Adaption of the Identity Management Regarding new Requirements of a Long-Term Psychosis Biobank

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- “Genotype-phenotype relationships and neurobiology of the longitudinal course of psychosis“

1000 patients with bipolar disorder
2200 patients with schizophrenia
3000 controls

6200 participants

0  6  12  18 month
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4 participants per day = 20 tubes of blood per day (without aliquots)
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Per participant per visit up to:

- 11 clinician-rating scales
- 9 self-rating scales
- 8 neuropsychological test

Young Mania Rating Scale (YMRS)

Instructions: For each item below, circle the response that best describes how you felt or behaved during the past 48 hours.

1. Elevated Mood
   0 Absent
   1 Mildly or possibly increased on questioning
   2 Definite subjective elevation, optimistic, self-confident; cheerful; appropriate to content
   3 Elevated, inappropriate to content; humorous
   4 Euphoric; inappropriate laughter, singing

2. Increased Motor Activity/Energy
   0 Absent
   1 Subjectively increased
   2 Animated; gestures increased
   3 Excessive energy, hyperactive at times; restless (can be calmed)
   4 Motor excitement; continuous hyperactivity (cannot be calmed)

3. Sexual Interest
   0 Normal; not increased
   1 Mildly or possibly increased
   2 Definite subjective increase on questioning
   3 Spontaneous sexual content; elaborates on sexual matters; hypersexual by self-report
   4 Overt sexual acts (toward patients, staff, or interviewer)

4. Language/Thought Disorder
   0 Absent
   1 Circumstantial, mild distractibility; quick thoughts
   2 Distractible; loses goal of thought; changes topics frequently; racing thoughts
   3 Flight of ideas; tangibility; difficult to follow; rhyming; echolalia
   4 Incoherent; communication impossible

5. Thought Content
   0 Normal
   2 Questionable plans; new interests
   4 Special project(s); hyperevangelical
   6 Grandiose or paranoid ideas; ideas of reference
   8 Delusions; hallucinations

6. Disruptive/Aggressive Behavior
   0 Absent, cooperative
   2 Sarcastic; loud at times, guarded
   4 Demanding; threats on ward
   6 Threatens interviewer; shouting; interview difficult
   8 Assaultive; destructive; interview impossible
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Infrastructure as basis for the Cohort of the German Association for Psychiatry and Psychotherapy (DGPPN)

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TMF – Technology, Methods, and Infrastructure for Networked Medical Research

Synergy, quality & standards – shared solutions for health
IT support for workflows of biobanks
Adapted identity management
Discussion

• Linking data from different databases gets more complex

• Access to the data must be ensured without making the system ineffective

→ Access (rights & roles) concept
Outlook

Addition of further database

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Questions?