Learning from Data: the Nivel experience with data from nursing homes and bias

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Program Learning from Data (2019-2024)

Reusing health data for **improvement of quality of care** and **knowledge development** in the nursing home sector

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Improving standardization and defining a minimal dataset

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Collecting and analyzing health data from one EHR system

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Setting up a nation-wide registry, to collect a minimal dataset from all EHR systems

Registry Learning from Data in Nursing Homes

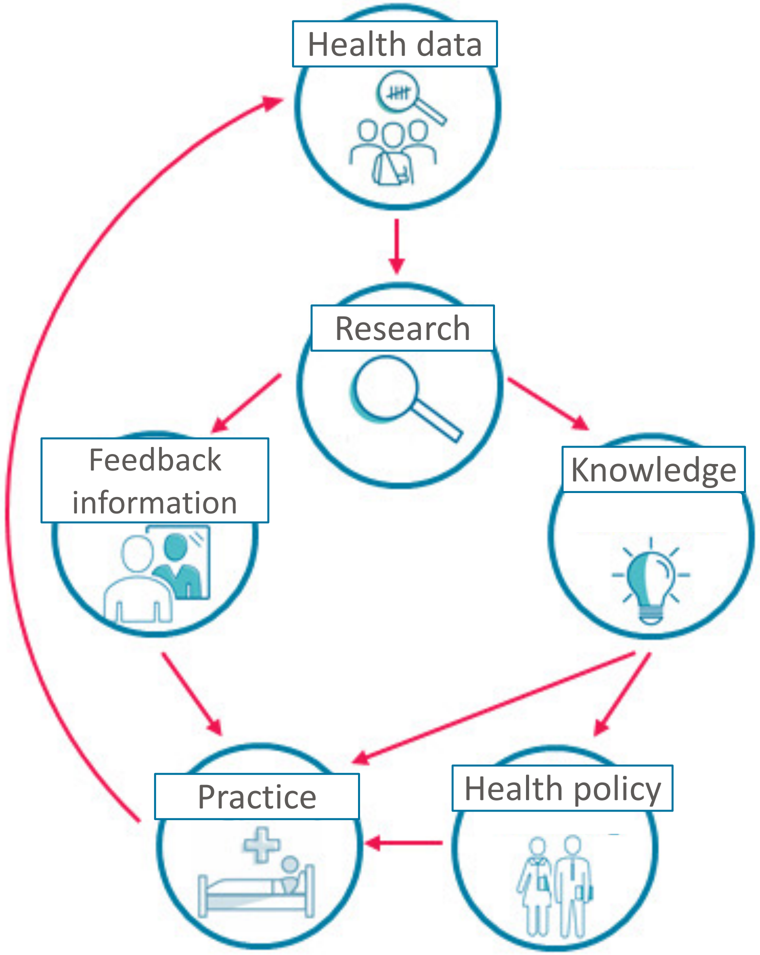
The Registry includes

1. Data from different EHR systems
2. Routine health data on nursing home residents recorded by elderly care physicians: a minimal dataset

