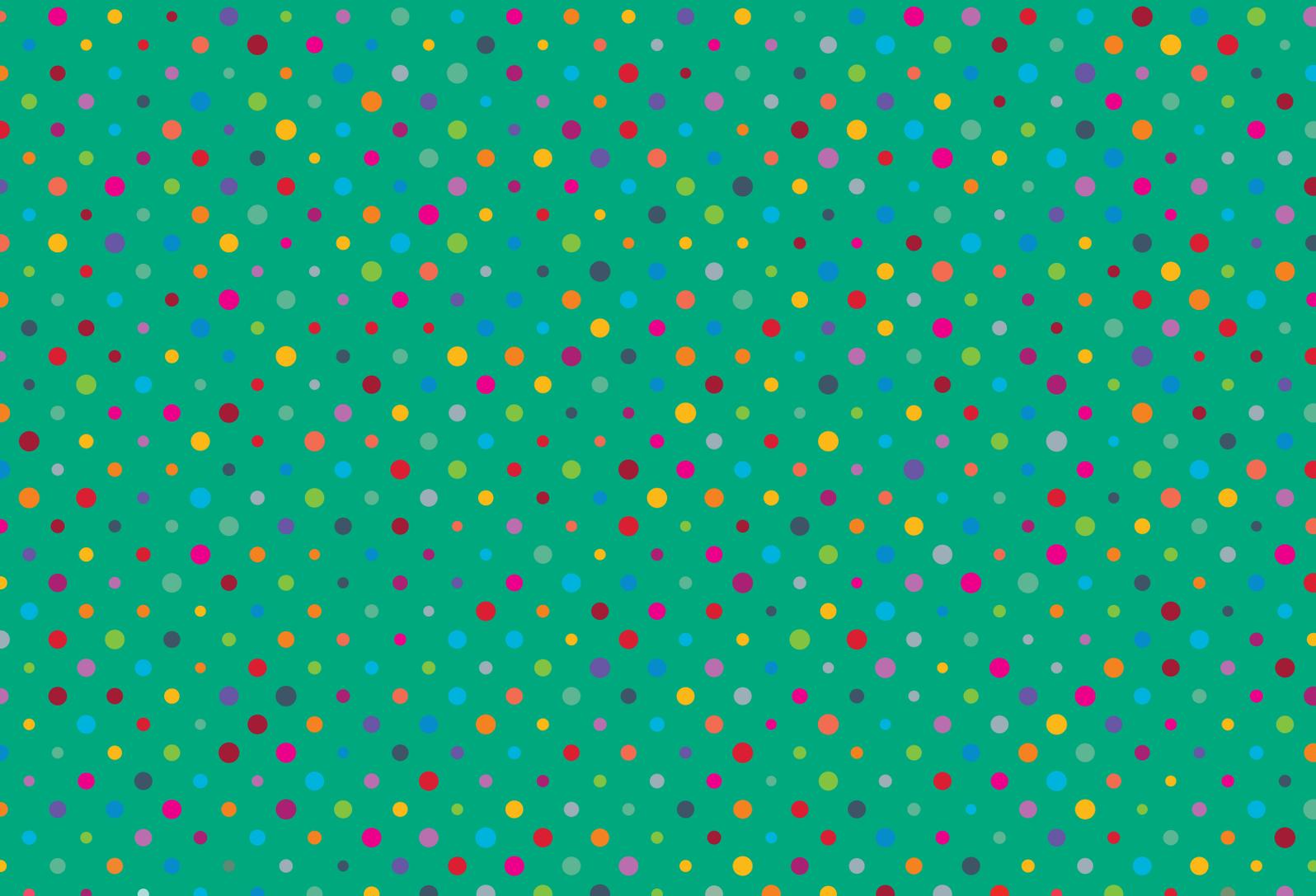


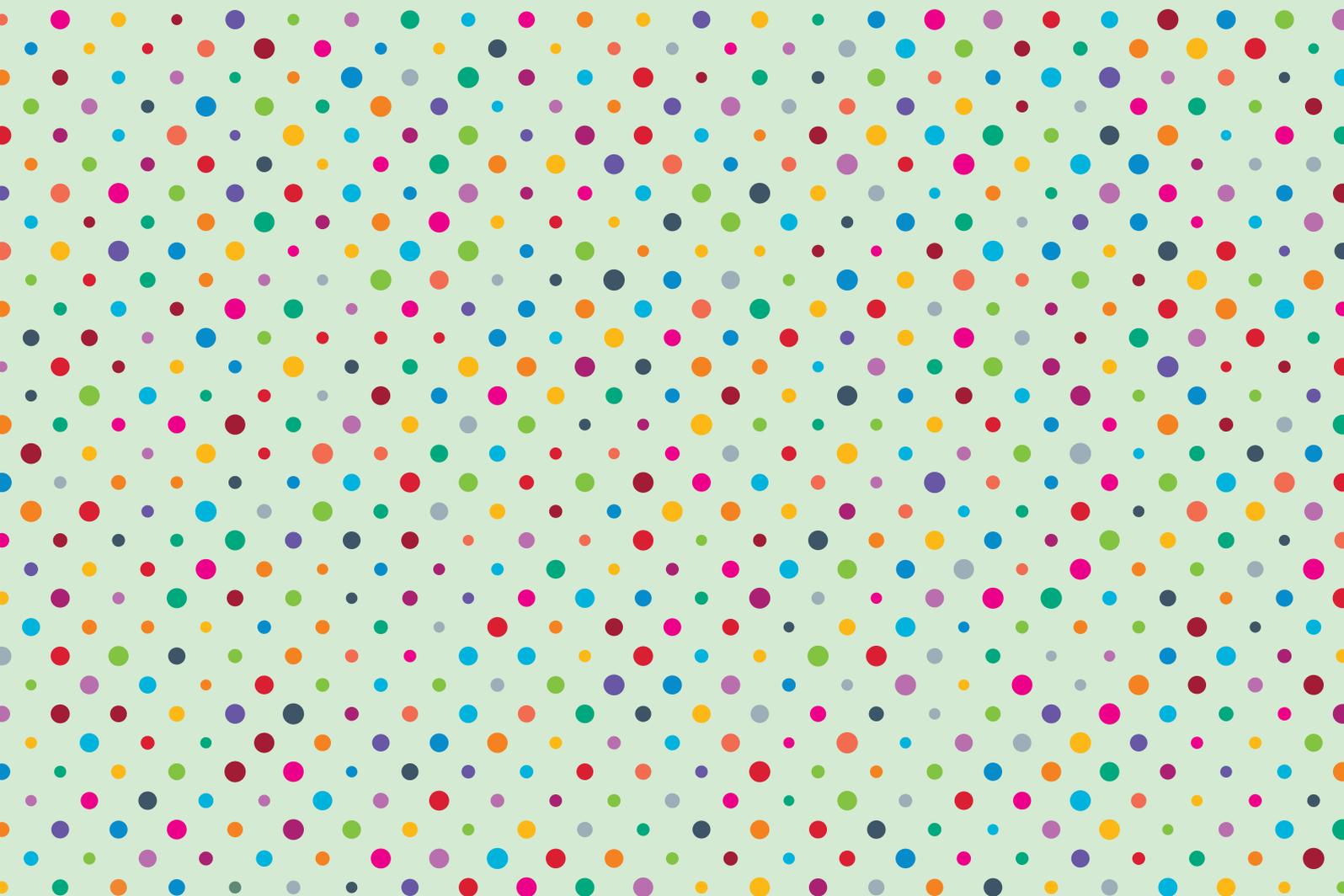


PARENT/GUARDIAN

Information and Consent Booklet



Ethics approval numbers: RCH 33225, AIFS 14/26



Dear Parents/Guardians,

This booklet comes with a letter inviting you and your child to take part in **Growing Up in Australia's Child Health CheckPoint**. It gives you important information about what is involved in this project. It also has details about who to contact if you have any questions.

Before you decide to take part, it's important for you to understand why the Child Health CheckPoint is being done and what is involved. Please take the time to read this booklet carefully, and discuss it with others if you wish.

We enclose a consent form. If you and your child take part, we will ask you to sign the consent form for the Child Health CheckPoint team to keep. We'll also ask you to sign and keep the copy of the consent form at the end of this booklet.

If anything isn't clear, or if you would like more information, please call us free of charge on 1800 784 748, or email us at Isac.childhealthcheckpoint@mcri.edu.au. There will be further opportunity to ask any questions that you might have when we call you in the coming weeks, and on the assessment day before we begin the activities.

Thank you for taking the time to consider taking part in the Child Health CheckPoint. All this information is also on our website (www.Isac-childhealthcheckpoint.org.au).

1. What is *Growing Up in Australia's* Child Health CheckPoint?

The Child Health CheckPoint is a one-off physical health assessment offered to the 11–12 year old children in *Growing Up in Australia*. It aims to help researchers and policy-makers understand how a child's first decade determines their health as they approach the teenage years. Because health issues can run in families, we also offer a health check to a parent or guardian of the child in the same session. Combined with future waves of *Growing Up in Australia*, the CheckPoint will highlight what makes for healthy adolescents and adults.

For many years, *Growing Up in Australia* has hoped to collect more specialised health measures than can be taken at the usual home visits. New funding has made this possible in 2015.

In 2015, the Child Health CheckPoint centre is travelling to cities around Australia. We're inviting children to visit our centre with a parent or caregiver for a 3½ hour health assessment. If you can't come to the centre, we might be able to visit you at home for a shorter assessment.

2. What is the purpose of the Child Health CheckPoint?

Over the last ten years, you've told us so much about you, your family and your child from the time they were a baby. These early years build the foundations of good health for life. We are lucky in Australia that most children are healthy. Unfortunately, Australian adults still have high rates of heart and lung disease, diabetes, and many other problems.

