

2018-2019

Looking ahead: why we've been talking to you



Together, we've reached an important time in the study. The Children of the 90s young people have reached early adulthood and are at peak health. We will have recruited 1,000 children of the children by the middle of next year and the original parents remain a core part of the study. Now we're busy preparing for the next decade of the study.

Preparation is underway for the next wave of clinics and data collection. We have talked to you and the researchers who analyse the data and samples to find out what is important to study in the future. The next phase will continue to involve fathers, mothers, young people, grandparents and babies.

Some changes that you could notice during 2019 and beyond:

- more face to face clinics;
- Children of the 90s web portal to allow easier access to the study;
- more feedback on our findings;
- shorter questionnaires charting lifestyle and family health issues.

Children of the 90s is a world leading study and the data and samples we collect are widely used by the international health and social science community. None of our recent findings on issues such as maternal mental health, autism or eating disorders would be possible without your help.

Thank you for your contributions and I look forward to working with you as we shape the study for the future.

Nic Timpson
Principal Investigator (scientific lead for the study)

Children of the 90s in the news

Did you know that our discoveries have been reported worldwide this year? Children of the 90s research findings have been reported on BBC Breakfast and in The Times, Mail and Telegraph. Our research has also been featured in the Huffington Post, The Pool and Nursery World.



Welcome back

Did you know that you can re-join the study at any point of your life? Theo Davies moved to London and stopped participating for a while. Now he's back in Bristol with his own family and they are all involved: "As well as contributing to such a massive and valuable study, it's also nice to have Abe's, our toddler, development tracked to know that he is healthy, and if there were any issues they would be flagged. Equally my wife Hebe was born in 1993 and so missed out on being a participant, her sister was a participant and she was always jealous that she came back with vouchers and 'stretchy Gene'. Now she can go and take part with Abe."

You told us...



It was great to see so many of you at our consultation event in the summer at We The Curious.

We asked for ideas about re-engaging

with 'lost' participants, where we should be holding clinics, what we should be collecting, if you'd like an app and the potential names, locations and style of clinics.

All the feedback is now on our website including ideas from the research community.

Lynn Molloy
Chief Operating Officer



"My husband, my parents and I decided to participate in the We The Curious event as I have felt over the years Children of the 90s has done such a wonderful job of collating information from the many study participants.

We wanted to help them to continue this in the future, especially as our little girl is now a member of Children of the Children of the 90s. We also feel it is important for people to know the findings that come from the research, to help others live their lives and raise their children in the best way possible."

Lydia Andrews

"Through the online questionnaire I've given support to the ideas around an app and increased electronic communications. I'm a great believer in the study and would love to hear more about what has been discovered through it. As data collection has become more ingrained in our everyday lives I also suggested that Children of the 90s could put this to good use such as activity collection through our fitness and step trackers."

Pete Griffin-Hix



What's behind the latest questionnaire?

Professor Jean Golding is looking at your family health history:



"Children of the 90s is at the forefront of research on the possible effects of the environments of our ancestors on the development of their grandchildren.

"So far we have concentrated on the smoking history of grandparents, but are anxious to obtain more details on events in their childhoods to see whether traumas of various kinds have any benefits or disadvantages to their grandchildren and great grandchildren. Many of the answers we have about ancestry are fascinating and we look forward to putting the stories together as we progress."

We've had a lot of feedback on the latest questionnaire that went out during August and some of you asked about the words used. We've asked the academics behind the questions to explain why the questions were put in this way.

Professor Anita Thapar from Cardiff University (with colleagues from Bristol) wants to know why some children 'grow out of' autism or attention deficit hyperactivity disorders and some do not:



"We know that when we have questions about certain types of traits e.g. autistic or ADHD - it is better to ask Children of the 90s parents and partners as well as the participants themselves. I appreciate that many of you had queries about this approach and the nature of the questions.

"The questions were designed in such a way so that we can learn more about real-life experiences and look at the natural history of autistic-like and attention deficit disorder traits in the general population. Asking questions of the people close to the participant as well as the participant themselves is the best way to make the science more accurate."