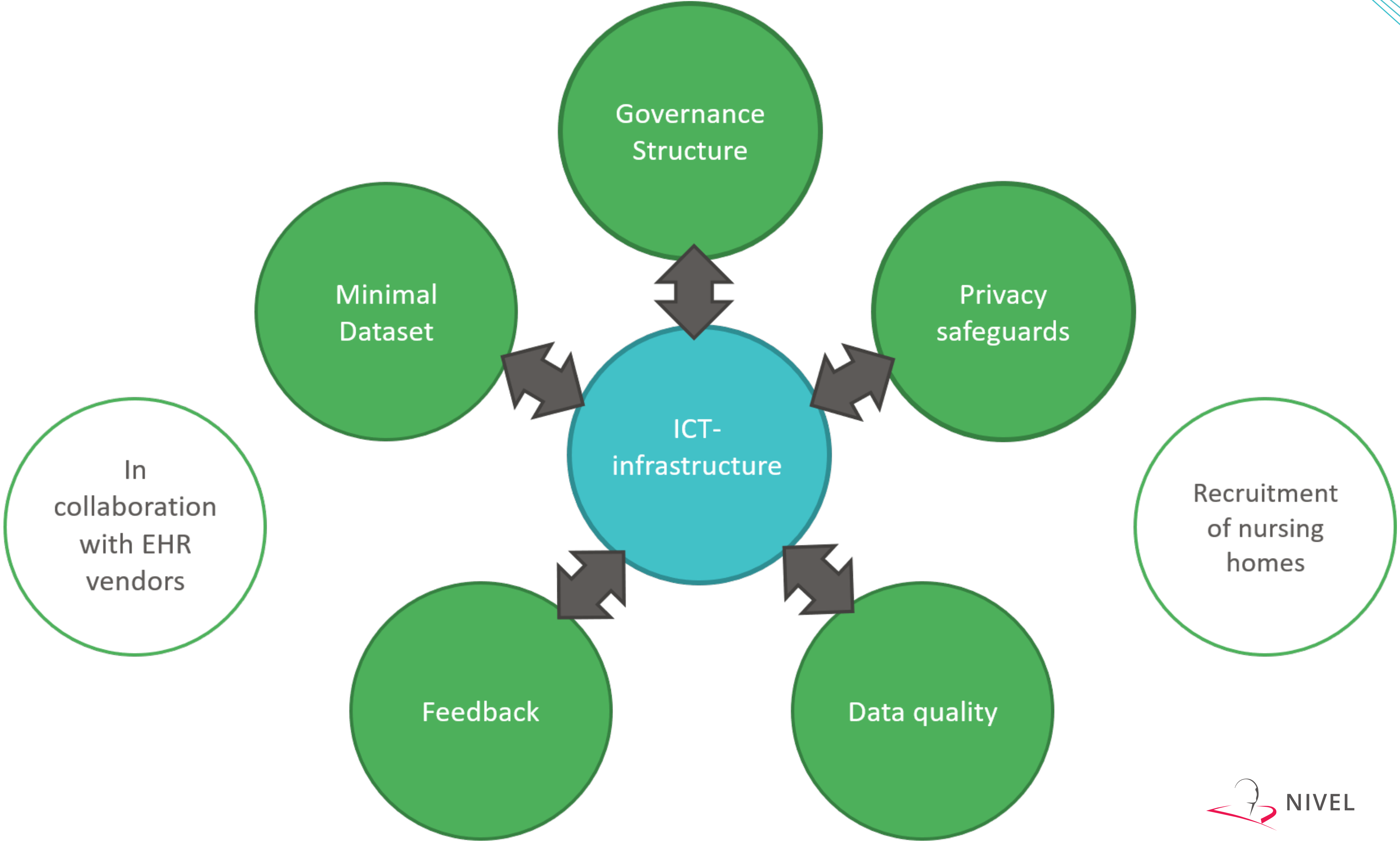
Requires **no** additional recordings

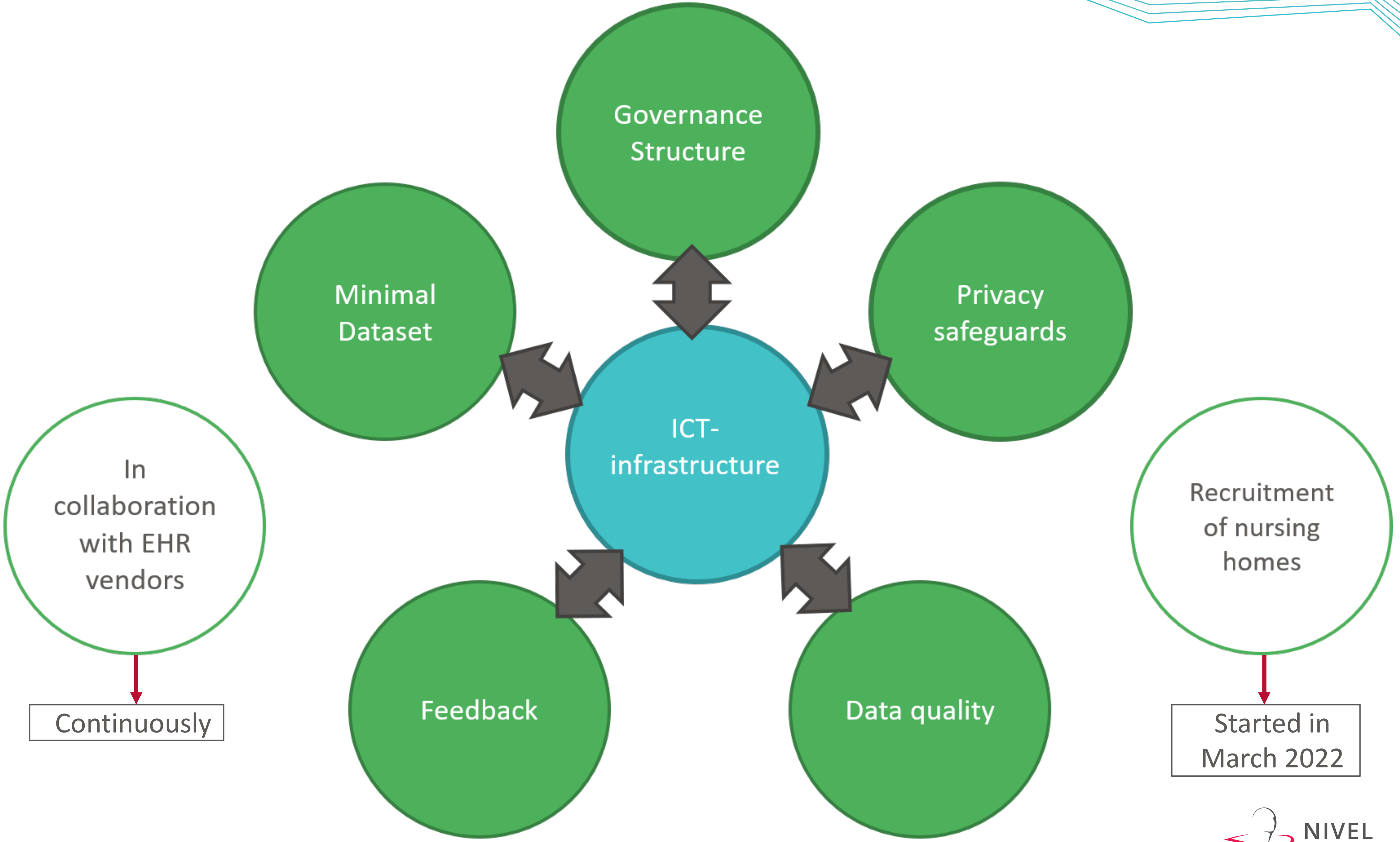
The Registry provides:

1. feedback information to elderly care physicians
2. datasets to third parties for **research** purposes



What is needed for setting up the Registry?





