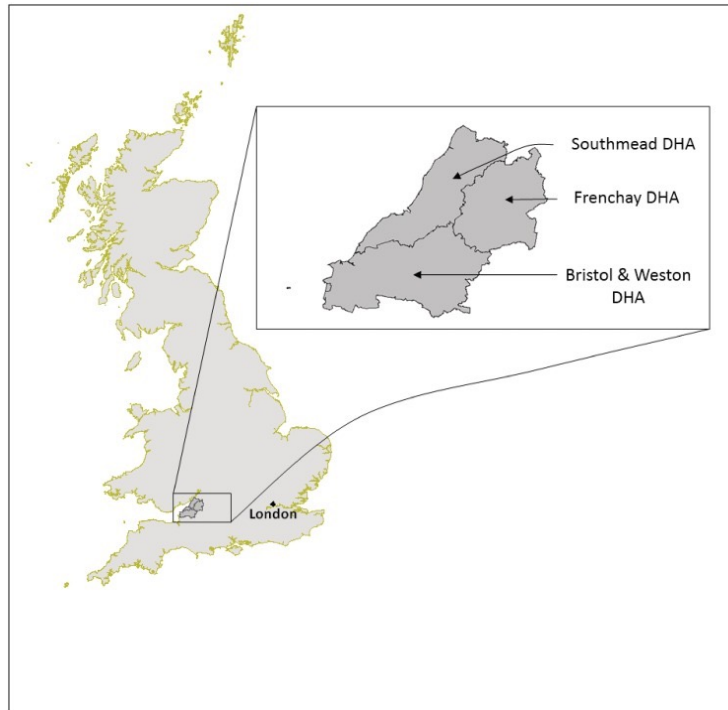
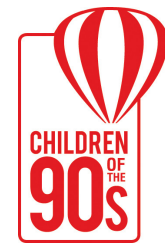


The Avon Longitudinal Study of Parents and Children: Re-engaging 'lost' participants

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ALSPAC (Children of the 90s)



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 Nelson⁴ and Debbie A Lawlor^{1,2*}

International Journal of Epidemiology 2013;**42**:97–110

doi:10.1093/ije/dys066

COHORT PROFILE

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

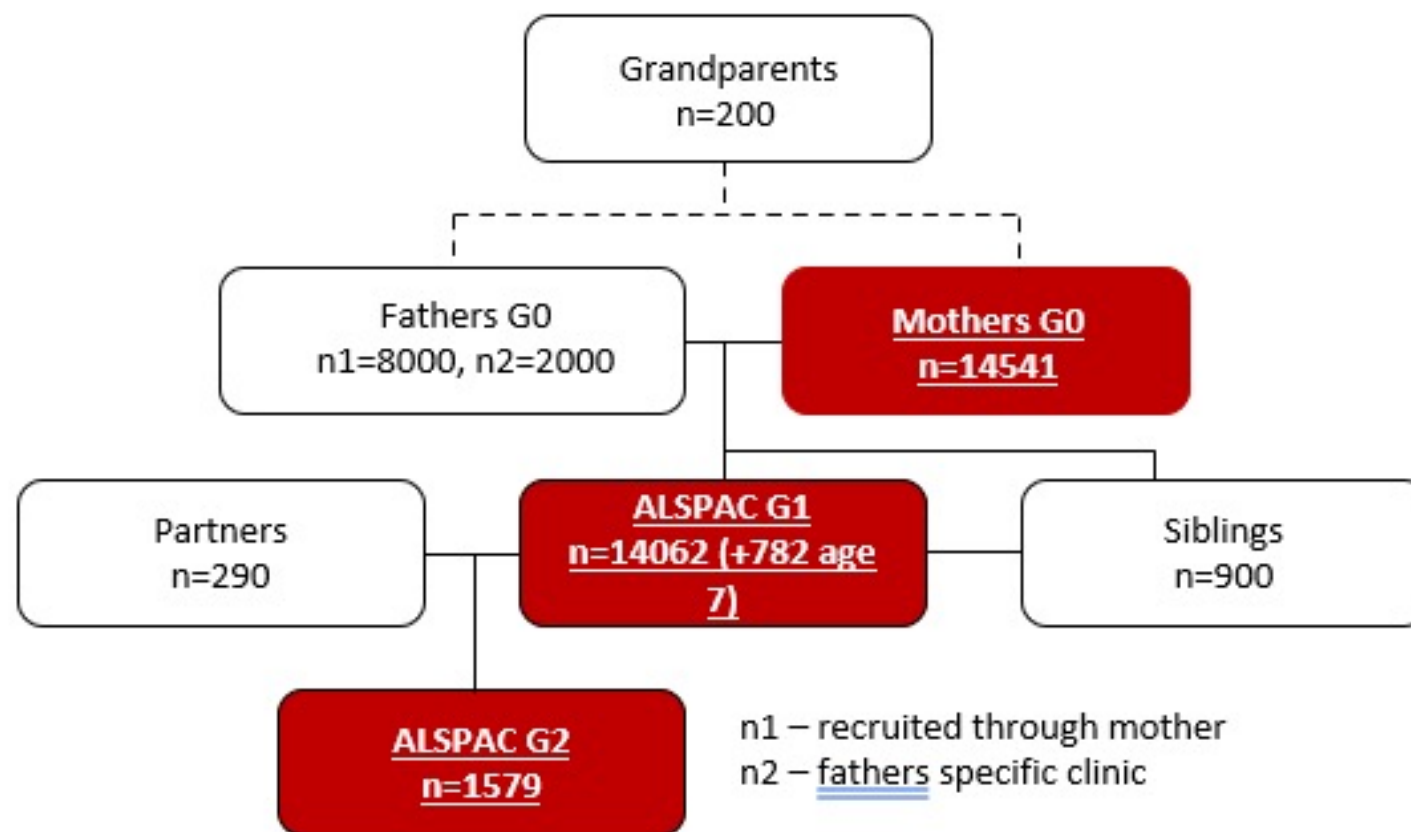
Andy Boyd,^{1*} Jean Golding,² John Macleod,¹ Debbie A Lawlor,³ Abigail Fraser,³ John Henderson,¹ Lynn Molloy,¹ Andy Ness,⁴ Susan Ring¹ and George Davey Smith³

