

Beyond Best Effort: Automated Feedback for Improved Data Quality in Clinical Disease Registries

*A Case Study of the
International Niemann-Pick Disease Registry (INPDR)*

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Dalian, Oct 13 2017



Outline

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Data Quality in Clinical Research: Friend or Foe?



Data Quality Dimensions

thresholds

Case validity

plausibility
completeness
accuracy

Variable validity

comparability
completeness
eligibility
trustworthiness

timeliness
variation
reliability
...

“Data has high quality when it represents the needs of the researcher.”

(Abate et al., 1998)

Weiskopf & Weng, 2012; Batini & Scannapieco, 2006



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Data Quality Measurement

Integrity

- Consistency
- Missing compulsory items
- Implausible entries
- ... (27 more)

Organization

- Count of Follow up data
- timeliness
- Recruitment rate
- ... (12 more)

Correctness

- accuracy
- completeness
- ... (4 more)

$$DQ = \frac{1}{n} \sum_{k=1}^n QD_k$$



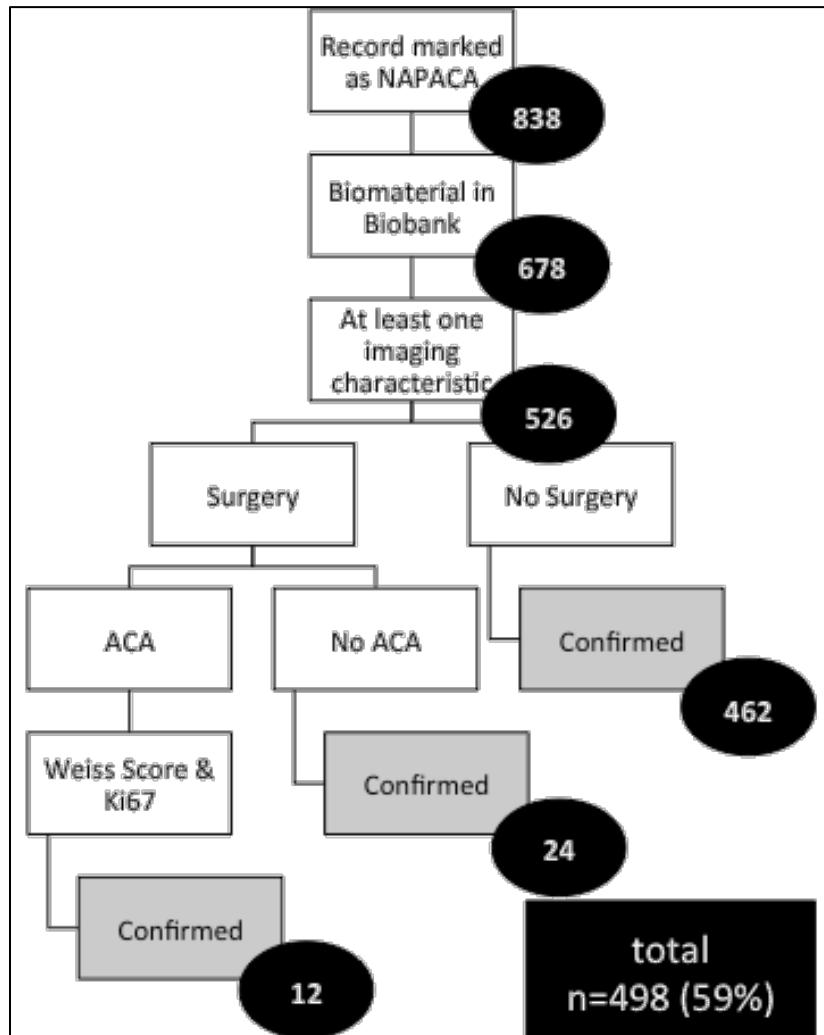
Nonnemacher et al., 2014



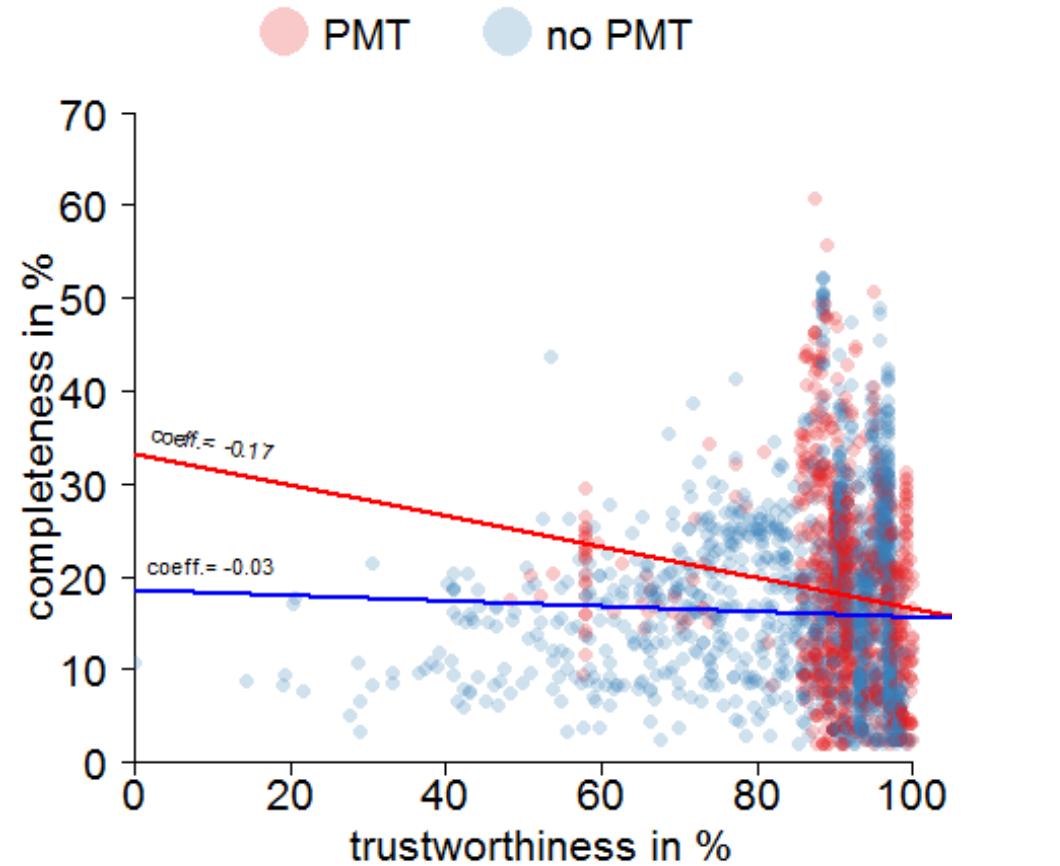
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Examples: Record Eligibility & Data Trustworthiness



