**The Avon Longitudinal Study of Parents and Children
A longitudinal and multigeneration platform for
collaborative research**

Nic Timpson & Lynn Molloy

University of BRISTOL

CHILDREN OF THE 90s

wellcome

Supported by
NIHR

MRC
Medical
Research
Council

Experience from a Wellcome 4 year PhD programme leads meeting

"… do you think that we could get your (another programme) students using ALSPAC?"

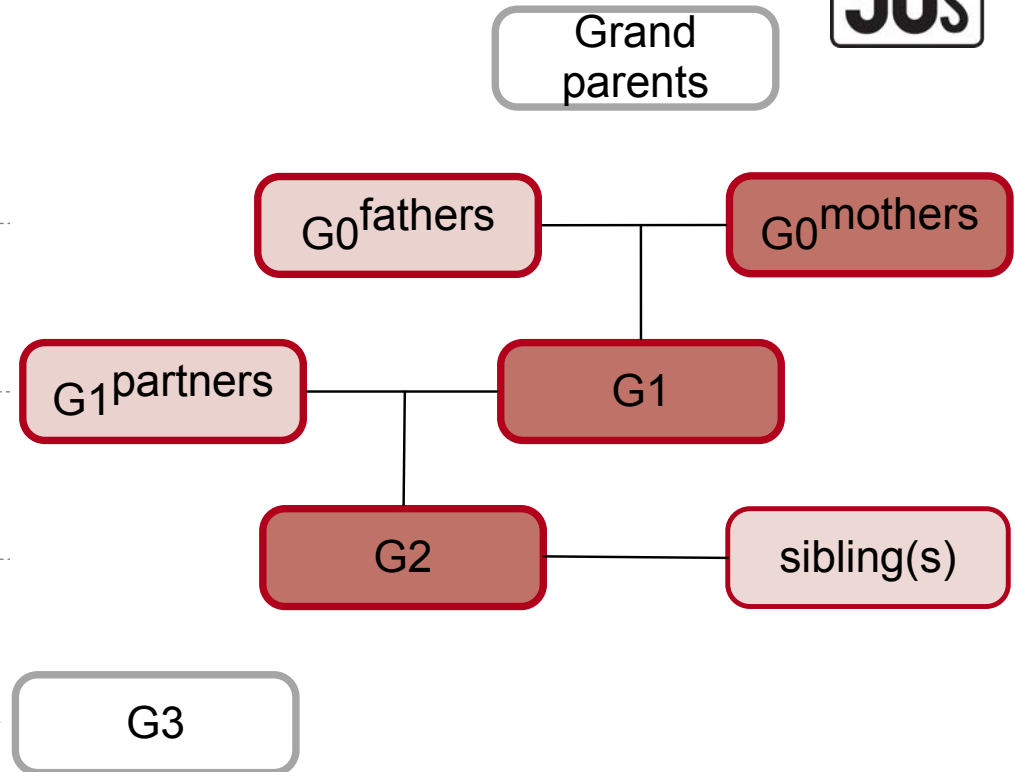"… but ALSPAC is a biomedical study."

ALSPAC

>30k participants, >1.2million bio-samples, >80k variables,
29 years of deep longitudinal study, just under 1,000 (979) researchers,
>2500 papers
20 proposals/month for data/samples

>14541 pregnancies, 75% of all
Linkage consented and >8000 active

>9k at 8yrs, >6k at 18yr, 4.5k stable
>80% linked and 6500 active

>1200 new pregnancies
3300 pregnancies over next 5 years
Linkage consented

(Eldest G2 already 12
G3 likely over the next 5 years)

Grand parents

G0 fathers — G0 mothers

G1 partners — G1

G2 — sibling(s)

G3

International Journal of Epidemiology 2013;**42**:97–110
doi:10.1093/ije/dys066

COHORT PROFILE

Cohort Profile: The Avon Longitudinal Study of Parents and Children: ALSPAC mothers cohort

Abigail Fraser,[1,2] Corrie Macdonald-Wallis,[1,2] Kate Tilling,[2] Andy Boyd,[2] Jean Golding,[2] George Davey Smith,[1,2] John Henderson,[2] John Macleod,[2] Lynn Molloy,[2] Andy Ness,[3] Susan Ring,[2] Scott M Nelson[4] and Debbie A Lawlor[1,2]*

International Journal of Epidemiology 2013;**42**:111–127
doi:10.1093/ije/dys064

COHORT PROFILE

Cohort Profile: The 'Children of the 90s'—the index offspring of the Avon Longitudinal Study of Parents and Children

