

Brain-CODE Common Data Elements:

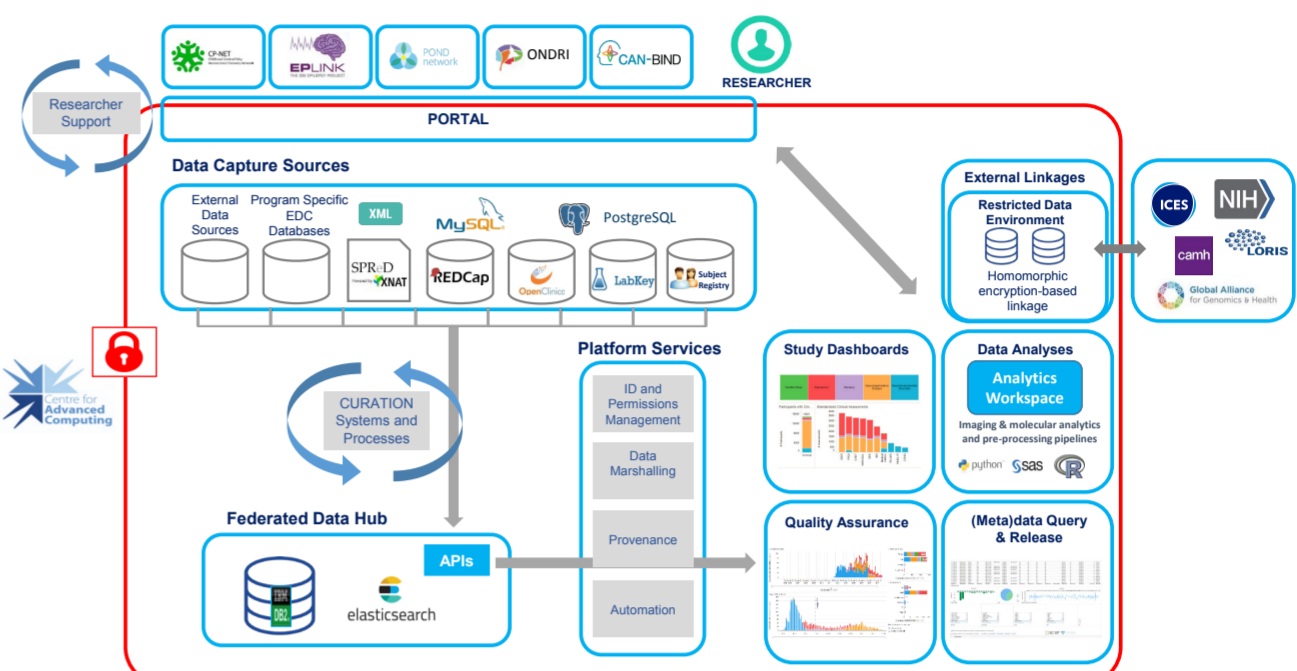
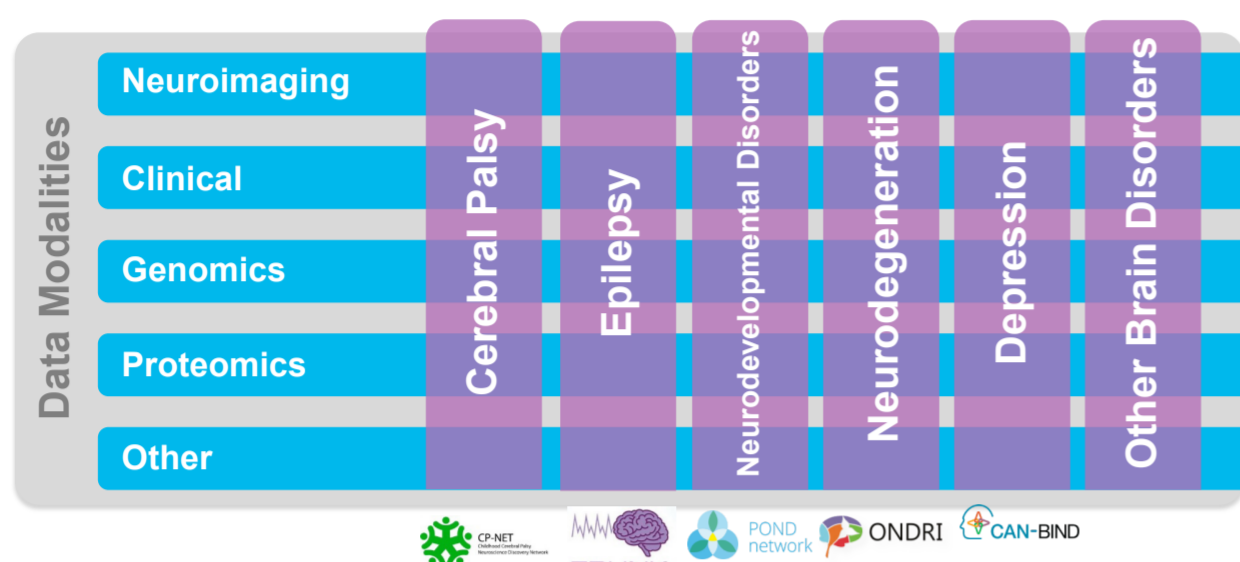
Assessing Neuropsychiatric Comorbidity Across Brain Disorders