Our

key discoveries from the last 12 months



Men's heart health and marriage

For men there are links between the quality of their marriage and the health of their heart. Researchers from the University of Bristol looked at 620 married fathers over time and found small changes in the cardiovascular health of those men whose relationship had either improved or deteriorated. Deteriorating relationships were associated with worsening diastolic blood pressure.



Eczema in children

There are five subgroups of eczema in children. Working together, researchers from the Universities of Bristol and Netherlands looked at 13,500 children from birth to 11 or

16 years, born in the UK or Netherlands to determine different groups who had eczema starting at different ages. They wanted to know if it became a long-term problem or not. Now sufferers have more hope of a clearer prognosis and more targeted treatment.

Toy guns

Playing with toy guns or using violent video games doesn't mean that your child will grow up to be violent or criminal.



Researchers from Stetson University, Florida examined your survey data and found that 'toxic masculinity' did not manifest itself after playing with toy weapons. Similarly, shooter-type video games "are not associated with violence or severe conduct problems among kids."



Depression in pregnancy

Symptoms of depression in young pregnant women have increased by 51 per cent in a generation. Our researchers looked at survey data in women pregnant before the age of 24 and found that the current generation

are more likely to feel anxious and show other depressive symptoms. This research was the first to compare mental health conditions across generations. This research has only been possible thanks to Children of the Children of the 90s data.

Who's looking at what now?

You've filled in the questionnaire and given the samples but what's going on now? Here's a snapshot of what researchers are currently doing.

Serious psychotic illnesses

Stanley Zammit at the University of Cardiff has taken your questionnaire and interview information to see how commonly people hear voices or see visions, and how this changes as participants get older. As part of his work to understand more about psychotic illnesses his team are examining if experiencing traumatic events during childhood or adolescence increases the risk of developing these disorders.



History of infections

Ruth Mitchell at the University of Bristol is looking at your blood samples to learn more about the history of infections. She will use this to answer questions about infection and disease and by linking to your genes to see if one particular infection can cause certain diseases.



Blood flow and memory

Kim Graham and her colleagues at the University of Cardiff have been running different types of MRI scans to learn more about blood flow to the brain, and how different parts of the brain are used during tests of memory and perception. This data is also used to look at how particular genes might influence blood flow during memory.



Eczema treatments

Sinead Langan at the London School of Hygiene and Tropical Medicine is looking at your skin swabs and skin and blood samples to assess why some people respond better to eczema treatments than others.



No surprises:

how we look after your data



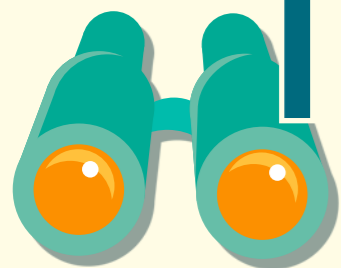
Everything we collect – your blood samples, questionnaires or your school records – is used by research experts worldwide to advance our knowledge in health and social care.

It's important to us that you understand how your information is used, where it might end up and your rights to make changes. Since the General Data Protection Regulations (GDPR) have come into force this year it's a good time to look at the journey your information can take from when we collect it, process it, to how it goes into research, improving knowledge and changing our laws and policies.

The data lifecycle

1

The search begins for data including extra efforts to find participants who might have changed address.



2

- We collect your data through
- questionnaires
 - visits to clinic
 - samples such as blood or urine
 - linking records such as your school or benefits history
 - a digital app.

Potentially in the future we will be using social media, loyalty cards or mobile phone sensors to learn more about you.



3

- We make your data suitable for researchers to use by:
- removing your identification
 - archiving (so it can be found again at any point in the future).



4

We store everything you give us in a secure warehouse with a separate database of your records, which only Children of the 90s can access.



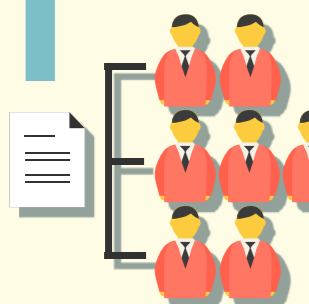
6

- Your data contributes to:
- scientific papers published in international journals
 - evidence to policy makers for new guidance or changes to the law
 - tools such as software algorithms
 - improved research methods
 - new data created in projects is added back to our warehouse for other researchers to use.