Andy Boyd,[1]* Jean Golding,[2] John Macleod,[1] Debbie A Lawlor,[3] Abigail Fraser,[3] John Henderson,[1] Lynn Molloy,[1] Andy Ness,[4] Susan Ring[1] and George Davey Smith[3]
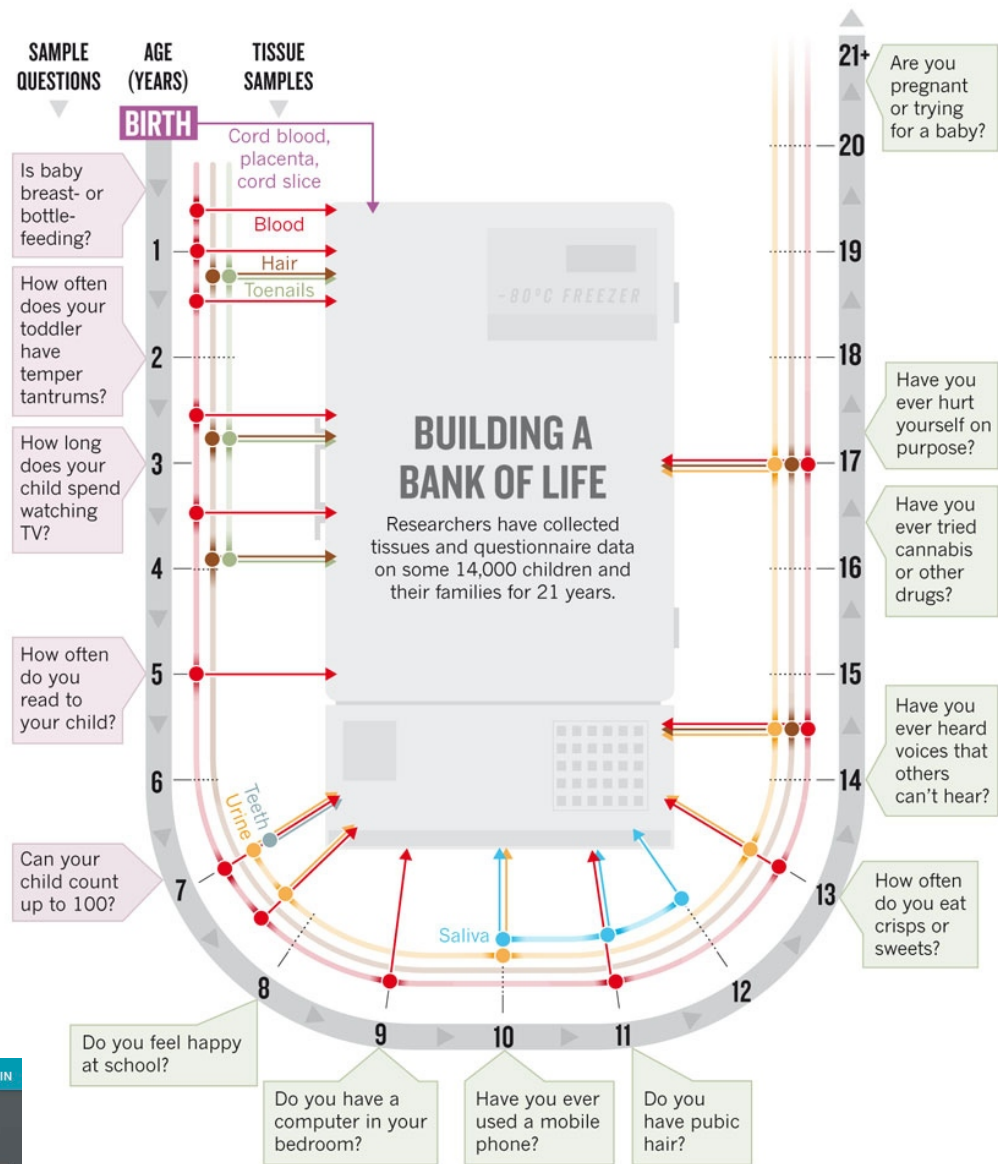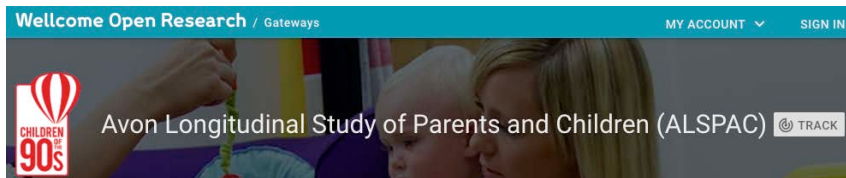
Pearson, Nature 2012

