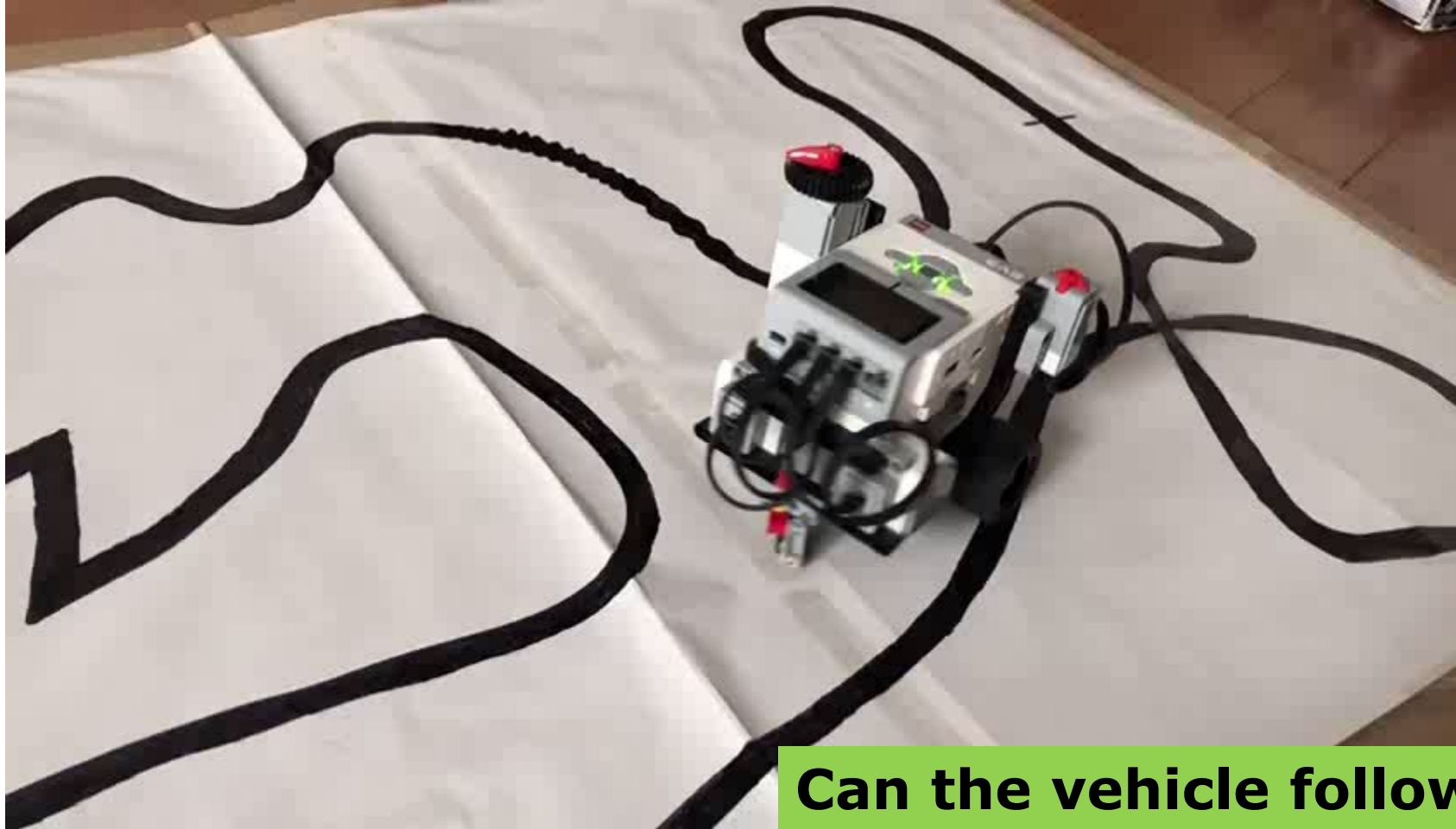Implementation of the road map
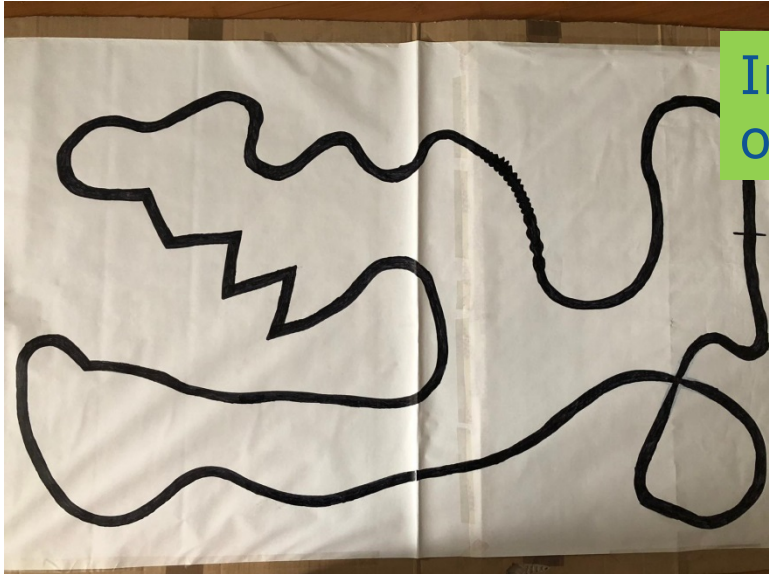
Standardisation

On the Road

European Commission

Testing Prototype: 2017-2018

Stress testing:

- *Going life*
- *Internal tensions*
- *External demands*
- *Tools fine tuning*
- *Workload*
- *Coordination with National Systems*
- *Integration at hospital level*

Can the vehicle follow the road design ?