A. Vaccarino¹, D. Beaton², S. Black³, E. Finger⁴, M. Freedman², B. Frey⁵, S. Kennedy⁶, D. Kwan³, R. Lam⁷, A. Lang⁸, G. MaQueen⁹, R. Milev¹⁰, N. Mirotnick¹¹, S. Parikh¹², S. Rotzinger⁶, C. Soares¹⁰, K. Sunderland², C. Tartaglia⁸, R. Uher¹³, L. Zinman³, K. Evans¹

¹Indoc Research, Toronto, Canada, ²Rotman Research Institute, Baycrest Centre, ³Sunnybrook Research Institute, ⁴University of Western Ontario, ⁵St Joseph's Healthcare, ⁶McMaster University, ⁷Dept Psychiatry, University Health Network, ⁸Dept Psychiatry, University of British Columbia, ⁹Toronto Western Hospital, ¹⁰Hotchkiss Brain Institute, University of Calgary, ¹¹Dept Psychiatry, Queen's University, ¹²Ontario Brain Institute, ¹³University of Michigan, ¹⁴Dept Psychiatry, Dalhousie University

Introduction

The Ontario Brain Institute's large-scale informatics platform, Brain-CODE, is designed to support collection, storage and integration of diverse data types across several brain disorders, including neurodevelopmental and neurodegenerative disorders, cerebral palsy, epilepsy, and major depressive disorder.¹ By providing access to aggregated datasets, Brain-CODE supports scientific inquiry and analytics both within and across multiple brain disorders. To help achieve these goals and facilitate cross-disease comparisons, a set of core clinical outcome measures were identified and collected across brain disorders. These CDEs provide standard definitions and formats so that investigators collect data consistently across studies and increase opportunities for sharing and conducting integrated analyses across diseases.



Methods

A modified Delphi consensus process was used to identify core demographic and clinical variables to be collected across studies.¹ There was agreement that when possible, the measures should be patient-reported, brief and easy to administer, widely used and validated. The CDEs were used to assess comorbid depression and anxiety and their impact on quality of life in neurodegenerative disorders (Alzheimer's disease, Amyotrophic lateral sclerosis, Frontotemporal dementia, Parkinson's disease, Vascular cognitive impairment) and MDD, as part of the Ontario Neurodegenerative Disease Research Initiative (ONDRI)² and Canadian Biomarker Integration Network in Depression (CAN-BIND)³

Results

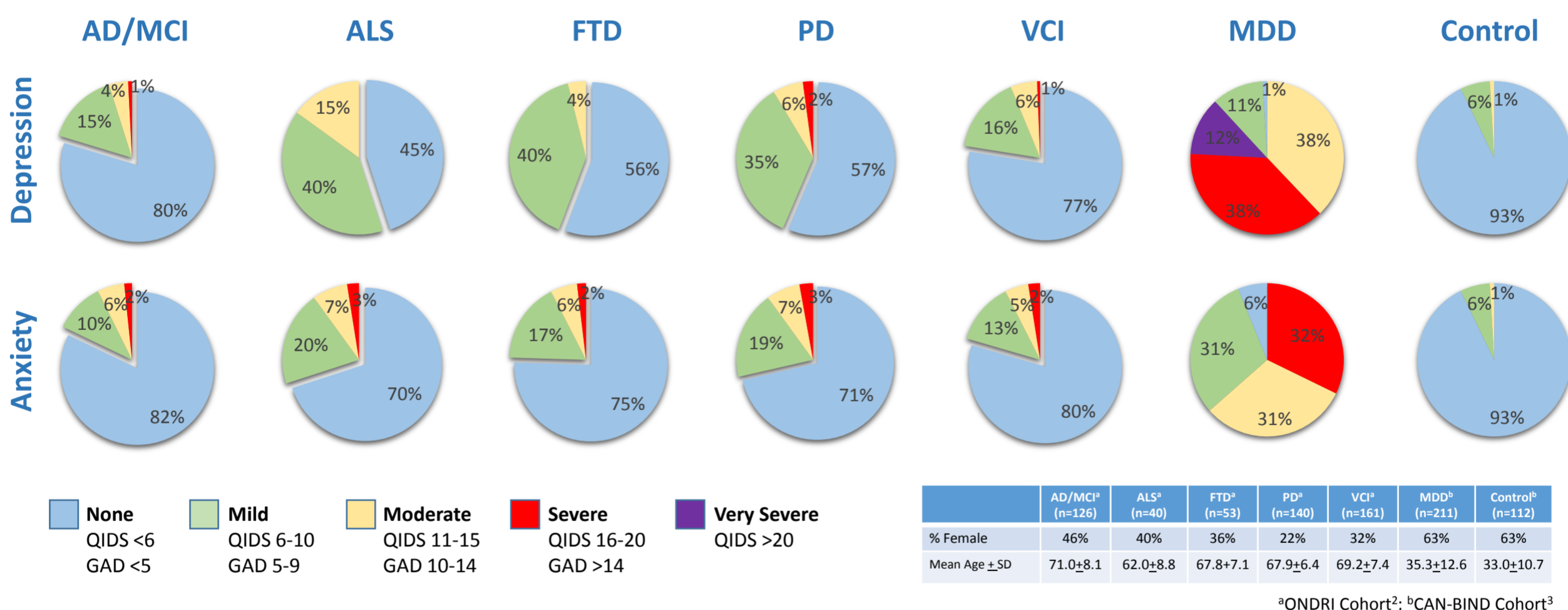
Brain-CODE demographic and clinical CDEs