By 11-12 years of age, children already show wide variations in their health measurements. In the same way that healthy children vary greatly in their height and weight, measures such as blood pressure, lung function and blood cholesterol also vary between children even when they are fit and well. These 'normal' differences between healthy children can predict future adult health. So can children's existing health problems, like asthma, obesity, and poor vision.

The purpose of the Child Health CheckPoint is to gather detailed information on the health of Australian 11-12 year old children. Your information will be used for many years to support a wide range of research. When the data are added to *Growing Up in Australia*, researchers can study how parent/guardian health and early life shape children's

In 2015, the Child Health CheckPoint centre is travelling to cities around Australia. We're inviting children to visit our centre with a parent or caregiver for a 3½ hour health assessment.

current and future health. We hope the data will help improve prevention and treatment of illness, and the promotion of health throughout society.

3. Who is funding and organising the Child Health CheckPoint?

The Child Health CheckPoint is being run from the Murdoch Childrens Research Institute (MCRI, located in Melbourne), supervised by senior health researchers from *Growing Up in Australia*. Its core funding is from the Australian National Health & Medical Research Council, supplementing the Australian government funding of the main *Growing Up in Australia* study.

Professor Melissa Wake is leading the project. She is a paediatrician and researcher who has led the health aspects of *Growing Up in Australia* since it began. Professor Steve Zubrick, Professor Michael Sawyer and Dr Peter Azzopardi are all involved in *Growing Up in Australia* as well as the Child Health CheckPoint. They are joined by other experts in children's health, biostatistics, biosamples and health economics to ensure the project has all the special skills it needs. See our webpage for more information about the team.

The main *Growing Up in Australia* team is also closely involved with the Child Health CheckPoint. It is providing guidance, advice and support throughout the project.

4. Why are we invited to be in the Child Health CheckPoint?

You are invited because your child is one of the 5,000 younger children in *Growing Up in Australia*, now aged around 11-12 years. At your last *Growing Up in Australia* interview, you agreed for your contact details to be passed to the Child Health CheckPoint team so we could send you this invitation.

We would like children and a parent/guardian to take part in the assessment whether they are in good health or have health problems. If you or your child has a disability or may need help during the assessments, please let us know when we make your booking, or call us on 1800 784 748.