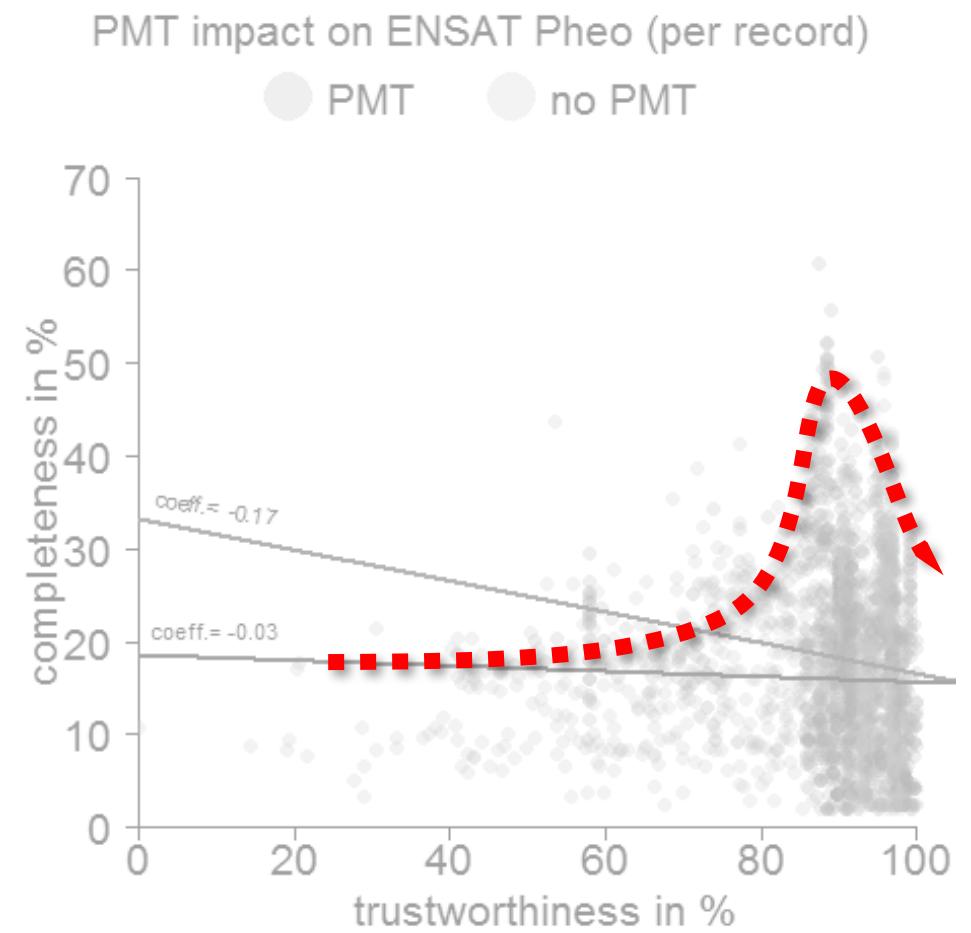
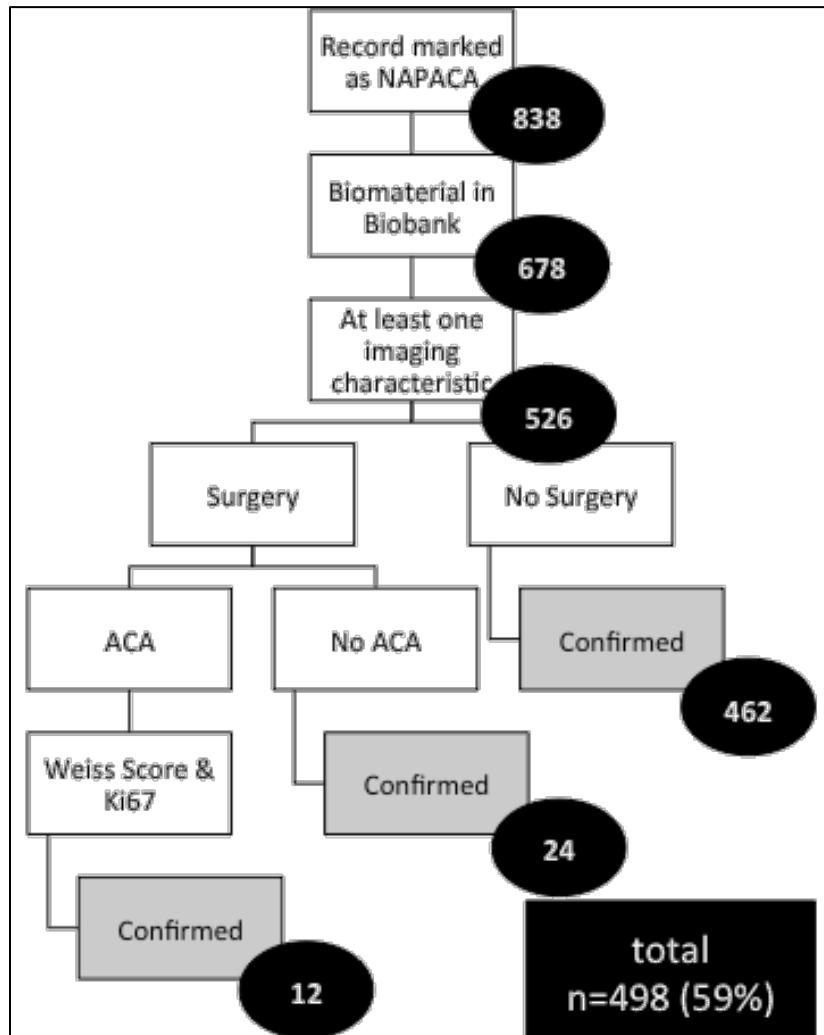
PMT impact on ENSAT Pheo (per record)