Governance Structure

Minimal Dataset

Privacy safeguards

ICT-infrastructure

Feedback

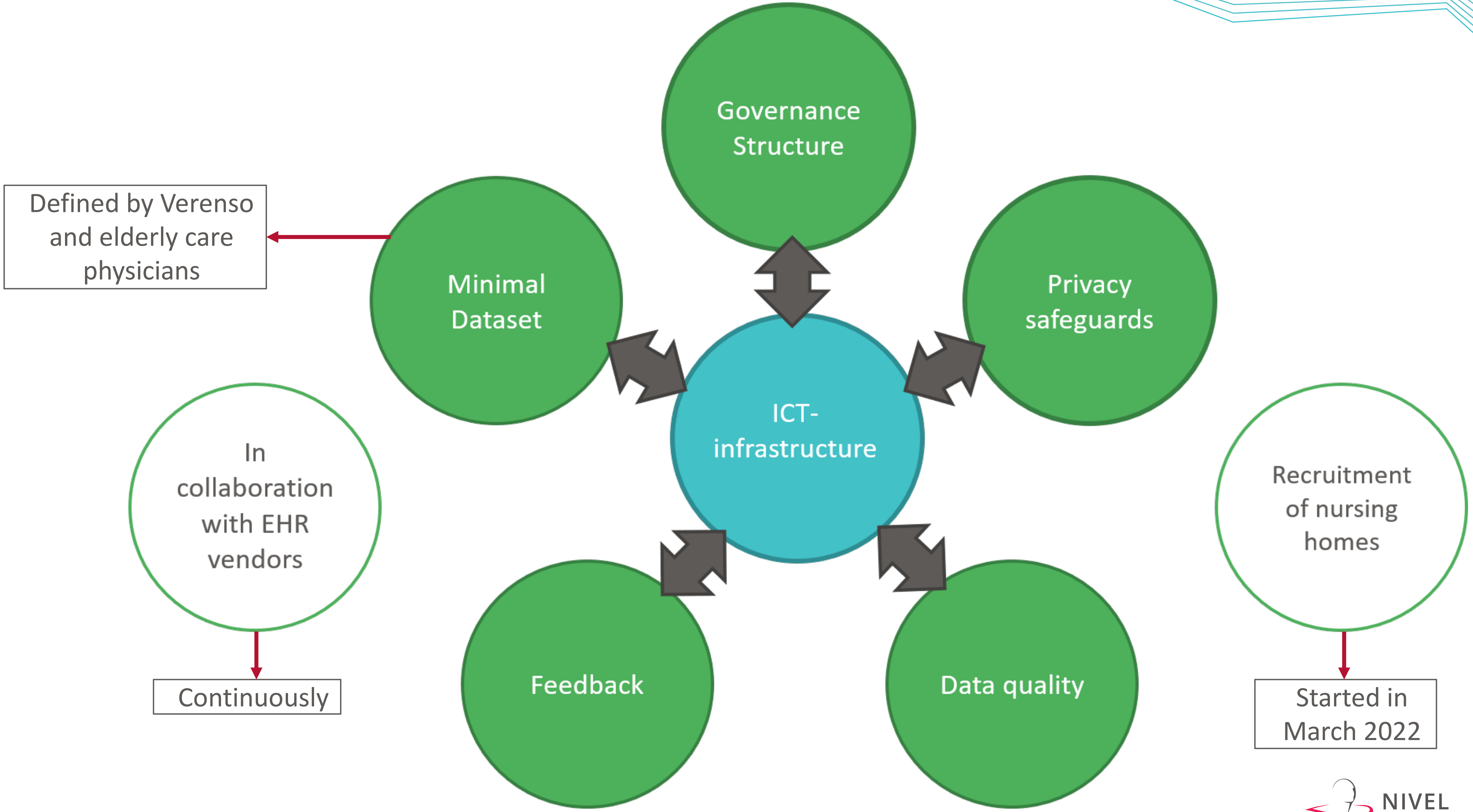
Data quality

In collaboration with EHR vendors

Continuously

Recruitment of nursing homes

Started in March 2022



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Defined by Verenso and elderly care physicians