5. What types of information are collected in the Child Health CheckPoint?

The Child Health CheckPoint collects three main types of information:

- **Physical health measurements**, like height and blood pressure – these tell us about children's and parents' health now.
- **Biological samples**, like blood, saliva, urine and hair (if you agree to them) – these can show how people's body systems adapt to their life experiences and stresses. They provide information about genetic makeup (like DNA) and environment (like exposures to everyday pollutants), and how these might contribute to health and disease. They may also show how the micro-organisms we all have in our bodies can influence our health – for better or worse.

We would like children and a parent/guardian to take part in the assessment whether they are in good health or have health problems.

- **Digital information**, like 3D images, physical activity monitors and time diaries – these store very detailed information that researchers can come back to again and again in new ways. It includes things like minute-by-minute variation in activity, subtle differences in blood vessels in the eye, skin colouring, bone structure, ear shape, and much more. Using this kind of information on a large scale has only recently become possible.

6. What does taking part in the Child Health CheckPoint assessment centre involve?

We invite your child to take part in the assessments, along with one parent/guardian. Taking part in the Child Health CheckPoint would involve:

• You (the parent/guardian) and your child:

- attending the Child Health CheckPoint 'pop-up' health assessment centre. We will ask you to make a booking for a day and time that suits you. We may be able to visit you and your child at home if you can't attend the centre (see section 10 of this booklet).
- answering computer questionnaires and having standard measurements
- wearing an activity monitor on the wrist for a week after the visit, then mailing them back to us
- giving small amounts of various biosamples if you agree. We hope to collect blood, saliva, a small sample of hair and urine (plus toenail clippings from your child only).
- each receiving a summary report form on the day about your health.

• You (the parent/guardian) also:

- filling out a consent form. Even if you consent overall, you or your child can still opt out of any activity at any time.

• Your child also:

- receiving a phone call from us in the week after the visit to tell us their daily activities over the previous two days.



The child and parent both wear activity monitors on the wrist for a week after the visit

7. What happens DURING the assessment centre visit?

The appointment takes about 3½ hours. We run sessions in the morning and afternoon, with occasional early evening and weekend sessions. You and your child come to the local assessment centre. We ask that a parent/guardian brings the child, so they can ask questions, give consent, and take part in the parent activities. (If someone else brings the child, we'll talk with you by phone beforehand so you can fill out the consent form and ask your questions then. We won't ask other adults to take part in the parent activities.) Up to ten children and ten parents are invited to attend each session. Most activities are done privately, with some done together in small groups.

During the centre visit, we ask **you and your child** to go through a series of activities. There are five sets of activities, called Circuits A to F. While parents do Circuit A (consent, computer questionnaire and body measurements), children do Circuit B (Life at 25 and body measurements). Next, children do Circuit C while parents are doing Circuit E.

Circuit D is the blood sample followed by a snack break. Then parents and children swap over, so parents do Circuit C while children are doing Circuit D. Circuit D is shorter for parents, because they don't do the physical activity measures or time diaries. Finally, parents and children come back together for Circuit F (Endgames). Then we say goodbye, except to a few who may stay back for a more detailed hearing test if they didn't pass the hearing screen.

We hope to collect a urine sample from each child and parent. This can be done at the start or end of the visit, during the Lung Fun booth, or at the snack break.

Each child is given an iPad to complete a series of questions during the visit. It has a short computer survey covering their health and wellbeing, signs of puberty, any parts of the body where they frequently feel pain, and how often they eat different foods. They can fill it out in the quiet moments in and between activities. For children who finish early, the iPad has some quiet but fun games so they don't get bored.

Circuit A

45 minutes; parents only – while children are doing Circuit B

During Circuit A, we ask **you** to:

- Hear more about the Child Health CheckPoint, and ask any questions you may have
- Give your written consent before the assessments start. However, you can still decide not to take part even after you've arrived
 - We ask you which samples we can collect (your child can still refuse at the time if he/she wishes)
 - We also tell you about the various extra consent options for using your and your child's information. You can choose to allow the samples and digital images to be used in more studies in the future, and for us to collect information about your child from the birthing hospital when he/she was born. Section 14 has more information.
 - The consent form is copied at the back of this booklet
- Tell us or re-confirm any information we need to know for the session, like any allergies, medicines, or things you or your child may need extra help with
- Answer a short survey about your own health and the health services your child has used
- Let us know who else lives at home with your child. Does this include a birth parent? If so, we hope this parent will consider providing a small sample of saliva or mouth swab at home – see Section 16 for more detail. This is very easy and quick to collect using a kit that you would take home for them, along with some basic instructions. If you agree, we'll give these to you at the final 'Endgames' booth.
- Do the private 'Measure Up' booth, as described for your child below, if you agree
- Leave any handbags in a secure locker until it's time to leave.

Circuit B

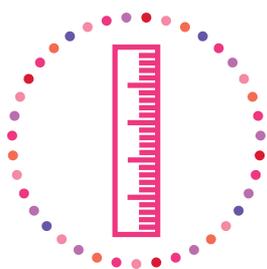
20 minutes; children only – while parents are doing Circuit A

During Circuit B, we ask **children** to do the following two booths:



Life at 25

To help children settle in as a group, we ask them to spend a few moments writing about how they imagine their life will be when they are 25 years old. With your verbal permission, we'll get them started while you are doing your consent form. We'd like to keep the story, and will put a copy on a USB memory stick for your child to take home.



Measure Up

This is done privately one-on-one in usual light clothing. We measure height, weight, and waist, like at the usual *Growing Up in Australia* home visits. We also measure body composition using a 4-limb BIA scale (like a bathroom scale with handles).

Circuit C

90 minutes; children before the Food Stop, parents after the Food Stop

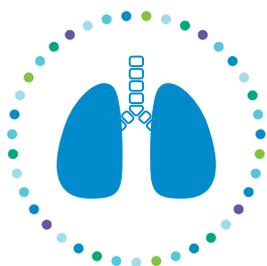
All Circuit C activities are done **one-on-one**, with each participant moving from booth to booth. Most adults and children find them interesting, and none are painful.