5

We only share your data for a limited time with verified experts who have good scientific reasons for using it.



Why Children of the 90s is different

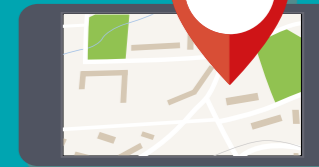
Not all of the GDPR and the new Data Protection Act applies to studies like ours to ensure there are no barriers to ethical research.

Instead of the GDPR rights (that you can find at ICO.org.uk) we promise to make sure that you understand how your data is used, that taking part is voluntary and that you can also opt-out of parts that do not appeal to you.

This means you can opt-out of a particular type of data collection (such as where we use your health records) or you can choose not to answer a specific question in a questionnaire (or you can just send back the whole questionnaire blank – this will stop the reminders).

You can find out more on our web pages at 'our commitment to you'.

What's changed?



Essentially nothing has changed! But as technology is developing and GDPR is new it's important that you understand our commitment to your data.

New technology means new research opportunities. For example, your phone tracks where you are, and Children of the 90s could use this to understand how much air pollution you are exposed to. Or, in the future there are the possibilities of looking at your social media or store loyalty card information (a focus group is currently being asked about this). When we start collecting data in new ways, we will get in touch first to explain this.

The legal bit

We have a legal basis for using your information. This includes data which some might find sensitive and personal, such as information on your beliefs, sexual orientation, health status, criminal behaviour or genetics.

Our legal basis for using your information, under GDPR and the Data Protection Act 2018 is:

1. Performance of a task carried out in the public interest.
2. Scientific or historic research purposes or statistical purposes.

The data and biological samples you gift to us are owned by the University of Bristol who ensures they are used legally and ethically. Sometimes data is used under licence from other organisations such as the NHS and we will then share responsibility with them.

Often, but not always, we will contact you for extra consent. Consent is required by law for items such as blood samples.

You always have the right to ask us to stop collecting new data about you, or to ask us to stop using the data you have given in the past.



Want to know more?

You can find out more about our privacy commitments, research proposals and how we link your records (such as school, employment and financial data) at childrenofthe90s.ac.uk

Your contact at Children of the 90s for any data query is info@childrenofthe90s.ac.uk

The University of Bristol has an Information Governance Manager whose job it is to ensure the University complies with the law.

You can contact them at data-protection@bristol.ac.uk or telephone (0117) 3941824 for any complaints in this area.

How the information you have given could change the way autistic teenagers are treated



Thangam Debbonaire MP with Dr Dheeraj Rai

Bristol psychiatry academic and clinician Dheeraj Rai wanted to know if children with autism or autistic traits were at more risk of depression by the time they were aged 18 and if their genetics or bullying had anything to do with it.

He asked Children of the 90s for questionnaire

information and received thousands of de-identified items to examine with fellow researchers. By linking different types of information together he was able to accurately understand which young people had autistic symptoms. This meant his research more accurately reflected the lives of all our participants. Dheeraj concluded that tackling bullying could reduce depression and called for a more targeted approach to protect vulnerable children.

Dheeraj was able to explain his findings at a special information session for MPs and it's likely that his research will inform future government education and health policies.

COCO90s*

*Children of the Children of the 90s

One of the unique aspects of the study is that we now collect information for researchers to compare and contrast across three generations – a feature that is not available anywhere else in the world.

Children of the children of the 90s is an increasingly busy part of the study with six to ten families in for assessments every week and we expect to have 1000 children enrolled by the middle of next year. We've now got more than 200 placentas photographed, documented and stored for future study.

Tots looking at you

At COCO90s we're pioneering a new way of looking at the interactions between parent and child. Using head cameras fitted to parents and toddlers we can get a much more accurate feel for moods and emotions at key points of the day. This is a first for the UK and it's hoped that the information will help influence policies and support for families who might be struggling with mental health issues.



Meet the team



Left to right, starting on the back row: Jess Harvey, Mel Lewcock, Susan Greer, Jayne Shapcott, Claire Rollings, Shelia Spence and Juliet Lansdown. Juliet is our newest fieldworker, having worked in different roles in the study since 2009.

Did you know?



