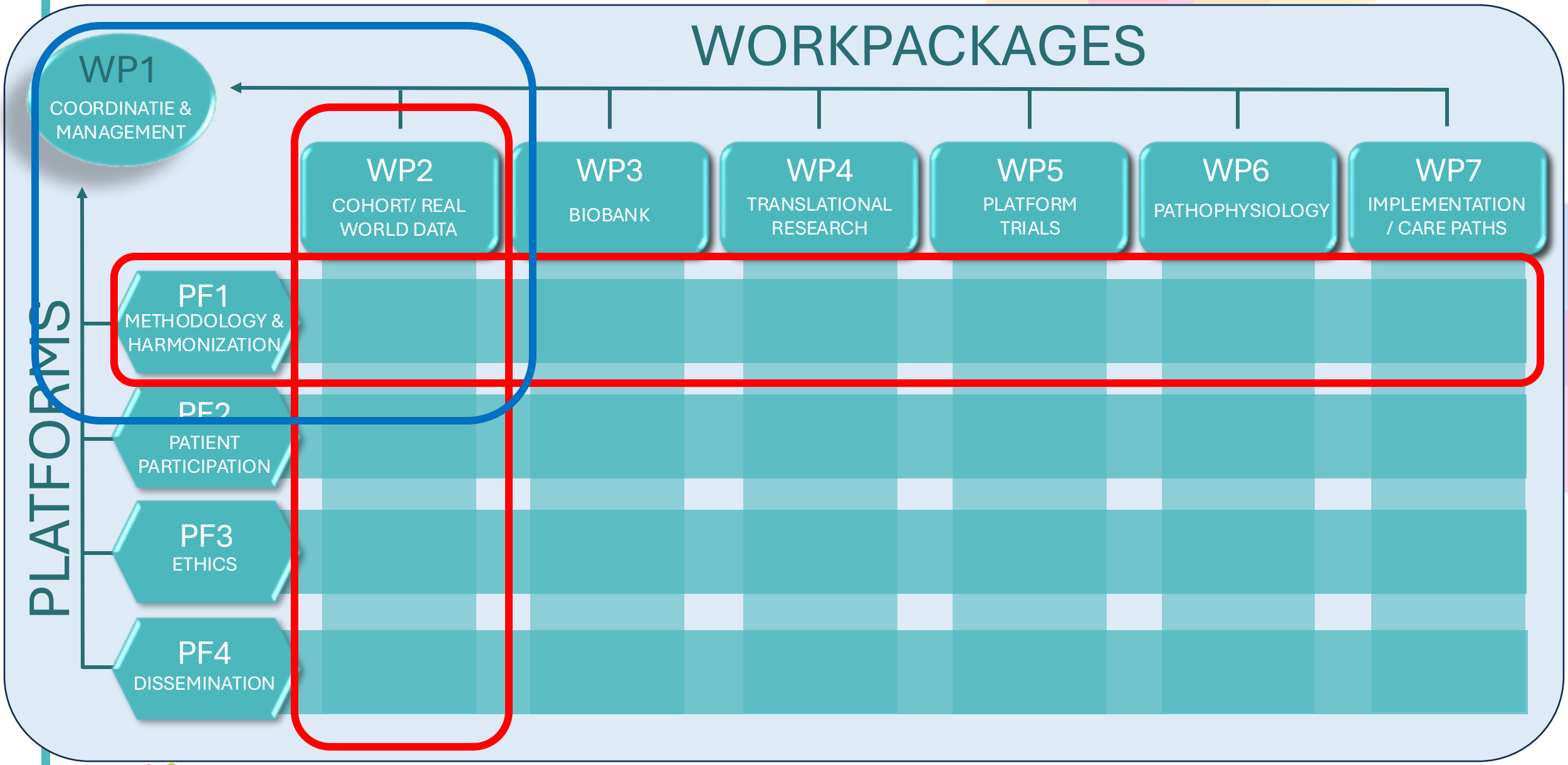
PCNN introduction – IHE Connecathon

xShare PH Long Covid workshop, Brussels, March 24th 2026

Dr. Bianca Boxma-de Klerk, on behalf of PCNN

Assistant Professor at Dept. Clinical Epidemiology, LUMC

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WP2 – Real world data

WP2a: Metadata dictionary

WP2b: Patient portal

WP2c: Data environment

Additional: Studymanagement tool

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WP2a: Metadata dictionary

Metadata format available in PCNN-Github (see QR code last slide)

- Inventory metadata of 32 pre-PCNN studies
- Collect metadata of new studies in PCNN

Build a searchable online tool to find/re-use data (metadata dictionary)

Align with EHDS developments

- Connect with Health DCAT (Dutch Metadata schema EHDS)

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WP2b: Patient portal

Online data collection: www.postcovidonderzoek.nl

- Started June 2024, 3-monthly follow up measurements
- ~16.000 Dutch Post-Covid patients registered voluntarily (baseline)
- PROMS, patient- and disease characteristics collected
- All patients gave informed consent to use their data for post-covid research

Patient selection and recruitment for research through the portal

Dashboard to monitor PROMs

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WP2c: Research environment

Collected portal data is stored at *Statistics Netherlands* (CBS) and merged with CBS microdata (e.g. hospital-, GP- and reimbursement data) in a secure microdata environment (PCNN CBS Basecamp)

Data is available at request for post-covid research purposes.

Studies performed within PCNN share back their collected data to add to PCNN CBS Basecamp and reuse.

CBS provides a secure data environment

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Studymanagement tool

To gain and keep insight in Post-Covid research within PCNN

Gateway to PCNN

To advise and assist researchers regarding methodology, ethics, harmonization, patient contact and plan knowledge dissemination in advance

To organize study logistics (data/samples (re)use) and use of the PCNN infrastructure (platform trials, implementation, dissemination)

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PF1 – Methodology & data harmonization

Codebook

- FAIR ontology
- Including all collected (research) data in PCNN, also including variables from metadata format and studymanagement tool

Harmonization

- Aligned data collection (timing + PROMs)
- Codebook provides centralized coding for data collection
- *Castor EDC* forms aligned with codebook as service for researchers

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Post-Covid Expertise clinics (PCEc)

6 PCEc for adults opened + 1 about to start

3 PCEc for children

PROM measurement harmonized with PCNN ~80%

Patients on PCEc waiting list asked to register at PCNN patient portal

Patient portal data used for evaluation of care in PCEc (controls)

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Desired future developments

Embed data collection patient portal in health care practice

Broaden scope to PAIS in due time

Combine more data sources, including PCEc data with research data

Develop the online tools: machine readable and aligned with international databases

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Thank you for your attention.

Feel free to ask questions,

now or later by email

Scan for PCNN GitHub:

For SOPs and documents

INTERESTED?
Check out:
www.postcovidnet.nl
or EMAIL us at:
PCNN@lumc.nl

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