The booths are:



Heart Lab

The participant lies on a bed with a blood pressure cuff on one arm and one leg, attached to a special computer program. As well as blood pressure, this measures heart rate and gives information about blood vessel function called pulse wave form and pulse wave velocity. While this is happening, a technician uses a small ultrasound to measure the thickness of the wall of the large carotid artery in the neck.



Lung Fun

Lung function is measured by blowing into a mouthpiece on a machine called a spirometer. After several practices, we record the best of 3 big blows. Your child then breathes in several puffs of Ventolin (the blue asthma puffer) via a spacer device, to see if that increases their lung function. (We don't ask parents to use an asthma puffer.) At this point, a toilet break can be taken for the urine sample. We also collect some strands of hair, covering about the area of the end of a shoelace and trimmed close to the scalp where it won't be noticed. From children only, we collect some toenail clippings, unless brought from home. We check for skin colouring and look for eczema on the hands and behind the knees and elbows. Lastly, children give 3 more big blows in the spirometer.



Lung Fun



Listen Up



Listen Up

Wearing headphones, the participant listens for very soft noises in each ear at different pitches from high to low and repeat spoken sentences against background noise. If the hearing seems poorer than expected, we may offer a more detailed hearing test before you leave. Participants repeat spoken sentences without background noise and identify a series of single spoken words.



Tooth Booth

Here, we take a series of digital images, to store and score later for many purposes. However, we never release images that could identify individuals. We take:

- A 3D image of the face and head – we ask participants to wear a disposable cap for a few moments to keep the hair back off the face and ears.
- Images of the teeth – we ask participants to help us by holding a plastic faceguard in place to give a good view inside the mouth. We take wide photographs showing the size, shape and placing of the teeth. We also take close-up photographs of the front and back permanent teeth with a very tiny camera that can see right inside the mouth. These can be scored later for things like fillings and decay.

We also sample the saliva that pools in the bottom of the mouth, and gently swab the teeth. The proteins, germs and other substances in everyone's saliva are now believed to be very important not just to tooth health but to the health of the whole body.



Bone Zone

Participants sit in a chair for a special bone scan called peripheral quantitative computed tomography (pQCT) scan (see Section 18). The scanner looks like a big flat donut standing on its side. Participants straighten one leg through the large hole in the middle and rest it on a foot stool. We take two images, one near the ankle and one just below the knee. These show things like bone density and shape, as well as the muscles around the bone.

Circuit D

Parents do this first (25 minutes), then the children (45 minutes)



Young Bloods

One-on-one

An experienced technician takes a sample (two tablespoonsful) of blood in a private booth. We apply an anaesthetic patch to numb the skin about 30 minutes beforehand, unless you tell us your child's skin reacts to this. Our technicians are great at minimising discomfort and anxiety. We ask children if they are willing to have a blood sample – it's OK if they say no. We can collect blood from a finger prick onto blotting paper, or even collect a sample of saliva instead. However, these don't give as much information as a standard blood sample.



Food Stop

In a group

We offer water and a standard snackbox with food suitable for most dietary needs. We're interested in how food choices may relate to the health assessments, so we collect the box at the end of the break – and request no sharing or swapping! The standard snack is nut-free. We can also offer dairy-free and gluten-free boxes. It's fine to bring a snack from home, but please don't bring food containing nuts for the safety of others.



Jumping Beans

Children only, in groups of 2–3

At the end of the break, we see how far each child can jump from behind a line. Groups of children have fun doing this together.



Bike Hike

Children only, in groups of 3–4

We test the child's fitness on a stationary bike. Your child will ride for three two-minute bouts. Each bout gets a little bit harder, but the child can stop at any time. There is a short warm-up before and warm-down afterwards.

Circuit E

Parents/guardians do this first (10 minutes), then the children (45 minutes)



See Here

Children and parents, one-on-one

We check each eye's vision on a computer chart, with and without glasses if worn. We also ask participants to look into a camera that takes a digital photograph of the back of their eyeball. This doesn't need eye drops and isn't uncomfortable. Lastly, we have some vision games on the iPad.



About Time

Children only, in groups of 3-4

Your child recalls what activities they did yesterday. This is a bit like the time diary they do for *Growing Up in Australia*, but on a computer.

Circuit F

Parents and children in a group (15-30 minutes)



Endgames

The 'Endgames' circuit includes:

- **Activity monitors (children and parents):** We give everyone their accelerometers. These small physical activity monitors are worn on the wrist like a watch. We ask you and your child to wear one for the next eight days. We give you an Express Post envelope to mail them back.
- **Follow-up phone appointment (child only):** We make a time to call your child in the next week to do two more time diaries by phone. This single phone call takes about 40 minutes.
- **Farewell:** At the very end, we give:
 - a USB memory stick to each child with their 'Life at 25' story and some digital images (if taken). We hope they enjoy these – to keep till they are 25!
 - brief written feedback about your and your child's results from the day
 - the sample kit for your child's other birth parent, if relevant (see Circuit A)
 - your pre-paid EFTPOS card to help with your expenses.

Finally, if you or your child didn't pass the hearing screen, we may offer a more detailed assessment before you leave. This takes about 10 more minutes, after the other families have left.

8. Do we need to do anything BEFORE the assessment centre visit?

The main thing is to **make a booking to attend** on a day and time that is convenient to you. We will contact you in the coming weeks to ask you if you would like to make this booking. Then we send you written confirmation of your appointment, along with instructions on how to get there. We also include two short pre-visit checklists, one about you and one about your child. These let you record any health conditions that might affect the visit, plus your child's medicines and past hospital admissions.

We will remind you by email and/or SMS (text) a day or two before, if we have these details.

In case you need them, we will provide you with **letters for your employer and your child's teacher** with your appointment confirmation. Given *Growing Up in Australia's* national importance, we hope they will be understanding about the absence. We are happy to speak to them by phone if they need more information.

9. How do we prepare for the assessment centre visit?

You can both have **breakfast or lunch as usual**, and **take any regular medicines**.