International Journal of Epidemiology 2013;**42**:111–127

doi:10.1093/ije/dys064

- Avon Longitudinal Study of Parents and Children
- Birth cohort in Bristol, UK
- 14,500 pregnant women in 1991 – 1992
- Last 30 years original children, mothers and fathers
- Extended recruitment to children of children
- Biomedical study, face to face data and sample collection gold standard

ALSPAC generations



ALSPAC

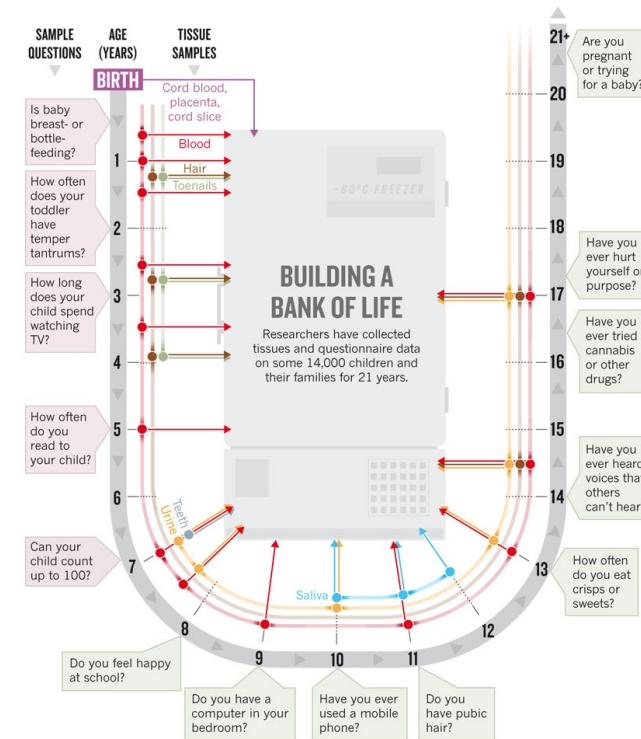
>30k participants, >1.2million bio-samples, >80k variables,
30 years of deep longitudinal study, 1,000+ researchers
>2500 papers (operating cost of <£8k per paper),
~18 proposals/month for data/samples

>14541 pregnancies, 75% of all
Now linkage consented and 8954 active

>9k at 8yrs, >6k at 18yr, 4.5k stable
Now >80% linked and 6778 active

Now >1500 new pregnancies
3000 pregnancies over next 5 years
Linkage consented

Eldest G2 already 14
G3 likely over the next 5 years



The problem



- New clinic from September 2021 for 2 years
 - Original participants @30 clinic – G1
 - Parents – mothers and fathers – G0
- Encourage attendance from disengaged – no participation in any exercise in previous 5 years or ever – 16,830 (53%)
 - G0 Mothers 7704 (57%)
 - G0 Fathers/partners 1101 (30%)
 - G1 8025 (54%)

Disengaged categories



- Last participated
 - Group 1 – 5-10 years ago
 - Group 2 – 10-20 years ago
 - Group 3 over 20 years ago
 - Group 4 never