CLOSER – April 2021

Electronic health record linkage

- ✓ Birth records
- ✓ Primary Care (GP) Records
- ✓ Hospital Episode Statistics (HES)
- ✓ Death certificates and cancer registrations
- ✓ Education
- ✓ Geographical & Neighbourhood
- ✓ **Criminal records**
- ✓ Pillar linkage (COVID_19)
- ✓ Children Looked After & In Care
- ○ Employment & tax
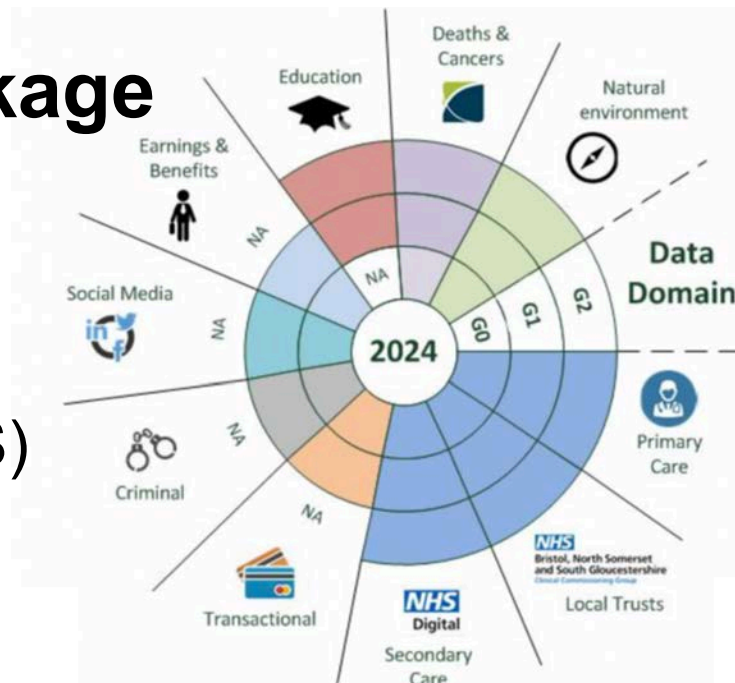
Adversity/violence through life.

Rosie Cornish University of Bristol

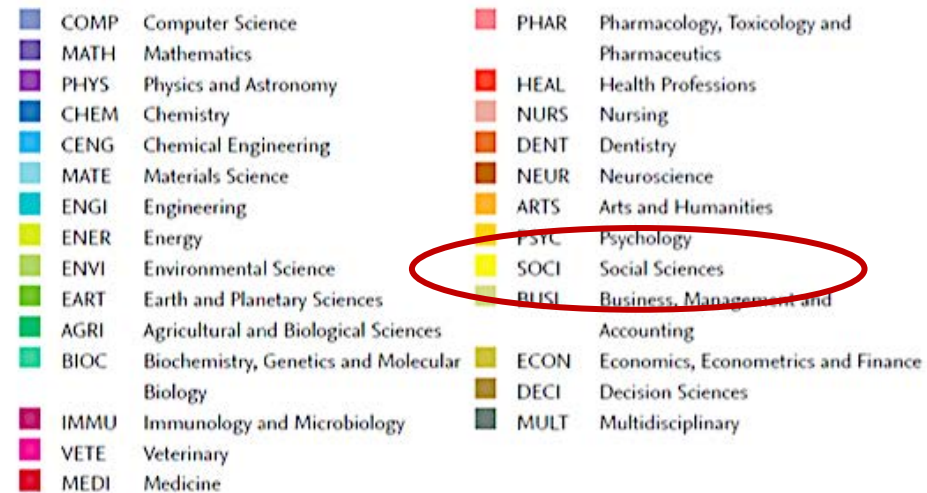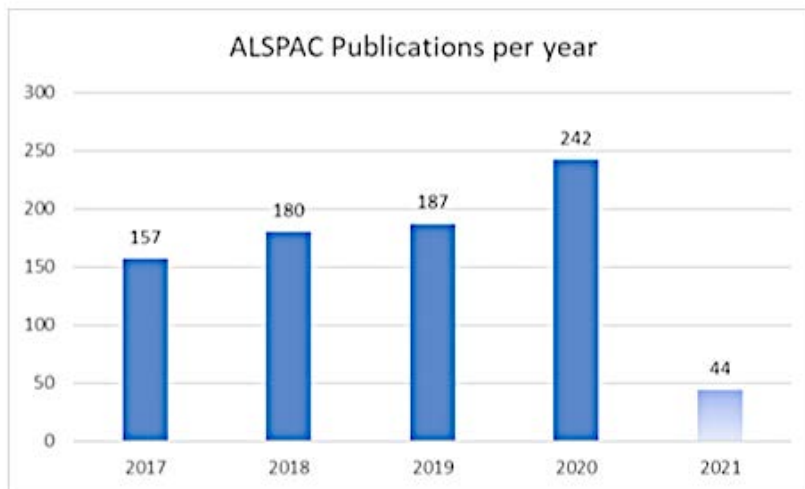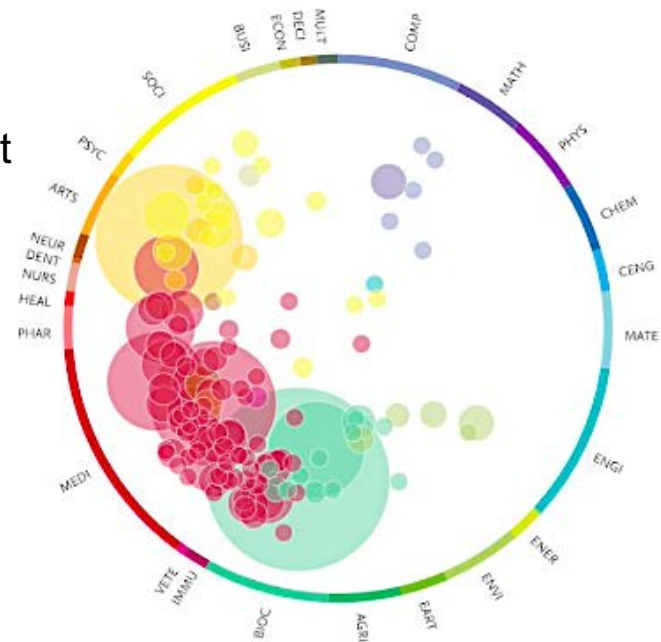**Project to Enhance ALSPAC through Record Linkage (PEARL)**

