#### LONG TERM HEALTH AFTER BLOOD PRESSURE PROBLEMS IN PREGNANCY

You are invited to take part in a survey to gain insight into what women like yourself who have been pregnant before know about women's heart health. We are interested in the views of all women especially women who had high blood pressure (hypertension) or preeclampsia in pregnancy.

You can complete the survey if you are currently pregnant (with no major issues so far this pregnancy) or have been pregnant in the last three (3) years. You may have experienced high blood pressure in pregnancy OR you may have experienced a pregnancy without any serious complications.

The study is being conducted by the University of NSW, University of Technology Sydney and the Sydney Partnership for Health, Education, Research and Enterprise (SPHERE). The study is being undertaken by:

- Dr. Amanda Henry Obstetrician at St George and Royal Hospital for Women, Randwick, Senior Lecturer UNSW and SPHERE member
- Distinguished Professor Caroline Homer UTS, Midwifery Faculty of Health and SPHERE member
- Dr. Clare Arnott Cardiologist, Royal Price Alfred Hospital
- · Mrs. Heike Roth PhD Candidate at University of Technology, Sydney
- · Mrs. Lynne Roberts Research Midwife at St George Hospital, SESLHD.

This work is occurring as part of Mrs Heike Roth's PhD studies and the NHMRC Fellowship of Dr. Henry. Apart from salary support for Dr. Henry, the study is otherwise unfunded.

If you agree to take part in this survey, it should only take about 15 minutes to complete and will involve answering questions about you, your pregnancy and your understanding of long term health in women who have been diagnosed with blood pressure problems in pregnancy.

Participation in this study is entirely voluntary and if you do not wish to take part it will have no effect on the care you are currently receiving. If you decide to participate, and throughout the survey think you would like to withdraw/not complete the survey, you can simply stop and not submit your answers. If you have already submitted your survey, it will not be possible to withdraw the data you have provided as the surveys are anonymous.

The information you provide will not be identifiable and will be kept securely until destroyed as per the South East Sydney Local Health District's requirements.

The study results will be published in a research thesis, in peer reviewed journals and presented at conferences and other professional forums. No one will be able to identify you from this information.

If you would like to personally receive results, you will have the option to leave your email details. The results will be available one (1) year after conclusion of the survey and your email will not be used for any other purpose.

If you would like any further information about the study or you experience any distress or concern as a result of completing this survey, please contact the Principal Investigator, Dr Amanda Henry on 02 91132315 or via email Amanda.henry1@health.nsw.gov.au. For medical assistance you can consult your General Practitioner. If you would like further information about the topic addressed in this study, you can visit the Australian Heart Foundation on the following link: https://www.heartfoundation.org.au/your-heart/women-and-heart-disease/womens-stories.

If you have any concerns or complaints about the conduct of this study, you should contact the Research Support Office of the South Eastern Sydney Local Health District Human Research Ethics Committee which is nominated to receive complaints from research participants. You should contact them on 02 9382 3587, or email SESLHD-RSO@health.nsw.gov.au and quote HREC 18/156.

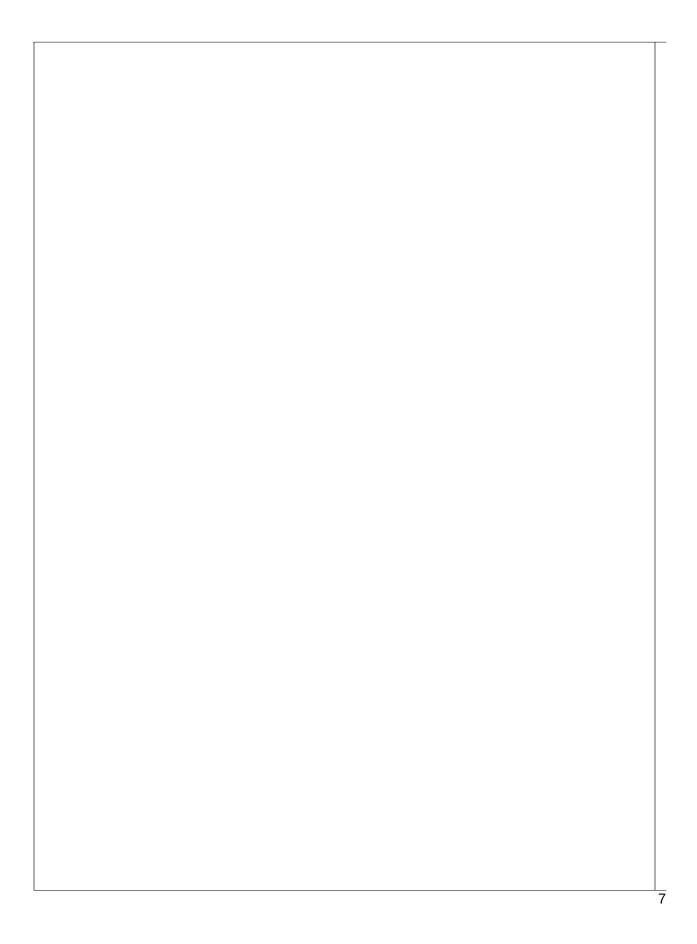
* 1. I acknowledge that participation in the survey is voluntary
Yes

JNG TERM HEALTH RISKS AF	TER HIGH BLOOD PRESSURE IN PREGNANCY - Survey for women
BOUT YOU	
-	l out about you, your background, and occupation. erisk (*) simply mean that they must be answered in order to
* 2. What age group are you in?	
18-25	46-55
26-35	56+
36-45	Prefer not to answer
* 3. What ethnic group do you identify	y with? (Please select one answer)
Caucasian	Aboriginal or Torres Strait Islander
Asian	European
Polynesian or Maori	Prefer not to answer
Other (please specify)	
* 4. What is your highest level of form	
Secondary school	University degree
Trade Certificate/Diploma	Prefer not to answer
Other (please specify)	
5. What is your usual occupation/pre	ofession?
* 6. Are you currently in a relationship	ງ?
Yes	Prefer not to answer
No	