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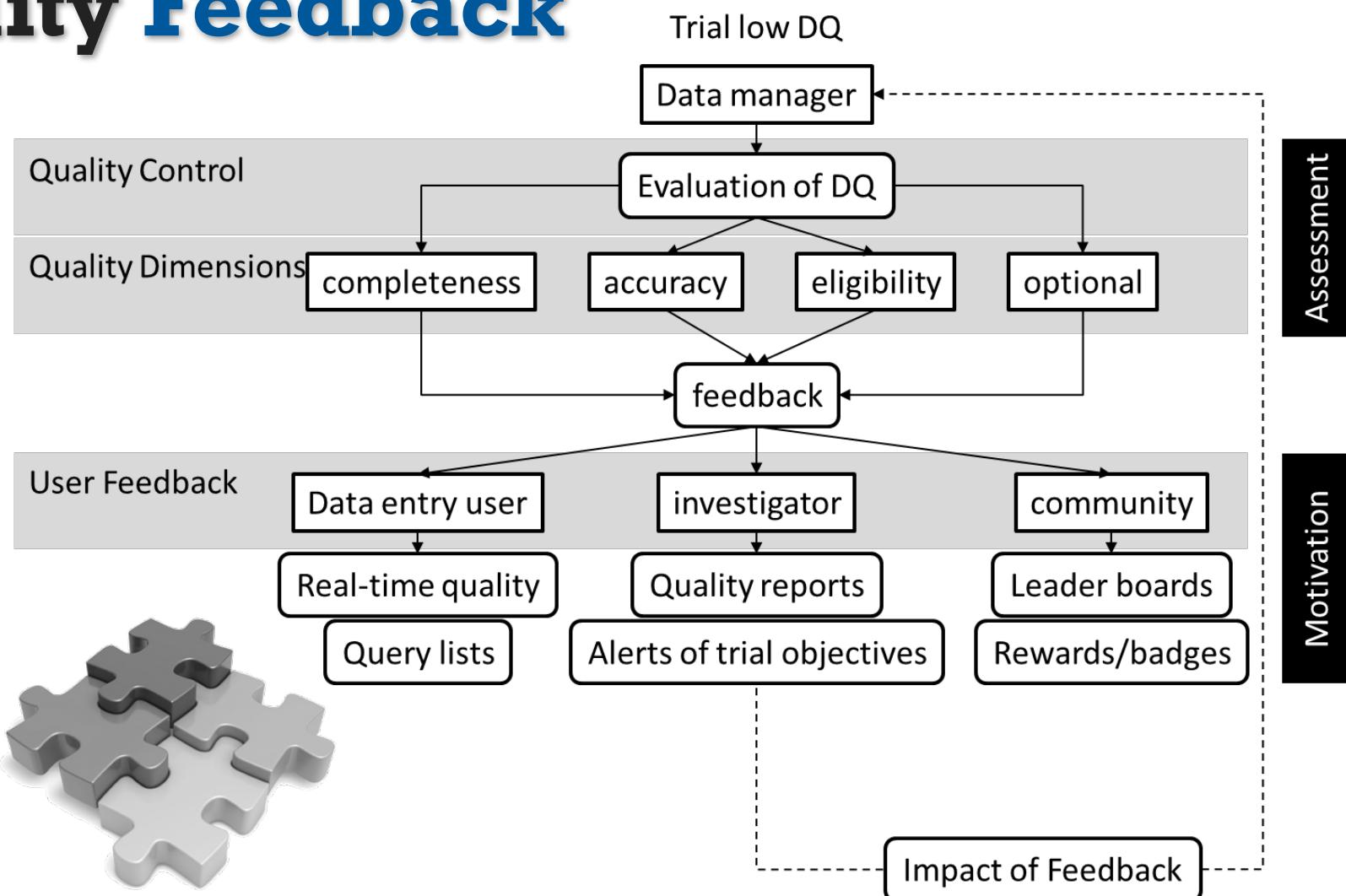
Examples: Record Eligibility & Data Trustworthiness



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Data Quality Feedback



Own concept



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2

Evaluating Data Completeness : One Size fits all?