DOMAIN	SUB-DOMAIN	Brain-CODE CDE
Patient Characteristics	Demographic	Brain-CODE Demographic Form
	SES	Brain-CODE Demographic Form
Physical and Mental Health	Quality of Life	WHO-QoL-BREF (adult) KINDL-R (child & adolescent)
	Activities of Daily Living	Sheehan Disability Scale (adult)
	Medical Comorbidity	NINDS Medical History (all)
	Psychiatric Comorbidity	BSI (adolescent & adult)
Clinical Endpoints	Depression	QIDS-SR (adolescent & adult) RCADS (child & adolescent)
	Anxiety	GAD-7 (adolescent & adult) RCADS (child & adolescent)
	Sleep	PSQI (adolescent & adult) CSHQ (child)

Brain-CODE CDEs collected across programs (to date)



Depression (QIDS-SR) and anxiety (GAD-7) across neurodegenerative disorders



Linear regression analysis to assess impact of depression and anxiety on quality of life (WHO-QoL-BREF) across neurodegenerative disorders

Physical Health

	AD/MCI		ALS		FTD		PD		VCI	
	B	Sig	B	Sig	B	Sig	B	Sig	B	Sig
Age	.00	NS	.05	NS	-.01	NS	.00	NS	-.03	NS
Sex	-.08	NS	-.11	NS	.71	NS	-.01	NS	-.30	P=0.08
MOCA	-.11	P=0.08	.12	NS	-.02	NS	-.08	NS	.06	NS
QIDS-SR	-.25	P<0.01	-.52	P<0.01	-.23	P=0.09	-.38	P<0.01	-.39	P<0.01
GAD-7	-.09	NS	-.15	NS	-.37	p>0.01	-.11	P=0.06	-.09	NS

Psychological Health

	AD/MCI		ALS		FTD		PD		VCI	
	B	Sig	B	Sig	B	Sig	B	Sig	B	Sig
Age	.00	NS	.02	NS	.02	NS	.00	NS	.00	NS
Sex	.05	NS	.75	p<0.05	.29	NS	.13	NS	-.38	p<0.05
MOCA	-.06	NS	-.11	NS	-.12	NS	-.02	NS	.11	p<0.05
QIDS-SR	-.17	P<0.05	-.76	P<0.01	-.24	P<0.05	-.37	P<0.01	-.37	P<0.01
GAD-7	-.18	P<0.01	.05	NS	-.43	p>0.01	-.15	P<0.01	-.18	P<0.01

Social Relationships

	AD/MCI		ALS		FTD		PD		VCI	
	B	Sig	B	Sig	B	Sig	B	Sig	B	Sig
Age	.03	NS	.05	NS	.06	NS	.04	NS	.01	NS
Sex	.75	P<0.01	.95	p<0.05	.96	p<0.05	.74	p<0.05	-.14	NS
MOCA	-.04	NS	-.21	NS	-.02	NS	-.04	NS	.13	P=0.09
QIDS-SR	.00	NS	-.27	P=0.09	.05	NS	-.48	P<0.01	-.31	P<0.01
GAD-7	-.19	P=0.05	-.15	NS	-.40	P<0.01	.01	NS	-.12	P=0.09

Environmental Health

	AD/MCI		ALS		FTD		PD		VCI	
	B	Sig	B	Sig	B	Sig	B	Sig	B	Sig
Age	.02	NS	.06	NS	.00	NS	.04	NS	.03	NS
Sex	.16	NS	.39	NS	.53	NS	-.15	NS	-.37	p<0.05
MOCA	-.03	NS	-.15	NS	-.05	NS	.14	p<0.05	.13	p<0.01
QIDS-SR	-.07	NS	-.41	P<0.01	.02	NS	-.23	P<0.01	-.21	P<0.01
GAD-7	-.04	NS	-.10	NS	-.27	p>0.01	-.08	NS	-.08	P=0.08

Conclusions

- Brain-CODE CDEs facilitate data sharing and cross-disorder comparisons
- Comorbid depression and anxiety were observed across neurodegenerative disorders
- Depression and anxiety impact quality of life in neurodegenerative disorders, and should be considered in treatment
- Brain-CODE Demographic and Clinical CDEs have been successfully implemented within all participating programs and data will be available to the research community for analyses

References

- Vaccarino *et al.* Front Neuroinformatics (2018) 12:28
- Farhan *et al.* Can J Neurol Sci (2017) 44:196
- Lam *et al.* BMC Psychiatry (2016) 16:105

Acknowledgements

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