Current output from ALSPAC

Medicine/molecular epidemiology contribution, but social science is a major area of activity.

These metrics are likely to be limited and we clearly need to do more to work with social scientists and to engage with methods and approaches aligned to social science studies.

Good overlap between social and medical sciences.

ALSPAC Publications per year

COMP	Computer Science		PHAR	Pharmacology, Toxicology and Pharmaceutics
MATH	Mathematics		HEAL	Health Professions
PHYS	Physics and Astronomy		NURS	Nursing
CHEM	Chemistry		DENT	Dentistry
CENG	Chemical Engineering		NEUR	Neuroscience
MATE	Materials Science		ARTS	Arts and Humanities
ENGI	Engineering		PSYC	Psychology
ENER	Energy		SOCI	Social Sciences
ENVI	Environmental Science		BUSI	Business, Management and Accounting
EART	Earth and Planetary Sciences		ECON	Economics, Econometrics and Finance
AGRI	Agricultural and Biological Sciences		DECI	Decision Sciences
BIOC	Biochemistry, Genetics and Molecular Biology		MULT	Multidisciplinary
IMMU	Immunology and Microbiology			
VETE	Veterinary			
MEDI	Medicine			

https://service.elsevier.com/app/answers/detail/a_id/12007/supporthub/scopus/

Visibility and Access

We see ourselves as one part of a rich portfolio

MACRO — MICRO

Country/region	Very large population based	Cohorts & bespoke studie
Record linkage based	Record linkage	Exhaustive phenotyping
Remote data collection	Omic data screens/clinics	(hypothesis driven)

Visibility and Access

C1	OPEN CLINIC Face-to-face data collection
C2	G0/G1/G2 remote data · G0/G1/G2 remote data · G0/G1/G2 remote data · G0/G1/G2 remote data
C3	Linkage
C4	Sample management & biosample programme
C5	MONGO DB/OPAL Adoption · Data management and access
C6	Operations, Governance & Participation

ALSPAC AVON LONGITUDINAL STUDY OF PARENTS AND CHILDREN

Access Policy

v. 13.0

February 2021

Visibility and Access

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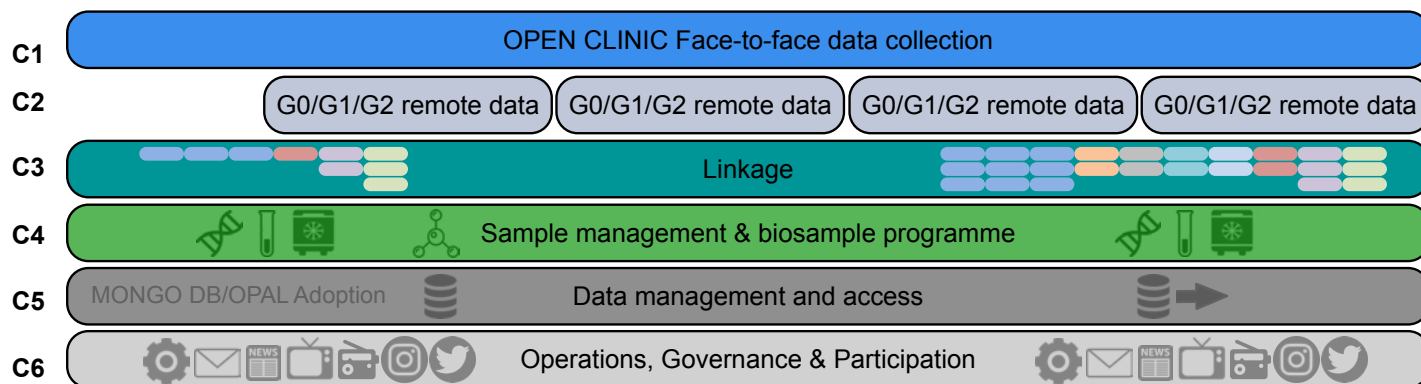
DISCOVERY **MANAGED ACCESS** **RELEASE**

Direct Release

Research question

Search for variables collected in the ALSPAC study
App version: 0.1.10 (11 May 2018)
Data version: 0.19.0

Data catalogue **Data searchables** **Online access**

Conferences **Publications** **Test data & training**

Powered by F1000 Wellcome Open Research

Access & Support

OPS

EXEC

ISAB OCAP
ALEC

Secure Access (eg UKSeRP)

Visibility and Access

C1	OPEN CLINIC Face-to-face data collection
C2	G0/G1/G2 remote data · G0/G1/G2 remote data · G0/G1/G2 remote data · G0/G1/G2 remote data
C3	Linkage
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Past approach to cost recovery

data preparation · data support

2019-24 approach to cost recovery

data preparation · data support

2024+ approach to cost recovery

OPEN

data preparation · data support

Managed access will be part of our approach, but with balance from preparation -> support

Exemplars – likely the best way to illustrate the possible utility of a studies like ALSPAC to social scientists.