We ask children to avoid Ventolin in the morning (for morning visits) or lunchtime (for afternoon visits) if possible. If your child is very wheezy on the day, it's best to reschedule for another time.

When you attend the assessment centre, please:

- **Bring:**
 - your completed **pre-visit checklists** and **directions** to the centre
 - **your and your child's glasses**, if you wear them. If either of you wear contact lenses, it is easier for the eye test if you wear your glasses on the day
 - **any medicines** your child takes
 - **a snack for you and/or your child** if our snack doesn't meet your dietary requirements
- Get your child to wear loose-fitting **sports clothes** if possible, e.g. shorts or loose leggings, t-shirt and runners. It's best if they can arrive in these, although

they can also change after arrival. If other clothes or coverings are needed for religious reasons, that is fine.

- We ask children and parents to **avoid wearing dresses and stockings/tights**. Wearing a separate top and bottom (e.g. t-shirt and pants) and being able to bare your feet will make some of the tests easier and more accurate (e.g. waist girth, measures needing bare feet).
- Be prepared to spend the full **3½ hours** in the assessment centre.

10. Can the CheckPoint assessment be done at home, like *Growing Up in Australia* visits?

Some of the equipment used to collect information in the Child Health CheckPoint can't be moved easily; some of the measures need space; and we need a team of technicians to collect the measures. It's not possible to do all of this in a home visit.

However, if you can't make it to the centre, we may be able to visit you at home. This is shorter (around two hours) because we only do some of the tests (e.g., we can't fully check your child's vision, hearing or teeth). A shorter assessment is still very valuable to *Growing Up in Australia*.

11. Can I claim travel and accommodation expenses to attend the CheckPoint?

We will help with your travel costs by giving you a pre-paid EFTPOS card before you leave.

If you have to stay overnight to attend, we can also help with your accommodation. Please tell us about this when we make your appointment.

If you have any questions about these expenses, please call or email (see end of this booklet).



12. How do I let you know that we want to take part?

You can phone 1800 784 748 to ask questions, book an appointment, or opt out. Or you can wait for the CheckPoint team to contact you in the coming weeks, to ask if you want to take part.

13. Do we have to take part in the Child Health CheckPoint?

No. It's up to you to decide whether or not you and your child take part. Whatever your decision, it won't affect your ongoing involvement in *Growing Up in Australia*.

Of course, we hope that as many children as possible do take part in the Child Health CheckPoint. The more children that take part, the more valuable the resource becomes.

14. What do I consent to, and do I need to agree to everything?

We will ask you (the parent or guardian) to complete two copies of the consent form – one at the end of this booklet for you to keep, and a loose copy for the Child Health CheckPoint team. You can do this before or at the beginning of the assessment session. We don't ask your child to sign a consent form. There are several parts to the consent, as follows. You can agree to none, some or all of the components for your child and for yourself.

- **General consent:** First, we will ask for your overall consent for your child and yourself to take part in the Child Health CheckPoint. This overall consent doesn't include the biological samples or birth information – these are covered in Sections 2 and 3 of the consent form.

If you do not want to take part in any of the activities, or feel uncomfortable about your child participating in any of the health measures, just tell the staff on the day. Your



Life at 25

child can also say no to any activity, right up to the time of that activity, and even if you gave permission. However, most children are willing to take part in all the activities.

By consenting to take part in the study, you allow the research team to use your and your child's data to answer research questions. You also allow the data to join the main *Growing Up in Australia* dataset, which is released for all researchers to use under licence. Hundreds of researchers in Australia and around the world already access this database.

• **Collecting biological samples from you and your child at the visit:** blood, urine, saliva, toenail clippings (child only), a few strands of hair. These will be stored so they are available for future ethically-approved research. Some of this may not take place for many years to allow the CheckPoint to contribute to future science. The Murdoch Childrens Research Institute will store the samples in a secure facility. You can say yes or no to each sample.

At present, we have funding only for basic analysis of the urine and blood samples. Over the coming years, a very

wide range of tests may be carried out on all the samples as funding becomes available. We won't come back to you for your consent, and cannot predict what these additional tests will be. All research will be approved by an ethics committee and also scientifically reviewed to make sure that the research is of high quality.

• **Genetic testing of you and your child's samples**

(if taken). Every person has about 23,000 genes. These are passed down in families from parents to children; you get half of your genes from your mother and half from your father. Our genes contain all the information that makes us what we are, including our eye colour, blood type, height and whether we are born as a boy or girl.

Some health conditions or diseases are caused by a change in just one or two genes. However, most of today's common diseases are influenced by small differences in or near many genes, as well as by the environments we live in. Studying genetic material like DNA helps researchers understand how traits and diseases are inherited (passed from parents to children) and expressed (an individual having or not having a specific characteristic).

It is likely that there will be genetic tests on your samples and your child's samples. Keeping this genetic information should not have any impact for you or your child, now or in the future. Researchers using the samples will not know it was you who gave them, as all samples will have your name and other identifiers removed. The specific tests that would be conducted are not known at this time; however, any tests will be used for research purposes only. As part of genetic testing for research purposes, researchers may find a genetic change that could have implications for someone's health. Results will not be given to you, your doctors or anyone else, even if an unusual genetic change is found.

- **Accessing your child's Perinatal Data Collection form,** if available. Across Australia, the birth hospital fills out this form for every baby born, recording details about pregnancy, delivery and the days after birth. Each state stores these forms securely, and they can be accessed for research purposes with parent consent. Including this information would help researchers understand how prenatal life contributes to child and adult health.

- **Accessing your child's newborn screening card,** if available. Across Australia, the birth hospital collects a small blood sample on a paper card (often called the Guthrie Card) for every baby born, to test for rare disorders that require urgent newborn treatment. All states other than Western Australia store these cards securely for many years, and they can be accessed for research with a parent's consent. Including this information in *Growing Up in Australia* would let researchers understand how life experiences turn genes on and off after birth, and how this shapes children's health. We could also check biochemical values at birth (like Vitamin D) that are now considered important to children's health.