International Niemann-Pick Disease Registry (INPDR)

- Severe metabolic disorder
(mostly children)
- Different types of NPD
- 6 European centers



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INPDR REGISTRY (TYPE-C)

Patients

Patient enrolment

Laboratory

Diagnosis

Family History

Clinical History

Treatments

Disability Scale

Additional

Investigations

Follow up visits

NPC Patient Listing

Enrol new NPC Patient

Patient ID ▾	Access Level	Date of birth	Gender	NPC type	Entry type	Consent	Details	Follow up
NPC-CZPR1-4	All	11/11/2008	Male	NPC1	Prospective	Yes	Details	Follow up
NPC-CZPR1-7	All	27/03/1991	Male	NPC1	Prospective	Yes	Details	Follow up
NPC-CZPR1-9	All	28/03/1987	Male	NPC1	Prospective	Yes	Details	Follow up
NPC-CZPR1-10	All	12/01/1993	Male	NPC1	Prospective	Yes	Details	Follow up
NPC-CZPR1-12	All	14/03/1991	Female	NPC1	Prospective	Yes	Details	Follow up
NPC-CZPR1-13	All	26/11/1985	Female	NPC1	Prospective	Yes	Details	Follow up
NPC-CZPR1-14	All	19/02/1988	Female	NPC1	Prospective	Yes	Details	Follow up
NPC-CZPR1-18	All	13/02/2008	Female	NPC1	Prospective	Yes	Details	Follow up
NPC-CZPR1-148	All	18/03/1982	Female	NPC1	Prospective	Yes	Details	Follow up
NPC-CZPR1-184	All	13/10/1986	Male	NPC1	Prospective	Yes	Details	Follow up

Form complete

Form complete Yes

Family history of NPC	No
Parents consanguinity	No
Father's origin	European
Mother's origin	European
Complication during pregnancy and delivery	No
Gestational age	Term: 37-42 weeks

Research registry
currently without running a
clinical trial



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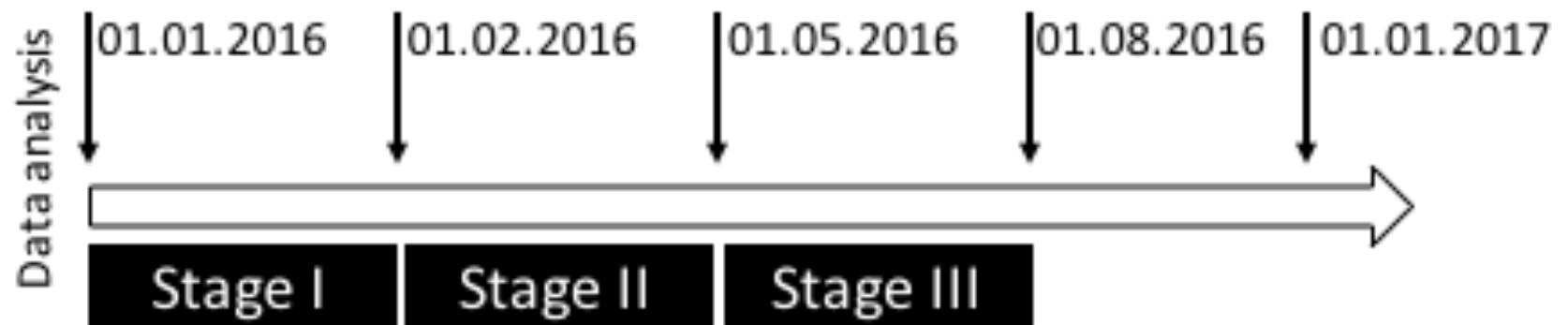
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Study Design

Stage I no feedback (data collection)