Elect to say "studies like ALSPAC" as this is clearly a general principle for many studies potentially viewed as "biomedical"

Exemplar 1. The anthropology of cohorts themselves – ethnography and participation

Sahra Gibbon
UCL

Why do Families Participate in Cohort Research:

- Pilot study research examining multi-generational birth cohort participation

- Method: ethnographic interview with 'paired participants' (G0 parent and G1 adult child who had own child(ren)enrolled in G2)

- '[Becoming Intergenerational in Birth Cohorts: kinship and the remaking of participation](#)' Sahra Gibbon and Rosie Mathers (2021) *Somatosphere* March 18th

Biosocial Lives of Birth Cohorts (2021-2025):

- 4-year Investigator Award examining Biosocial research in 4 birth cohorts (ALSPAC, Generation R-Rotterdam, Generation 21-Porto, Pelotas Birth Cohort Study – Brazil) as knowledge, social practice and **participation**

- Using ethnographic and participatory research methods to examine the experience and meaning of birth cohort participation

- All arguably "biomedical", but where new data may illuminate other fields and help the interpretation of data collected within studies.

Exemplar 2. Mental health and longitudinal population study data

Mental health is receiving great attention and is measured in great detail in longitudinal studies like ALSPAC – this also bridges organic and social domains and there is an opportunity to bring together data and researchers around this.

Prevalence of Prenatal Depression Symptoms Among 2 Generations of Pregnant Mothers
The Avon Longitudinal Study of Parents and Children

Dr Rebecca Pearson
Senior Lecturer in Psychiatric Epidemiology
Centre for Academic Mental Health
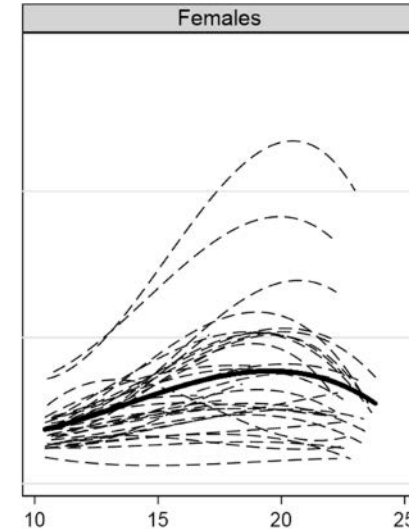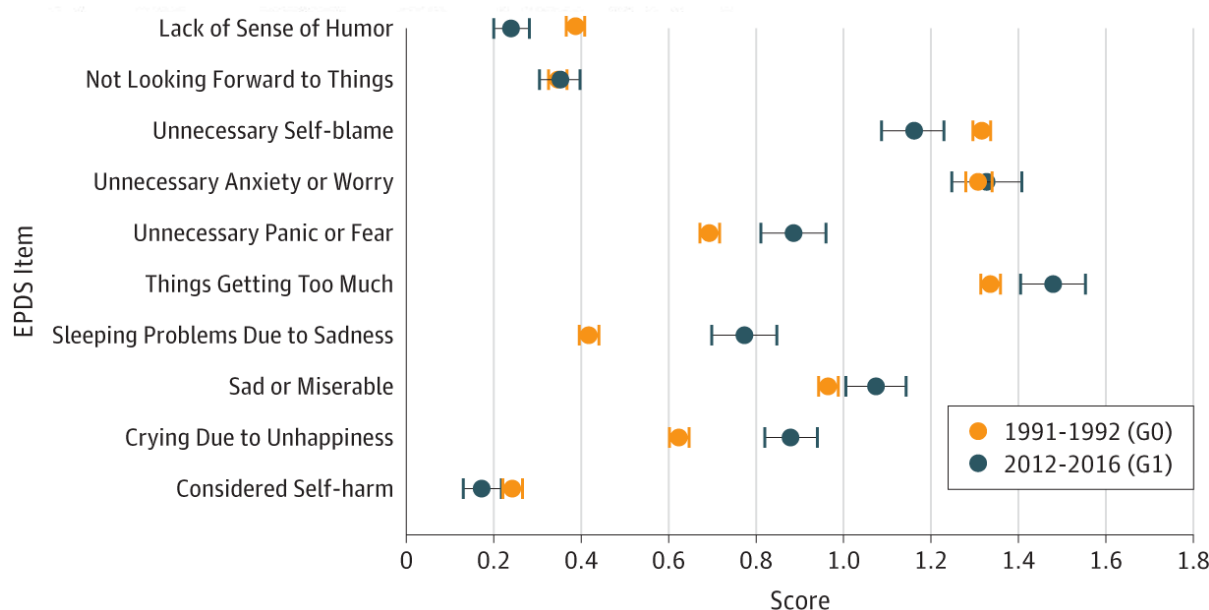University of Bristol