Redesign : 2019-2020

Resilience

Internal governance

Coverage and accessibility
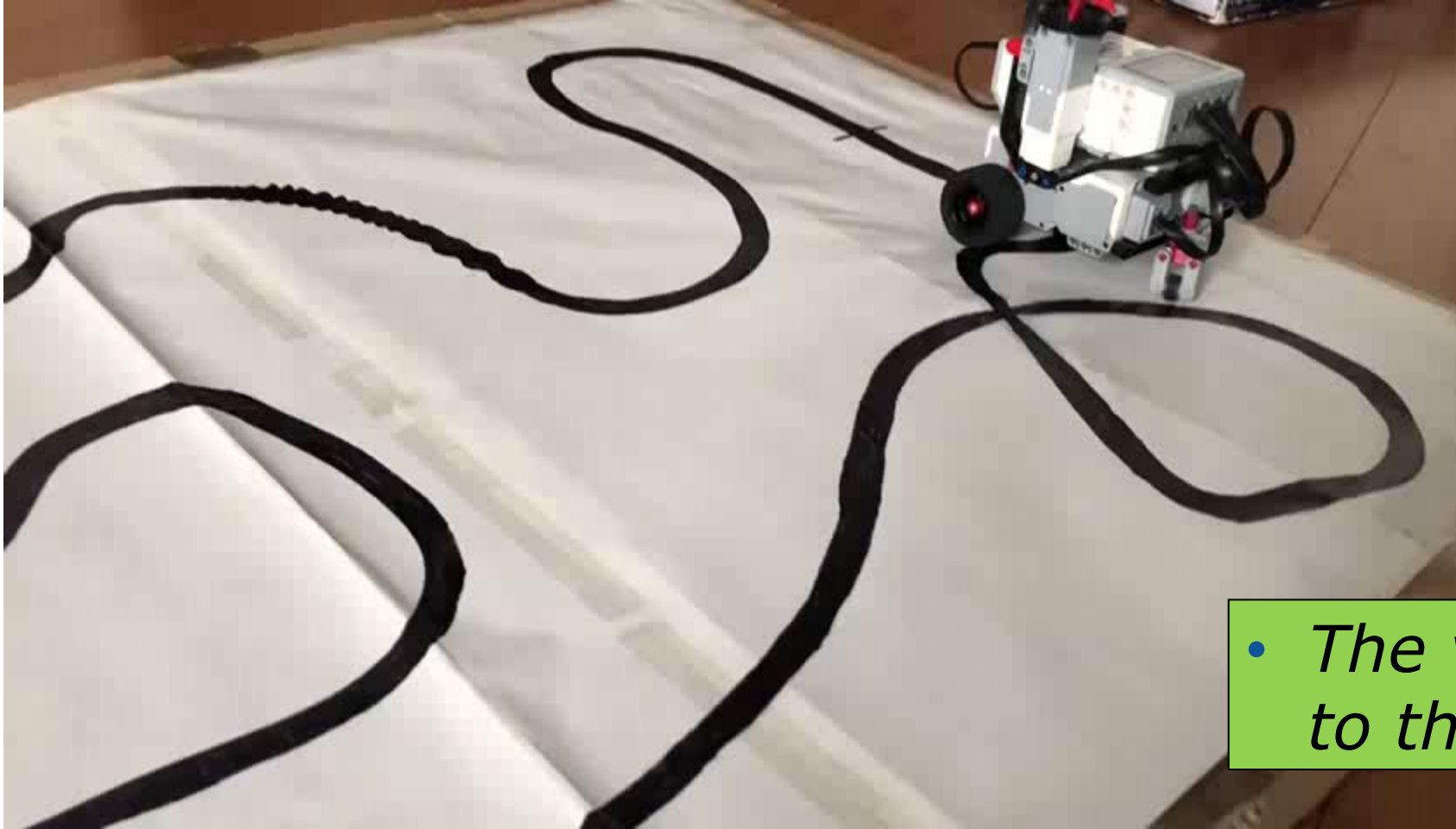
Patient outcomes measurement

Data management & registries

Integration into National HC systems

Monitoring – Evaluation system

Funding tools

Final product: 2021

- *The vehicle matches to the road design*

Thank you for your attention

Further information:
http://ec.europa.eu/health/ern/policy/index_en.htm