Stage II DC feedback to the user

Stage III Stage III + Community DC feedback to the user



3

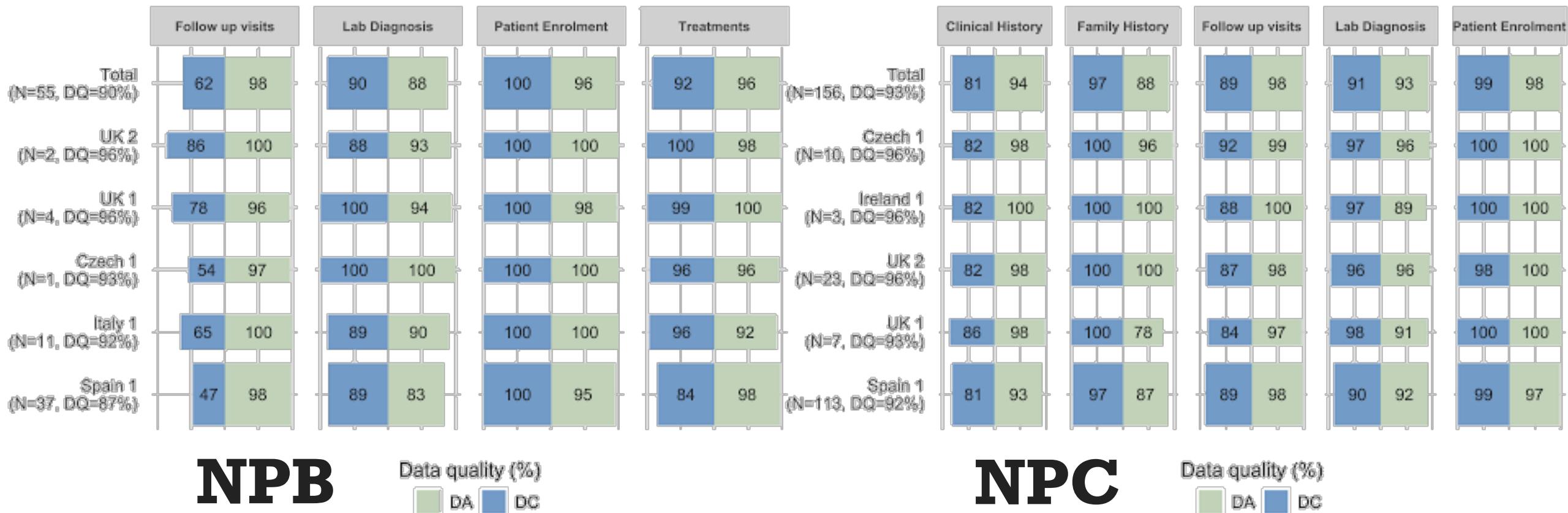
Is Data Quality Feedback efficient?



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Evaluation of Data Completeness



NPC

Data quality (%)
DA DC



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Data Quality Feedback

Center	Pre Stage I 01.01.2016	Pre Stage II 01.02.2016	Pre Stage III 01.05.2016	Post Stage III 01.08.2016
Czech 1	81.23 (8)	81.40 (9)	81.40 (9)	81.40 (9)
Spain 1	30.93 (103)	31.37 (106)	31.35 (107)	31.89 (108)
Ireland 1	66.00 (3)	72.67 (3)	72.67 (3)	73.17 (3)
Italy 1	81.56 (2)	38.51 (17)	38.51 (17)	38.51 (17)
UK 1	61.08 (3)	61.08 (3)	55.31 (4)	68.10 (6)
UK 2	53.17 (23)	53.17 (23)	53.52 (23)	53.61 (23)
TOTAL	63.33 (142)	56.37 (161)	55.46 (163)	57.78 (166)