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JAMA Network Open - Psychology 2018

Prevalence of Prenatal Depression Symptoms Among 2 Generations of Pregnant Mothers
The Avon Longitudinal Study of Parents and Children

Dr Rebecca Pearson
Senior Lecturer in Psychiatric Epidemiology
Centre for Academic Mental Health
University of Bristol

EPDS Item (y-axis):
- Lack of Sense of Humor
- Not Looking Forward to Things
- Unnecessary Self-blame
- Unnecessary Anxiety or Worry
- Unnecessary Panic or Fear
- Things Getting Too Much
- Sleeping Problems Due to Sadness
- Sad or Miserable
- Crying Due to Unhappiness
- Considered Self-harm

Score (x-axis): 0 to 1.8

- 1991-1992 (G0)
- 2012-2016 (G1)

Females

Alex Kwong
University of Edinburgh

Key point in the frequency and granularity of standardized data

Exemplar 3. Social inequality – measurement and implications

Size of circle
- ○ <1,000
- ○ 1–5,000
- ○ 5–20,000
- ○ > 20,000

- ● Participating cohorts
- ● Cohorts invited for participation
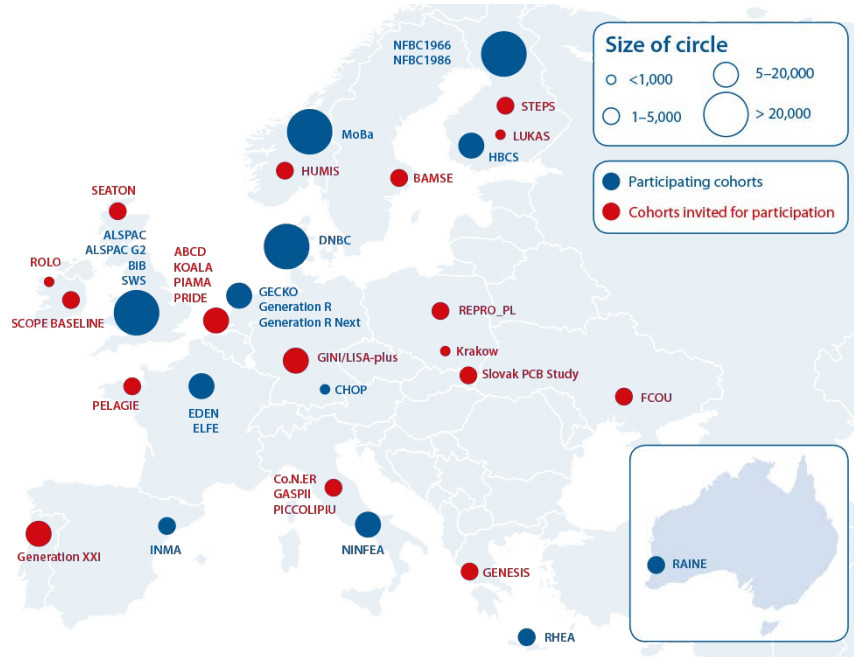
Tim Cadman
University of Bristol

Harmonised data on childhood for >250,000 children.

- Mental health outcomes at least 2 time points
- Data available for analysis via DataSHIELD

Consistent evidence that ***social inequalities in mental health*** are present from a young age for all cohorts

Inequalities reduce over time, but evidence that the rate of decrease slows and inequalities persist into middle childhood

Demonstrates ***meta-analysis of mental health trajectories*** across birth cohorts is possible:
- a) Pros: making use of measurement at different times points across cohorts to model complete trajectories
- b) Cons: non-equivalence of maternal education and mental health measurement.

Exemplar 4. The interplay between social and biomedical research – Certainly not only one direction

