

Press release

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Basic information

Name: Anna Sundby Email: anna.sundby@regionh.dk Phone: +4528729060

Department of: Clinical Medicine

Main supervisor: Professor Ole Mors

Title of dissertation: The voice of potential stakeholders in psychiatric genomic research

Date for defence: 2018-04-04 at (time of day): 2pm Place: Auditoriet, Aarhus University Hospital Risskov, Skovagervej 2, Entrance 30, 8240 Risskov

Press release (Danish)

Potentielle interessenter i psykiatrisk genomforsknings stemme

Psykiske sygdomme medfører mange helbredsmæssige problemer over hele verden. Årsagsmekanismerne er stort set ukendte, men genetisk forskning har i de senere år bragt betydelige fremskridt i vores biologiske forståelse af området. Flere og flere psykiatriske studier anvender kortlægning af den fulde arvemasse, total genomisk sekventering, som undersøgelsesmetode. Dette giver meget store datamængder og øger sandsynligheden for at gøre forventelige fund (relevante fund) i relation til forskningsprojektet. Dog kan forskerne også gøre tilfældighedsfund, som kan have stor klinisk relevans for forsøgsdeltagerne og deres familier, selvom disse fund ikke er formålet med det specifikke forskningsprojekt. Disse kaldes tilfældighedsfund (utilsigtede fund). Håndteringen af disse fund i forbindelse med genomforskning har medført en livlig debat om etiske og juridiske aspekter men få studier har undersøgt potentielle forskningsdeltageres og sundhedsprofessionelles holdninger hertil. Det overordnede formål med dette PhD-projekt var derfor, at undersøge potentielle forskningsdeltageres (personer med psykisk sygdom, pårørende og bloddonorer) og sundhedsprofessionelles (psykiatere og speciallæger i klinisk genetik) holdninger til brugen af total genomisk sekventering i forskning. Til dette formål, blev der udført både semi-strukturerede kvalitative interviews (N=13) og et web-baseret survey (N=2637). Det er håbet, at de præsenterede resultater kan bidrage til den fremtidige anvendelse af total genomisk sekventering i forskning samt bidrage til den fremtidige udvikling af samarbejdet mellem forskere og forskningsdeltagere i genomforskning.

Dette PhD-projekt fra Aarhus Universitet, Health er gennemført af Anna Sundby. PhD-forsvaret er offentligt og finder sted d. April 2018 kl. 14 Auditoriet, Aarhus Universitets Hospital Risskov, Skovagervej 2, Indgang 30, 8240 Risskov. Efter PhD-forsvaret vil der blive afholdt en reception.

Yderligere oplysninger: PhD-studerende, Anna Sundby, e-mail: anna.sundby@regionh.dk, tlf. 28729060.

Bedømmelsesudvalg:

- Kristien Hens, Visiting Professor, PhD, Department of Philosophy, University of Antwerp, Belgium.
- Aaro Mikael Tupasela, Associate Professor, PhD, Section of Health Services Research, Department of Public Health, University of Copenhagen, Denmark.
- Uffe Birk Jensen, Clinical Professor, PhD, MD, Department of Clinical Medicine, Department for Clinical Genetics, Aarhus University, Denmark (formand).

Press release (English)

The voice of potential stakeholders in psychiatric genomic research

Mental disorders cause significant health problems in the world. Our approach to mental disorders has changed over time, and genetic research has recently resulted in significant advances in our understanding. Increasingly more psychiatric studies use genome sequencing. This generates huge volumes of data and increases the likelihood of discovering the pertinent findings, i.e. findings relevant to the specific research project. But researchers may also identify results that could have important clinical relevance for the individual research subjects and their families, although such results are outside the scope of the specific study. These are termed incidental findings. The management of such findings in genomic research has fueled heated debate on ethical and legal issues but few previous studies have studied the potential research subjects and health professional's attitudes. The overall aim of this PhD study are to investigate potential psychiatric research subjects (persons with mental disorders, relatives and blood donors) and health professional's (psychiatrists and clinical geneticists) attitudes toward the use of genomic sequencing in research and whether there are differences between the stakeholder group's attitudes.

To investigate this, the PhD study was carried out with a mixed methods design: using both semi-structured qualitative individual interviews and focus-group interviews (N= 13), and quantitative web-based survey (N=2,637).

It is the hope that the results presented can contribute to the future use of genomic sequencing in research and contribute to the future development of the collaboration between researchers and research participant in genomic sequencing.

The project was carried out by Anna Sundby from Clinical Medicine, Health, Aarhus University. The defence is public and takes place on April 4th from 2pm in the Auditorium, Aarhus University Hospital Risskov, Entrance 30, Skovagervej 2, 8240 Risskov. After the defence, a reception will be held.

For more information, please contact PhD student Anna Sundby, email: anna.sundby@regionh.dk, Phone +45 28729060.

Assessment committee:

- Kristien Hens, Visiting Professor, PhD, Department of Philosophy, University of Antwerp, Belgium.
- Aaro Mikael Tupasela, Associate Professor, PhD, Section of Health Services Research, Department of Public Health, University of Copenhagen, Denmark.
- Uffe Birk Jensen, Clinical Professor, PhD, MD, Department of Clinical Medicine, Department for Clinical Genetics, Aarhus University, Denmark (Chairman).

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