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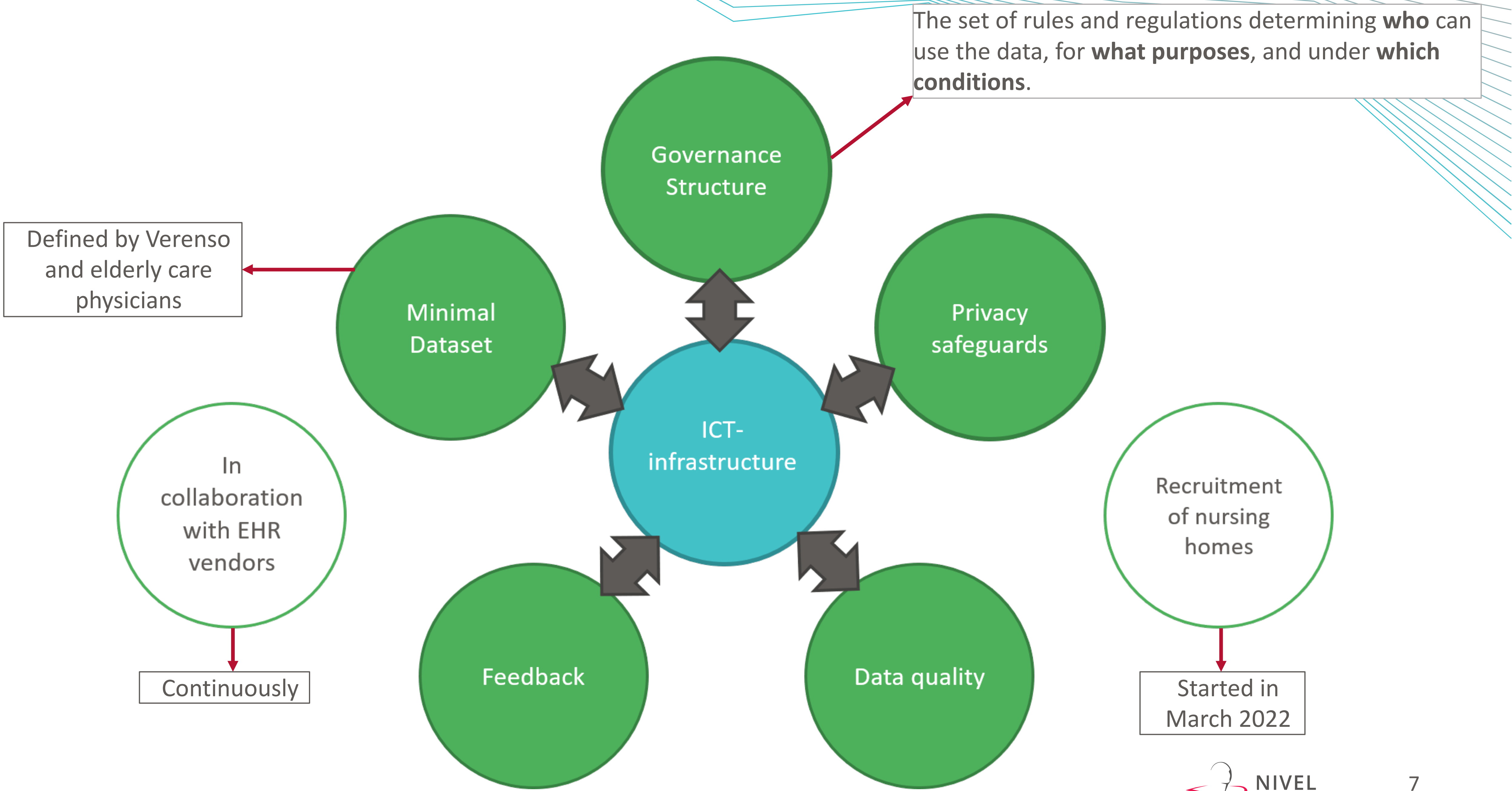

ICT-infrastructure

Governance Structure

The set of rules and regulations determining **who** can use the data, for **what purposes**, and under **which conditions**.