- **Sharing your and your child's data, samples and digital images** (if taken) with other researchers in the future, under strict ethical controls and protocols. This may include having biological samples analysed interstate or overseas, as some analyses can be done in only a few places worldwide. It may also include merging data with other studies for questions that can only be answered with very large numbers of participants (for example, investigating rare health conditions).

This means that your samples and digital data can be used to the full, even when analysis is very expensive, very specialised or very labour intensive.

The samples and data will only ever be identified by a code number, not by name. Note that data, samples or images sent to other countries for ethically-approved research are not covered by Australian regulations.

When your child turns 18 years old, the *Growing Up in Australia* study will try to get in contact with the child and ask if they consent to their data, images and samples remaining in storage and available for research use. If we can't contact your child, their information and samples will continue to be stored and used, however participants can withdraw at any time by contacting the CheckPoint team (see section 22 of this booklet).

15. Why don't you give results of tests on my and my child's samples?

If you give permission for biological samples to be collected, please know that we do not systematically screen your or your child's individual blood and other biological samples for signs of health problems, so we won't be able to give you this information. Similarly, we won't give you, your doctors or anyone else results from testing that may happen in the future.

This is because:

- We don't analyse the samples immediately – so it may be a long time (years) before some of your samples are tested
- Studies may use tests that are new or not designed for doctors to use with their patients. Also, they are analysed without knowledge of your or your child's medical history or any symptoms being experienced at the time. So it may not be clear what the results mean for a person's current or future health.

When your child turns 18 years old, the *Growing Up in Australia* study will try to get in contact with your child and ask if they consent to their data, images and samples remaining in storage and available for research use.

16. I'm a birth parent of the child, but I won't be at the visit – can I still take part?

Yes. You can give a genetic sample at home. We don't ask this for step-parents, or for birth parents who are living elsewhere.

The process is very simple. At the visit, we provide a consent form, sample kit and instructions. Samples are collected from the mouth, either by rubbing a small swab on a stick up and down against the inside of the cheek, or collecting about 4ml of saliva in a special bottle. Then you mail your sample back with the activity monitors, in the same envelope.

These samples are only used for genetic testing. This is explained above in 'Genetic testing of your and your child's samples'. Having samples from both birth parents gives more information about how traits and diseases are passed between generations. However, genetic samples from even one parent are still very valuable to *Growing Up in Australia*.

Like every other aspect of the Child Health CheckPoint, this is optional. There are no other questionnaires, assessments or samples for this parent.

17. Are there any benefits for me or my child?

The Child Health CheckPoint isn't intended to directly benefit those who take part.

We hope it will give future generations a better chance of living lives free of health conditions and diseases. We also hope it will help more children to enjoy the best possible quality of life throughout their lives.

Before you leave the assessment centre, we will give you 'snapshot' reports of some of your and your child's

measurements on the day – height, weight, body mass index, blood pressure, vision, hearing, fitness and lung function. For some of these, you may find it helpful to know if they are in the 'normal' range or not. You can choose to show the results to a doctor, optician, audiologist or anyone else. For fun, we also give your child some of their information on a USB memory stick – including their 'Life at 25' story and their retinal and 3D face photograph (if taken).

As noted above, we won't release results to your doctor or anyone else. The only exception is if you or your child has unexpected high blood pressure, we would give you a letter for your doctor and recommend how soon you should see him/her.

Please note that all tests are done by technicians. They aren't medically trained and cannot provide medical advice.

18. Are there any risks or inconveniences for me or my child?

Taking part in the Child Health CheckPoint should not cause you or your child any harm. All the assessments are safe for children and adults. We check before starting each activity that your child is happy to go ahead. Neither you nor your child needs to undress, except shoes and socks briefly. The activities shouldn't cause embarrassment but, just in case, most are done privately one-on-one. This also avoids feeling any pressure from other participants – if you choose not to do an activity, you can just sit quietly and privately in that booth. The only group activities are the start, snack and finish, plus (for the children) the jumping and cycling. Children usually enjoy doing these active things together.

The main inconvenience is likely to be the time taken for travel and the assessment. We will try our best to find the most convenient time. We can help with travel and time costs for your visit.



Children and adults usually tolerate the blood test very well, especially with the anaesthetic skin patch. However, there can be some discomfort, even though our staff are trained to minimise this. It can also leave a small bruise. Our staff will check with you and your child before going ahead.

In the Bone Zone booth, you and your child are invited to have a scan of your lower leg to measure bone density and muscle. This is called a peripheral quantitative computed tomography (pQCT) scan. Therefore, this research study involves exposure to a very small amount of radiation. As part of everyday living, everyone is exposed to naturally occurring background radiation and receives a dose of about 2 millisieverts (mSv) each year. The effective dose from this study is about 0.0014 mSv. At this dose level, no harmful effects of radiation have been demonstrated, as any effect is too small to measure. The risk is believed to be minimal. Have you (or your child) participated in any other studies that involve radiation? If so, please tell us. We will ask you this on our pre-visit checklist and at the start of the assessment visit.

The other assessments are not generally distressing. We use questions and measures that have been tested with many children and adults. However, if you or your child feels anxious about any activity, then you can simply stop and move on to the next question or activity.

In the unlikely event that you or your child hurt yourself, get upset, or feel unwell, our staff have first aid certificates and will know what to do.

19. What happens to the information collected from me and my child?

The biosamples and digital information will be stored securely at the Murdoch Childrens Research Institute (MCRI) for many years. Over time, researchers will analyse them in many different ways to answer new and diverse questions important to human health – therefore, the value of your and your child’s information will keep growing long after this assessment. Analysis can only happen under strict guidelines for access and confidentiality.

The Child Health CheckPoint team will start to analyse the data in 2015-16. By late 2017, the first data will be added to the *Growing Up in Australia* dataset, in a way that can’t identify you or your child. As more researchers access the data, more will be added to the *Growing Up in Australia* dataset in years to come.

Your and your child’s samples and digital images will not be analysed straight after collection. On the day, we only label the samples and make them stable for transport and storage. Then they are transported to the MCRI Children’s BioResource Centre where they are stored for future ethically approved health-related research. Likewise, the digital images are transferred securely to a computer. Images and samples are identified by an ID number only – names and personal details are not stored with any samples or data. They will have an ID number, which only the project staff can connect back to your name and personal details.