More than 100 children have now had speech and language assessments at the ages of two, three and four. These tests will help researchers find out if different ways of eating or sucking affect the way our children speak.

Did you see us on **ITV Westcountry** to mark one of our children turning ten? Meet the Barbosa family in the item on our YouTube channel.



Our oldest COCO90s are now **11 years old** so we've prepared for the needs of older children with a new booklet. "Focus on your COCO90s visit" is a step-by-step guide for children aged seven and older that they can also use to keep their own records.



Save the date
On Sunday 2nd December, all sorts of activities are planned for our family Christmas party. Please save the date to join us, invitations will be sent out soon.

Could you be the face of Children of the 90s?

We're always keen to hear from participants who could act as ambassadors for the study.

This could involve contributing to our Instagram account, taking part in science fairs and festivals and generally helping to promote the study. If you'd like to know more please contact info@childrenofthe90s.ac.uk



When I let the BBC into my mum's house

Participant Jasmine Hanks from Bitton worked with us to help illustrate new research where it was found that depression during pregnancy has risen by 51 per cent in a generation. BBC Breakfast television spent a morning filming with her, her mum Sandra and daughter Jorja.

What did you expect?

I think initially I anticipated it would be a photo or telephone interview but when it transpired it involved being filmed by BBC reporter John Maguire I felt a bit more nervous.

Why did you agree to talk to the BBC?

I attended the Planning for the Future event at We The Curious and got chatting to some of the communications team. One of them had a long chat with me about my involvement in the study over the years and life now and happened to ask if I would ever be interested in doing any media work in the future, and I agreed as I thought it would be a nice idea. A few days later I noticed a post on the Children of the 90s Facebook page asking if anyone would be interested in taking part, so I decided to email to enquire about it.

Did anything surprise you about the experience?

How smooth the process was, everyone was very professional, and the presenter and cameraman were quick to put us at ease.

What would you say to anyone else thinking about 'telling their story' on camera or for radio?

Go for it! It's a great opportunity to put your views across and a really enjoyable experience.

What sort of reaction did you have?

Cringe! I honestly hate my voice on video and am not a huge fan of having my photo taken so appearing on national TV is not something I would ever have imagined myself doing. However, I received loads of supportive feedback from friends, family and work colleagues and it was lovely having people who I don't usually speak to come up to me and identify with what I had said!



News in brief (in case you missed it)



Our legend

Children of the 90s founder Professor Jean Golding OBE was announced as a 'research legend' this summer as part of the celebrations to mark 70 years of the NHS. She spoke to BBC Radio 4 about why she set up the study and what it means to have legendary status. She also welcomed her very own statue to mark the achievements of women across the country.



Professor Jean Golding OBE

Puffing away for asthma across the globe

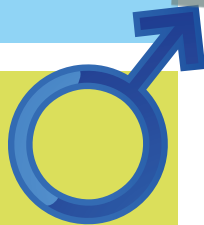
Bristol participants have been puffing away for us at special clinics as part of a four-year worldwide study into how asthma varies in different environmental and economic conditions.

This is Bristol participant George Sharp testing his lung capacity and a participant in Brazil giving a sputum sample.



Men matter

We're working towards a new focus group to look specifically at the needs of men and fathers. This will assist some new research looking at how dads approach parenting when their partners are depressed. If you'd like to know more about the research or focus group please contact info@childrenofthe90s.ac.uk



UK lead researcher Professor John Henderson commented:

"The engagement with this study has been phenomenal and, given what we asked the participants to do, their response was fantastic. We've nearly completed our recruitment target. We did so well that we're ahead of the other international centres (apart from New Zealand), so we're waiting for them to complete their projects before we can analyse all the data together."

Do you work with other studies?

If you've joined the UK Biobank you should know that we're working with them on learning how to link and make best use of this extra data while ensuring your privacy is protected.

How we use your official records

If you'd like to find out more about how we link to your official records (we call this data linkage), go to the 'using your official records' section of our website.

If you don't want us to use your records in this way, please just let us know by contacting us by phone, email, text or post as set out below.

Children of the 90s
Oakfield House
Oakfield Grove
Bristol BS8 2BN

0117 331 0010

info@childrenofthe90s.ac.uk

www.childrenofthe90s.ac.uk

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