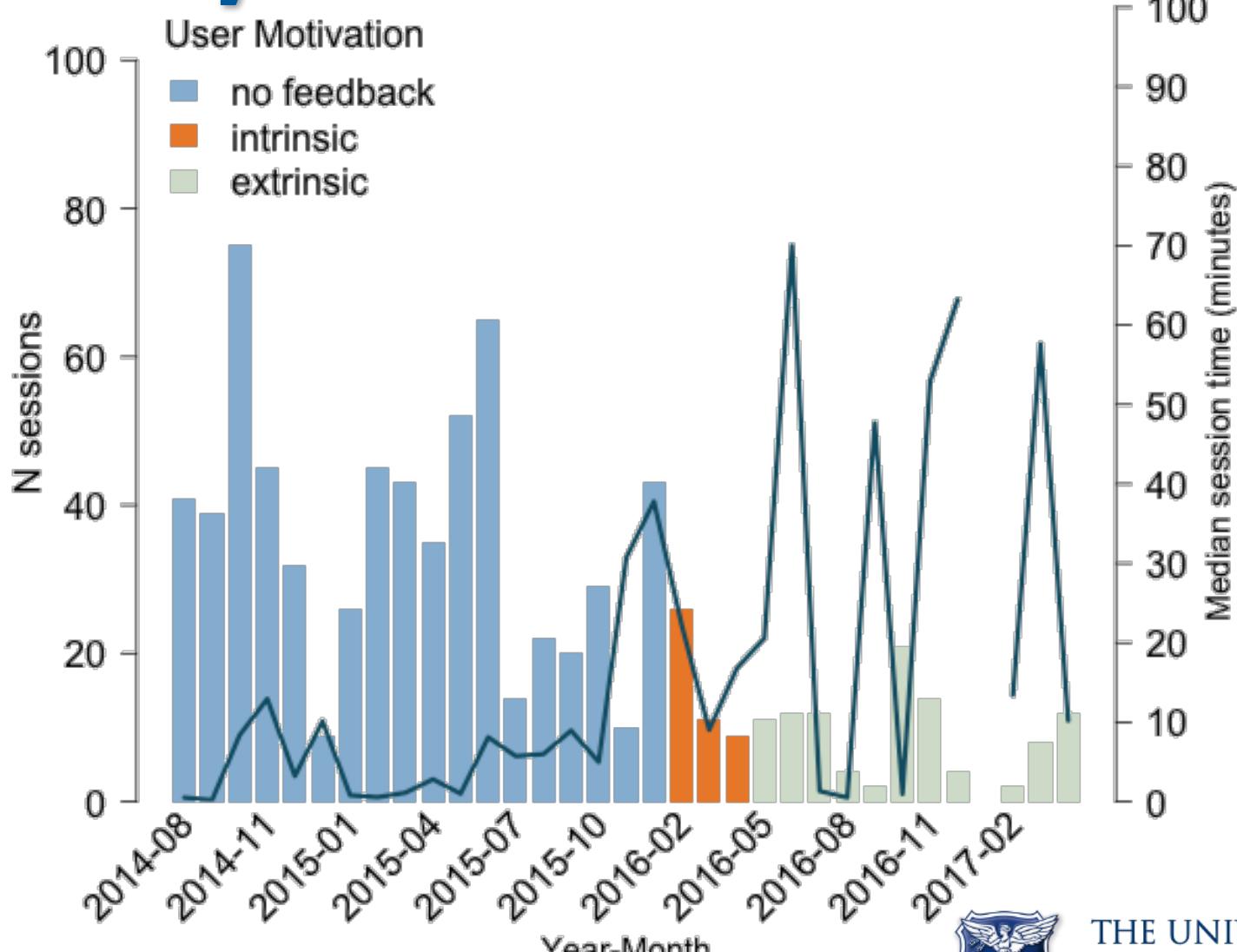
Data Completeness (n)



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User activity



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What have we learned?



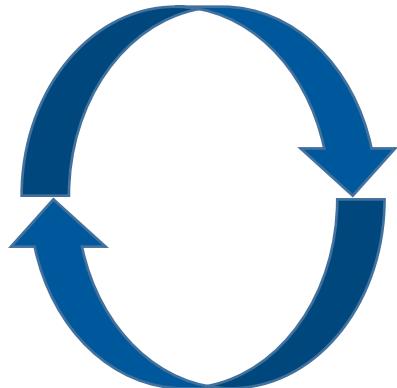
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Data Quality Feedback

A large blue circle containing a white exclamation mark.

Limitation: study population



Ongoing DQ assurance



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Evaluation of Data Completeness

A

Automated in CDBM

+

More DQ dimensions & thresholds



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Evaluation of User Activity

Dr

Activity insights needed:
What drives a researcher?

!?

Evaluating DQ and providing Feedback/
Improvements will drive researcher!?



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Thank you for your attention!