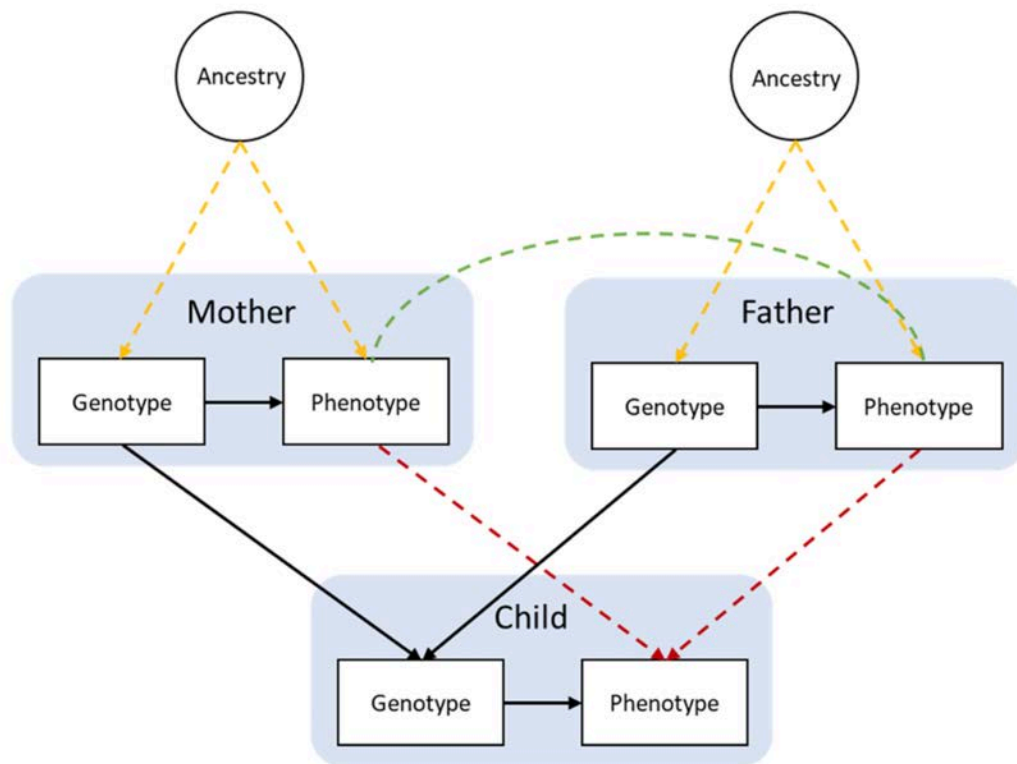SCIENCE ADVANCES | RESEARCH ARTICLE

SOCIAL SCIENCES

Population phenomena inflate genetic associations of complex social traits

Tim T. Morris[1,2]*, Neil M. Davies[1,2,3], Gibran Hemani[1,2], George Davey Smith[1,2]

Tim Morris
University of Bristol

University of BRISTOL

Exemplar 4. The interplay between social and biomedical research – Certainly not only one direction

Tim Morris
University of Bristol

Population stratification - yellow

Dynastic effects - red

Assortative mating - green

(+ assortative mating by phenotype will lead to genotypic correlation!!)

"… population phenomena can bias estimates of genetic contributions to complex social phenotypes from samples of unrelated individuals. The presence of genetic association … may reflect confounding by underlying population phenomena including population stratification, assortative mating, and dynastic effects"
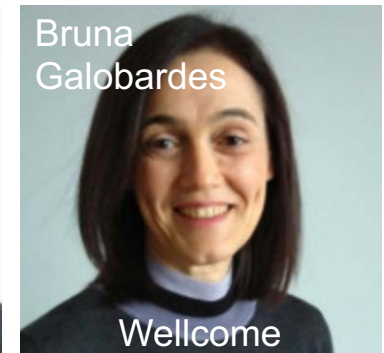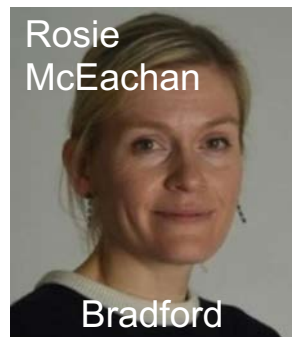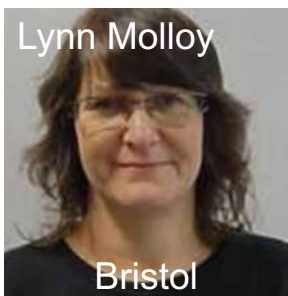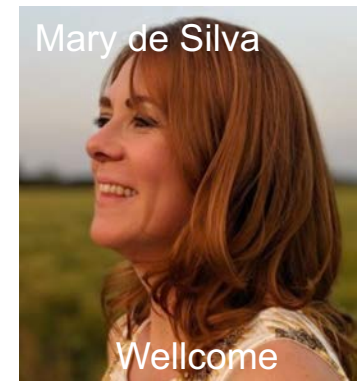
Exemplar 5. The implications of biological events – COVID-19 & social implications

Exemplar 5. The implications of biological events – COVID-19 & social implications

covid-19 questionnaire
wellcome

2X fully formatted questionnaires (REDCAP/QUALTRICS)
Free access and support for use
Aligned to multiple users