20. Who will be able to use our information and samples?

Access to your and your child’s samples and/or digital images will be available only to researchers with scientific and ethics approval for the planned research. Only the samples/images directly related to their research will be made available, and only for the approved research.

We expect that the samples/images will be used for important and pioneering questions. Some analysis is so specialised or expensive that only a few laboratories in the world can do it. This means that sometimes small amounts of sample are sent outside Australia to international researchers. This occurs under strict international guidelines and quality controls, and helps knowledge to advance faster. The research is never linked back to individuals.

Summary results from any further analyses of samples or digital images will go into the *Growing Up in Australia* dataset as soon as possible, to be available to all approved researchers.

Updates on research results from the Child Health CheckPoint and *Growing Up in Australia* will be posted on www.isac-childhealthcheckpoint.org.au and www.growingupinaustralia.gov.au

21. How will information about me and my child be kept confidential?

The Child Health CheckPoint has rigorous procedures to protect confidentiality. These include:

- Keeping information that might identify children and parents (like name and address) in separate databases from their other information

- Computer security to block unauthorised access to computers holding personal information
- Restricting access to personal information to the Child Health CheckPoint team, all of whom sign confidentiality agreements as part of their employment contracts
- Never including personal identifying details in data or samples provided to researchers.

This prevents identifiable information from being used – by accident or on purpose – for any purpose other than to run the project.

Just as with the main *Growing Up in Australia* data, any information about you and your child is confidential – it will never be used in any way that identifies you, your child or family. Strict procedures are followed to ensure that only authorised people have access to your information. All Child Health CheckPoint staff and others involved must comply with State and Federal privacy laws.

If you consent to having your research information stored for future use, we will store it indefinitely. Otherwise, we will keep the information until your child turns 25 years old, in accordance with all Australian privacy laws. After this time, it may be destroyed.

When you come to the Child Health CheckPoint, you will probably be in a small group of *Growing Up in Australia* parents and children. This does mean that you learn the first names of these parents and children. This is quite common in research, and families often enjoy this opportunity. However, if you want your participation to be absolutely private, you should ask for a home visit.

22. Are we able to withdraw?

During the assessment visit, you or your child can withdraw from the Child Health CheckPoint at any time by telling one of the staff. They will ask you to confirm your withdrawal with a signature.

After the visit, you or your child can withdraw by calling us on 1800 784 748 or by emailing or writing to us. We would like to speak with you to be clear which of the following you want:

- ‘No further contact’: This means that the Child Health CheckPoint would still keep and use your information, samples and digital images. We would not send you newsletters or summaries of the results of the research. You would continue to be contacted by the *Growing Up in Australia* team for your two yearly in-home visits, unless you ask them not to.

- ‘No further use’: The Child Health CheckPoint would destroy your stored samples and digital images (although it may not be possible to destroy small quantities of samples already sent out for analysis). If you withdrew before the end of 2017, your information would never join the main *Growing Up in Australia* dataset. If you withdrew in 2018 or later, it wouldn’t be possible to remove your de-identified information from the main *Growing Up in Australia* dataset. Researchers could still use it, but no new information could be added.

23. Who do I contact if I have any questions or concerns?

If you want to contact a member of the Child Health CheckPoint team, please call us on **1800 784 748** or email **Isac.childhealthcheckpoint@mcri.edu.au**

If you have any concerns and/or complaints about the project, the way it is being conducted or your child’s rights as a research participant, and would like to speak to someone independent of the project, please contact the Director of Research Development & Ethics at Melbourne’s Royal Children’s Hospital by phone on (03) 9345 5044 or the Australian Institute of Family Studies Ethics Secretariat on (03) 9214 7888.

Thank you again for taking the time to read this booklet. We hope you and your child will join the Child Health CheckPoint. If so, we hope you both find it a rewarding experience.

Principal Investigator

Professor Melissa Wake

Paediatrician
Murdoch Childrens Research Institute
Centre for Community Child Health
The Royal Children’s Hospital Melbourne

Project Contact

Dr Susan Clifford

Project Manager
1800 784 748
Isac.childhealthcheckpoint@mcri.edu.au
www.Isac-childhealthcheckpoint.org.au

Parent/Guardian Consent Form



This copy of the consent form is for you to keep

Section 1: General consent

I voluntarily give permission for my child and me to participate in *Growing Up in Australia's Child Health CheckPoint*.

- I have read and understood the Parent/Guardian Information and Consent Booklet.
- I believe I understand the purpose, extent and possible risks of our involvement in this project.
- This consent covers all the activities outlined in the Parent/Guardian Information and Consent Booklet except for our biological samples and birth information – I'll decide about those on Sections 2 and 3 of this form.
- I understand my and my child's details on this consent form will be kept confidential. I have received a copy of the Parent/Guardian Information and Consent Booklet to keep.
- I have had the opportunity to ask questions about my and my child's participation in the study.
- This project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee and the Australian Institute of Family Studies Ethics Committee, and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).

Section 2: Additional optional consent for *my child*

As part of the Child Health CheckPoint, we would also like to collect several samples from *your child*, and access your child's birth information.

