ProLong20+

Longitudinal study of pelvic floor dysfunction,
and its relationship with childbirth

PARTICIPANT NOTIFICATION

This notification has been posted to clarify one of the ways in which we use ProLong Study participants' information.

ProLong Study Background

This long-term research looks at how having a baby might be related to women developing problems with their pelvic floor, either at the time, or later in life. These problems can include urinary incontinence, faecal incontinence (leakage from the back passage), prolapse or sexual issues.

In 1993-94 more than 10,000 women from Aberdeen (Scotland), Birmingham (England) and Dunedin (New Zealand) were invited to take part in a study which involved completing a questionnaire 3 months after giving birth about any incontinence symptoms they were having. The same women were asked to complete another more detailed questionnaire about pelvic floor problems 6 years later, and another 6 years later in 2006/7. The information collected so far has helped identify some risk factors for urinary incontinence, bowel leakage and prolapse occurring after having a baby.

The current study, ProLong20+, will be inviting the group of women who were originally recruited in the United Kingdom (UK) to take part again 25 years after the first study. The findings from this study will be used to shed light on how pelvic floor problems change over a woman's lifetime, particularly around the menopause. We hope this will help us identify ways of improving women's health, for instance, by finding out how common these problems are, what treatment women might need, and what further research could be done.

Who is Carrying out the Study?

The ProLong20+ study is being run by Professor Suzanne Hagen in the Nursing, Midwifery and Allied Health Professions (NMAHP) Research Unit at Glasgow Caledonian University.

Obtaining your up-to-date contact details through the NHS

As it has been 12 years since the last survey we will be contacting the NHS to request access to up-to-date name and address information before sending out study invitation letters. This will ensure that we give as many women as possible the chance to take part.

First, we will obtain permission from the Public Benefit and Privacy Panel for Health and Social Care (PBPP) in Scotland and the Confidentiality Advisory Group (CAG) in England to do this.

Please note: we will not be requesting any information for participants who have previously withdrawn or opted out of future contact from the study.

What information is sent to (and received from) the NHS?

This process will involve sending identifiable information about you, including name, date of birth and NHS or CHI number, to the NHS in order to identify who we are wishing to access data for. The information we send is only needed to match study participants to the correct records that the NHS already has through GPs, hospitals etc.; we are not providing any new information to them.

The NHS will send us up-to-date name and address information for study participants who are still living in the United Kingdom. No information will be provided by the NHS for any participants who have registered with the National Opt Out programme (https://digital.nhs.uk/services/national-data-opt-out-programme/).

Can I opt out?

If you do not want us to obtain your current address details from the NHS, or you would like to opt out of taking part in the study, please contact us (details below). In addition, participants are free to withdraw from the ProLong study at any time. You don't have to give a reason. Your decision will have no effect on your care or treatment in the future. If you do opt out or withdraw we will not contact you again.

You can contact us in writing or by telephone or e-mail using the contact details below:

Ceri Sellers
Project Coordinator, ProLong20+ Study
NMAHP Research Unit
Glasgow Caledonian University
Cowcaddens Road
Glasgow
G4 0BA

Tel: 0141 331 8835

Prolong@gcu.ac.uk