David Porteous — Edinburgh

Kate Northstone — Bristol

Deborah Lawlor — Bristol

Simon Haworth — Bristol

Mary de Silva — Wellcome

Robin Flaig — Edinburgh

Lynn Molloy — Bristol

Rosie McEachan — Bradford

Martin Tobin — Leicester

Bruna Galobardes — Wellcome
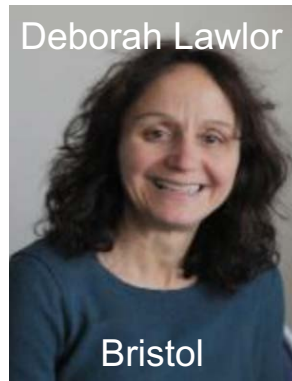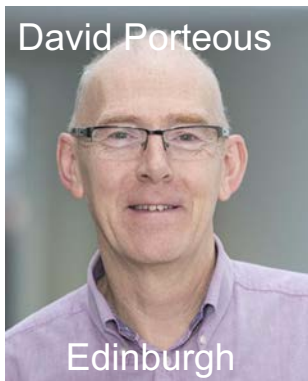
Steering group
Analysis group

https://bristol.ac.uk/alspac/researchers/wellcome-covid-19/

covid-19 questionnaire

wellcome

COVID-19 National Core Studies

The National Core Studies programme is enabling the UK to use health data and research to inform both our near and long-term responses to COVID-19, as well as accelerating progress to establish a world-leading health data and research infrastructure for the future.

The National Core Studies consists of six programmes:

- **Epidemiology and Surveillance** – collecting data to inform safe level of restrictions and protection against imminent outbreaks (led by Ian Diamond, UK National Statistician, ONS).

- **Clinical Trials Infrastructure** – building on established NIHR infrastructure (and equivalent in Devolved Administrations) to accelerate delivery of large scale Covid trials for drugs and vaccines. (led by Patrick Chinnery, Clinical Director, MRC and Divya Chadha Manek, Head of Business Development, Vaccines Task Force).

- **Transmission and Environment** – understanding and mitigating transmission of the disease in workplace, transport and public places (led by Andrew Curran Chief Scientific Adviser, Health & Safety Executive).

- **Immunity** – understanding immunity against Covid to inform back-to-work policies (led by Paul Moss Professor of Haematology, University of Birmingham).

- **Longitudinal Health and Wellbeing** – using data from longitudinal studies to address the impact of COVID-19 and of associated viral suppression measures on health and wealth to inform mitigating strategies (led by Nishi Chaturvedi, Professor of Clinical Epidemiology, University College London).

- **Data and Connectivity** – making data from all studies available and accessible to inform decision makers and catalyse COVID-19 research (led by Andrew Morris Director, HDR UK).

"Pretty nice to be able to say "social science is super impactful, and strengthened by the capacity to compare patterns/relationships across contexts" – cohorts enable that…"

Gareth Griffith & Alex Kwong
Universities of Bristol & Edinburgh

covid-19 questionnaire

wellcome

COVID-19 National Core Studies

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Mental health inequalities in healthcare, economic, and housing disruption during COVID-19: an investigation in 12 longitudinal studies

🆔 Giorgio Di Gessa, 🆔 Jane Maddock, 🆔 Michael J. Green, 🆔 Ellen J. Thompson, 🆔 Eoin McElroy, 🆔 Helena L. Davies, 🆔 Jessica Mundy, 🆔 Anna J. Stevenson, 🆔 Alex S.F. Kwong, 🆔 Gareth J. Griffith, 🆔 Srinivasa Vittal Katikireddi, 🆔 Claire L. Niedzwiedz, 🆔 George B. Ploubidis, 🆔 Emla Fitzsimons, 🆔 Morag Henderson, 🆔 Richard J. Silverwood, 🆔 Nish Chaturvedi, 🆔 Gerome Breen, 🆔 Claire J. Steves, 🆔 Andrew Steptoe, 🆔 David J Porteous, 🆔 Praveetha Patalay

Posted April 07, 2021.

This article is a preprint and has not been certified by peer review [what does this mean?]. It reports new medical research that has yet to be evaluated and so should _not_ be used to guide clinical practice.

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covid-19 questionnaire

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Mental health inequalities in healthcare, economic, and housing disruption during COVID-19: an investigation in 12 longitudinal studies

Posted April 07, 2021.

Characterisation, determinants, mechanisms and consequences of the long-term effects of COVID-19: providing the evidence base for health care services

UK Longitudinal Linkage Collaboration

NIHR | National Institute for Health Research

OpenSAFELY

Cohorts

To wrap up…

ALSPAC represents one of many "biomedical" studies welcoming more social science use.

The aggregate data available falls across ***many domains***, including social science.

Data are detailed, but also ***longitudinal*** and offer opportunities to look at life course & era.

An exciting component is the ***interplay*** between biomedical and social science analyses.

PLEASE reach out and help us to think imaginatively about multi-domain analyses…

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n.j.timpson@bristol.ac.uk

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Sahra Gibbon – s.gibbon@ucl.ac.uk   Gareth Griffith – g.griffith@bris.ac.uk
Rebecca Pearson – rebecca.pearson@bris.ac.uk   Alex Kwong – akwong@exseed.ac.uk
Tim Cadman – t.cadman@bristol.ac.uk   LPS group – wellcomecovid-19@bris.ac.uk

MRC | Medical Research Council   W wellcome   University of BRISTOL