I consent to *my child* providing the following samples and for these samples to be stored and used for non-genetic testing (please tick the box for each sample you agree to provide):

| Blood | Saliva | Urine | Toenail clippings | Hair strands |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| <input type="checkbox"/> Yes, I agree |

Optional additional uses of *my child's* samples and images (please tick one box on each line):

| | | |
|-------------------------------|-----------------------------------|--|
| <input type="checkbox"/> I do | <input type="checkbox"/> I do not | consent for genetic testing of <i>my child's</i> samples (if obtained), as described in the Parent/Guardian Information and Consent Booklet |
| <input type="checkbox"/> I do | <input type="checkbox"/> I do not | consent to <i>my child's</i> biological samples (if obtained) being shared anonymously with other researchers for use in future ethically-approved research |
| <input type="checkbox"/> I do | <input type="checkbox"/> I do not | consent to <i>my child's</i> digital images (if obtained) being shared anonymously with other researchers for use in future ethically-approved research |

PLEASE TURN OVER →

Optional consent to access *my child's* sample and information from when they were born (please tick one box on each line):

| | | |
|-------------------------------|-----------------------------------|--|
| <input type="checkbox"/> I do | <input type="checkbox"/> I do not | consent to my child's newborn screening card being accessed for use in this and future ethically-approved research |
| <input type="checkbox"/> I do | <input type="checkbox"/> I do not | consent to the release of my child's Perinatal Data Form (completed soon after his/her birth in the state or territory where he/she was born, usually by the birth hospital) to the <i>Growing Up in Australia's</i> Child Health CheckPoint dataset |

Section 3: Additional optional consent *for me*

As part of the Child Health CheckPoint, we would also like to collect, analyse and store several samples *from you*.

I consent to providing the following samples *for myself*, and for these samples to be stored and used for non-genetic testing (please tick the box for each sample you agree to provide):

| | | | |
|---|--|---|--|
| Blood <input type="checkbox"/> Yes, I agree | Saliva <input type="checkbox"/> Yes, I agree | Urine <input type="checkbox"/> Yes, I agree | Hair strands <input type="checkbox"/> Yes, I agree |
|---|--|---|--|

Optional additional uses of *my own* samples and images (please tick one box on each line):

| | | |
|-------------------------------|-----------------------------------|--|
| <input type="checkbox"/> I do | <input type="checkbox"/> I do not | consent for genetic testing of my own samples (if obtained), as described in the Parent/Guardian Information and Consent Booklet |
| <input type="checkbox"/> I do | <input type="checkbox"/> I do not | consent to <i>my own</i> biological samples (if obtained) being shared anonymously with other researchers for use in future ethically-approved research |
| <input type="checkbox"/> I do | <input type="checkbox"/> I do not | consent to <i>my own</i> digital images (if obtained) being shared anonymously with other researchers for use in future ethically-approved research |

Section 4: Names and signature

Please complete the following:

Child full name: Child DOB: / /

Parent/guardian name: Parent/guardian DOB: / /

Parent/guardian signature: Date: / / 2015

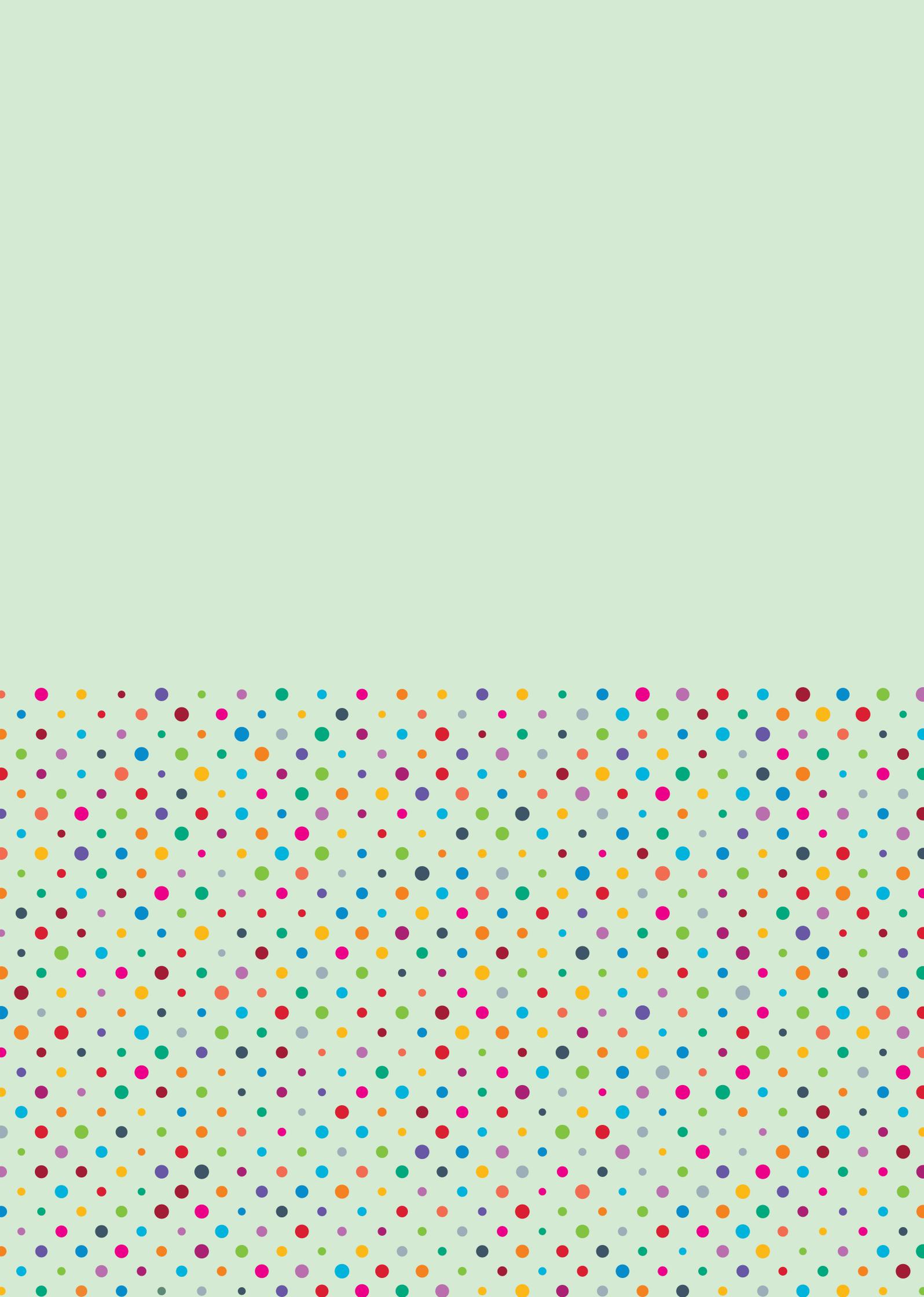




Notes



Notes



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