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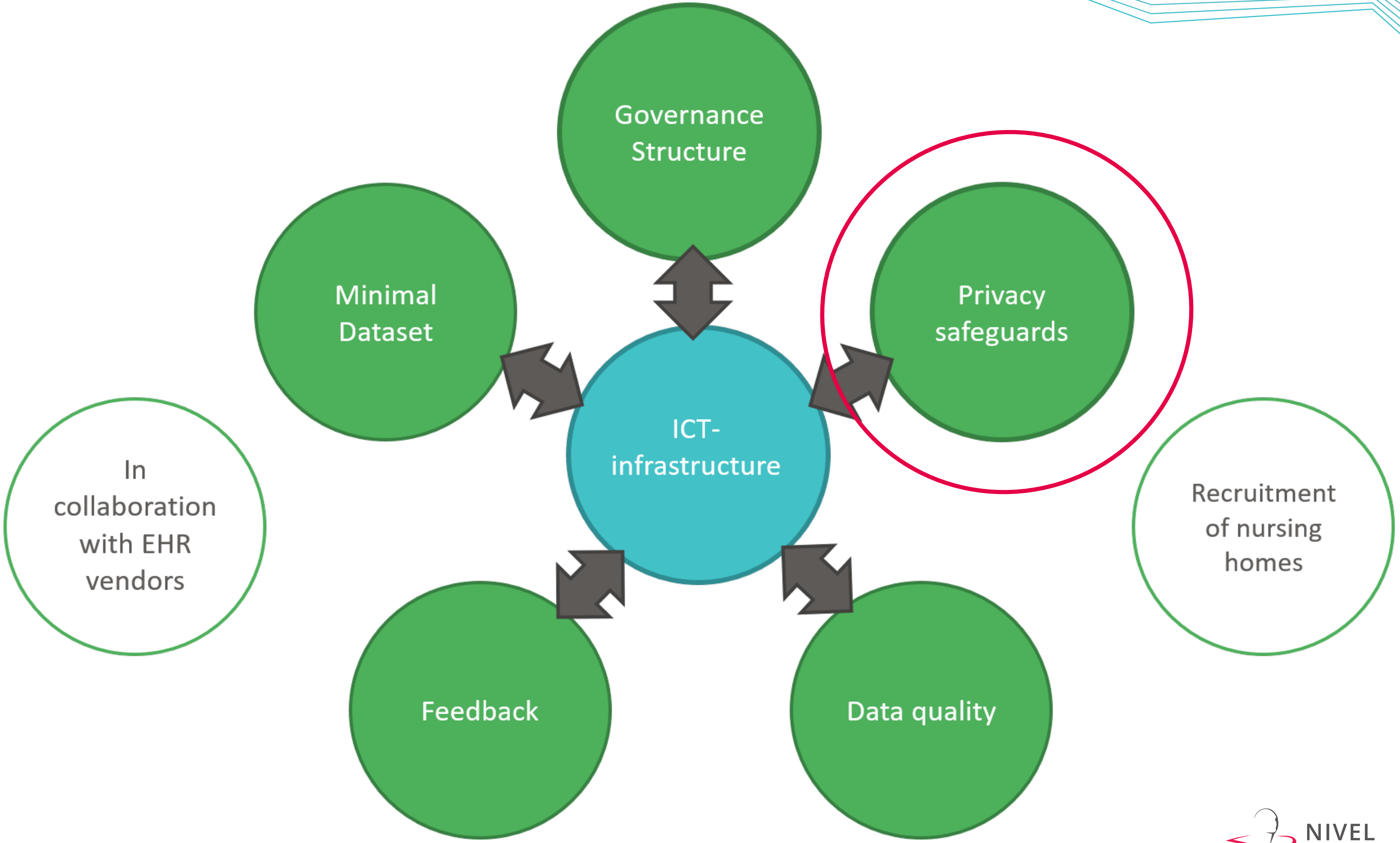
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General Data Protection Regulation (GDPR)

- GDPR generally prohibits the processing of sensitive data, except, for instance, in cases in which the data subject has granted explicit consent (opt-in).

- In the Netherlands:
  Exemption for statistics or scientific research in the general interest under the following conditions

Opt-in procedure is reasonably not possible. For example, as it

- would impose a too great burden for the patient, or
- would lead to a low and/or selective response or participation rate that cannot be corrected for (**selection or consent bias**), or
- for other reasons

Additional requirements: adequate technical and organizational safeguards (e.g., pseudonymization), proportionality, and the patient did not actively refuse

Registry: Opt-in or opt-out procedure?

Nursing home residents and their (legal) representative

Nursing home organizations and nursing staff

Research

Consent procedure in the Registry

Nursing home organizations choose whether they want to implement an:

1. Opt-in
2. Opt-out
3. Combination of opt-in and opt-out
   - opt-in procedure for new residents
   - opt-out procedure for residents who are already in the nursing home

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Thank you for your attention

https://www.nivel.nl/nl/register-leren-van-data-verpleeghuizen

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