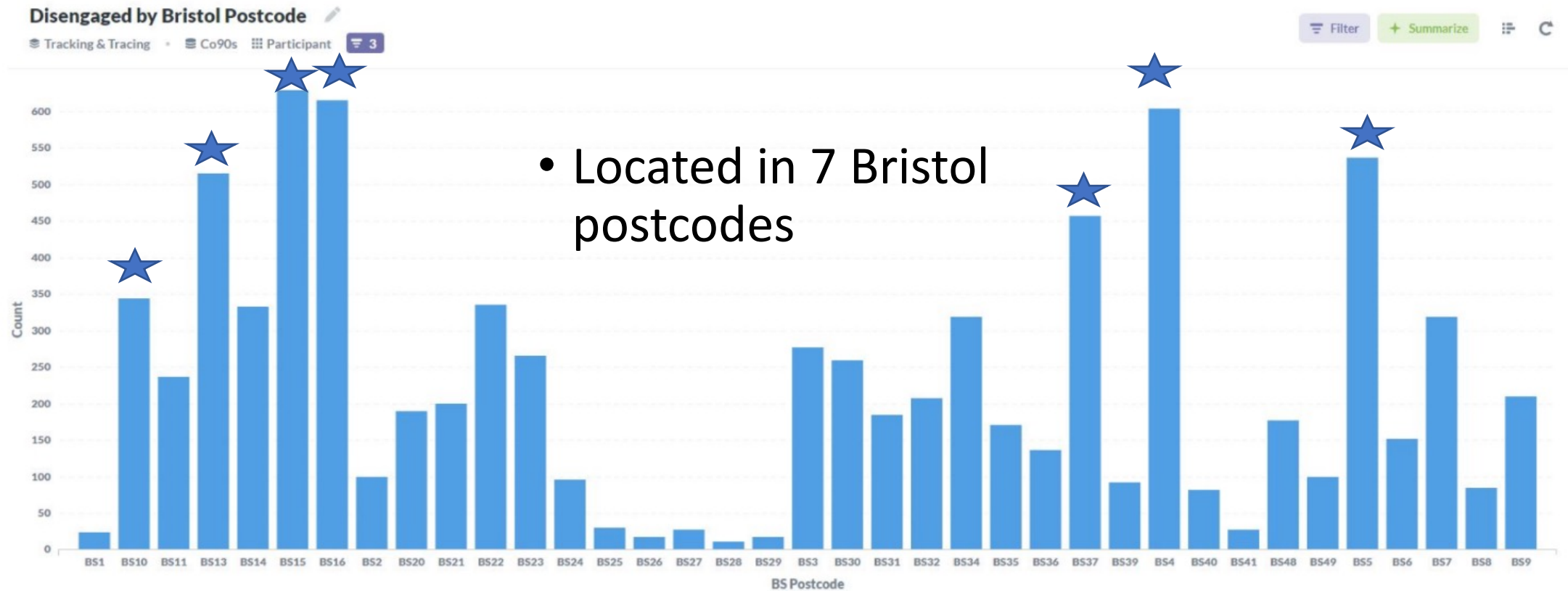
Group	Date range	G0 (M)	G0 (F)	G1	Total
Group 1 (5-10 years ago)	March 2016 – April 2011	1155	396	1375	2,926
Group 2 (10 -20 years ago)	March 2011- April 2001	2821	97	3216	6,134
Group 3 (20+ years ago)	March 2001 – April 1991	2194	57	212 ⁴	2,463
Group 4 (never participated)	N/A	1534	551	3222	5,307

Disengaged characteristics



- 3379 (21%) of the disengaged have an engaged relative
- 3512 G1 (44%) withdrawn by a parent before they were 18
- 172 (1%) are safeguarded
 - Sensitive circumstances, special needs etc
- 2903 (17%) No Clinics

Disengaged characteristics



Disengaged characteristics



- G1
 - Mother younger when they were born
 - Male
 - Lower family income and educational level (personal and family)
 - Ethnic minority
- G0
 - Younger at child birth
 - Lower income and education
 - Ethnic minority
 - Higher BMI

Re-engagement Importance

- Only collecting data from engaged participants
 - Selection bias
 - Engaged different from disengaged
 - Small sample size
 - Lack of statistical power
 - Imprecise results
- Less healthy less likely to engage in research – especially longitudinal research
 - Findings less representative of the whole population

Disengaged Strategy – Phase One

Activity	Action	Problems/Issues	Outcome
Clinic set up	Evening and weekend clinics	Staff availability	Now established and popular
	Online booking and easy appointment change	Technical issues	Work in progress
	G0 Focus Group on clinic set up	G0 recruitment good	To start summer 2022
GPs as Participant Information Centres	Target 17 GPs in areas with highest % of disengaged with list sizes of ~ 1M, discuss CRN funding of texts	Funding received from CRN	To start spring/summer 2022
Communication strategies	Participant communications focussing on virtual visits, weekend and evening slots etc	Primarily social media	Ongoing – mini targets reviewed monthly
	Tailored participant communications for different groups	Financial motivation and detail of tests and data collected	Ongoing – mini targets reviewed monthly
Incentives	Quicker ways to pay incentives – BACS	Not possible with university systems	Complete
	Reconnecting incentive for disengaged and prize draw	Ethics of paying disengaged rather than engaged. Cost ~ £4000	Ongoing Jan 2022

Disengaged Strategy – Phase Two

Activity	Action
Clinic set up	Bring a friend/family member (~£10 pp)
	Data collection van
	Home visits
GPs/ other health care professionals, community sites, advertising sites	GP surgeries to text potential G0 and G1 participants. Possibly annually
	Video/poster for GP practices to advertise the clinic
	CRN – how to engage with disengaged GPs
	CCG – how to engage with midwives and health visitors
	Sports clubs and community centres to advertise the clinic
Special disengaged groups	G1 withdrawn before 18 – letter and leaflet to be sent Safeguarded group – full review and bespoke letter with re-engagement pack No clinic – full review – re-engagement pack offering support and help