



# Opt-out information sheet

If you are a Victorian patient getting screened, treated or seeing a doctor for hip dysplasia, VicHip will collect your health information. You have the right to opt-out.

### What is VicHip?



The Victorian hip dysplasia registry (VicHip) is run by Murdoch Children's Research Institute and The Royal Children's Hospital, with help from other Victorian hospitals.



We study hip dysplasia, also known as developmental dysplasia of the hip (DDH). Early diagnosis and treatment are important to prevent problems later on. We aim to understand its causes, find better ways to detect and treat it, and improve future care and services for people with hip dysplasia.

#### What information do we collect?



We collect ultrasounds, X-rays, medical history, examination findings, treatment details and their related costs. We start collecting this data as soon as you confirm receiving this information sheet, at your appointment or over the phone, but we wait two weeks before using it. You can opt-out of VicHip at anytime by using the contact details below. If you opt-out, we will delete your information.

## Did you know?

hip dysplasia affects

1 in 100

babies worldwide

it contributes to

25% of hip replacements

under age 50

untreated, it can lead to long-term disability, pain or surgery



#### How can you help?

If you or your child has hip dysplasia, you may be asked to fill out short surveys (5-15 minutes) every 1 to 4 years. These surveys will be sent by email or text (from 0448 456 897) and are completely optional. They will ask about your daily activities, pain, treatment, experience of care and overall well-being. Your answers may help us and your doctors understand gaps in health care and improve outcomes for people with hip dysplasia.

**Want to be more involved?** Join our Consumer Advisory Group, share your thoughts and ideas in a focus group, or participate in other VicHip research or child health studies. If you're interested, visit <u>vichip.org.au/parents/become-a-consumer-advisor</u>



#### We protect your privacy

Your name and personal details are removed before we use or share your information for research. We only use your contact details to track appointments, send surveys or updates (if you want them), confirm information or invite you to take part in more detailed research. Australian privacy laws protect your information and only your clinician and approved researchers can access your data.

#### Your choice

If you do not want us to collect your health information, that's ok. You can opt-out anytime, and it will not affect your medical care.

#### Learn more

Read our detailed webpage at vichip.org.au/opt-out











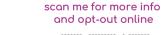
## How to opt-out

Contact us with your name, email, mobile number and your child's date of birth or

Phone: (03) 9936 6246

Text (SMS): 0439 310 318

Email: vichip@mcri.edu.au

















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