P4 Newsletter	Maternity Consumer Network
Australian Action on Preeclampsia (AAPEC)	Maternity Clinics
Tresillian	Social media (Facebook, Twitter)
Maternity Choices Australia	Australian College of Midwives
Other (please specify)	

LONG TERM HEALTH RISKS AFTE	ER HIGH BLOOD PRESSURE IN PREGNANCY - Survey for women
ABOUT YOUR HEALTH	
These next questions are about your Questions marked with a green asteri continue.	general health. sk (*) simply mean that they must be answered in order to
* 8. Are you currently pregnant?	
Yes	Prefer not to answer
No	

ONG TERM HEALTH RISKS AFTER HI	IGH BLOOD PRESSURE IN PREGNANCY - Survey for women
BOUT YOUR HEALTH	
ontinue.	simply mean that they must be answered in order to ovide whole numbers only, for example: 24)
10. How many children have you given birtl	h to (20 weeks gestation and over)?
* 11. Have you ever had any of the following apply)	, whilst pregnant or before or after pregnancy? (select all that
High blood pressure	Stroke
High BMI (overweight)	Significant illness
Angina	Heart attack
Diabetes	None of the above/ no significant other medical complication
Kidney problems	
Other (please specify)	
12. From the list below, which currently app	High cholesterol
Obesity	High blood pressure
Alcohol consumption	Diabetes
Family history of heart disease	None of the above
Other (please specify)	
13. Please provide the details of any prescribed medication	
i take prescribed medication (please list the med	dications or leave blank if you prefer not to answer)



#### **PREGNANCY**

This section is about your pregnancy history.

Questions marked with a green asterisk (\*) simply mean that they must be answered in order to continue.

#### **DEFINITIONS OF BLOOD PRESSURE PROBLEMS**

Here are some definitions of certain types of blood pressure problems in pregnancy. You may find these useful in order to more easily understand and answer the next questions.

Chronic hypertension: is if you had high blood pressure before falling pregnant, have high blood pressure outside of pregnancy, or were found to already have high blood pressure in the first half of your pregnancy. Chronic hypertension may have no known underlying cause (this is sometimes called "essential" hypertension), or it may be as a result of another underlying condition, such as kidney disease.

Gestational hypertension: is when you might have had high blood pressure for the first time in your pregnancy (after 20 weeks of pregnancy) but were otherwise well (that is, high blood pressure only but no effect on your baby's growth or on your health otherwise).

**Preeclampsia:** is when you have had high blood pressure in pregnancy (after 20 weeks of pregnancy) and some additional signs or issues in you and/or your baby. For example, you might have had protein in your urine, liver or kidney problems that showed up on blood tests, or there may have been concerns about the growth of your baby while you were pregnant.

### LONG TERM HEALTH RISKS AFTER HIGH BLOOD PRESSURE IN PREGNANCY - Survey for women **PREGNANCY** Questions marked with a green asterisk (\*) simply mean that they must be answered in order to continue. We understand that you may find some of the questions difficult to answer as they might remind you of a challenging time in your life. We are grateful for your participation and contribution to improving knowledge on future health for women who had blood pressure problems in pregnancy. You will find some explanations at the end of the survey and a contact, in case you would like to seek further clarification and/or assistance. \* 14. Choose the situation which best describes your pregnancy history At least one pregnancy is/was affected by gestational I had chronic hypertension before pregnancy and had/have hypertension pregnancies that were complicated further by higher than usual blood pressure At least one pregnancy is/was affected by preeclampsia I had chronic hypertension before pregnancy and had/have I have only been diagnosed with chronic hypertension pregnancies that were complicated further by preeclampsia No pregnancy is/was affected

LONG TERM HEALTH RISKS AFTER HIGH BLC wom	
YOUR HEALTH DURING YOUR PREGNANCY	
Questions marked with a green asterisk (*) simply r continue.	mean that they must be answered in order to
* 15. As someone who has chronic hypertension are y at risk of? (select all that apply)	you aware of any long term health issues that you are
Diabetes	Leukaemia
Kidney disease	Seizures
Breast cancer	Overall mortality risk is higher
Cardiac death	Ischaemic heart disease/heart attack
High blood pressure complications in another pregnancy  Stroke	I think there are health risks but unsure which conditions I may be at risk of
Peripheral vascular disease	I do not think that there are increased risks
Other (please specify)	

.6. How many years after blood pressure problems in pregnancy do you think the various signs and symptoms of the potential risks may start to appear?  < 10 years after pregnancy  10-15 years after pregnancy  16-20 years after pregnancy  Other (please specify)			IGH BLOOD PRESSURE IN PREGNANCY - Survey t women
symptoms of the potential risks may start to appear? < 10 years after pregnancy 10-15 years after pregnancy Not sure/do not know 16-20 years after pregnancy	Т		
symptoms of the potential risks may start to appear? < 10 years after pregnancy 10-15 years after pregnancy Not sure/do not know 16-20 years after pregnancy			
symptoms of the potential risks may start to appear? < 10 years after pregnancy 10-15 years after pregnancy Not sure/do not know 16-20 years after pregnancy	6 1	Llow many vacro ofter blood proceure	problems in programmy do you think the verious pigns and
< 10 years after pregnancy > 20 years after pregnancy Not sure/do not know 16-20 years after pregnancy			
10-15 years after pregnancy  Not sure/do not know  16-20 years after pregnancy			
16-20 years after pregnancy			
		(1	

LONG TERM HEALTH RISKS A	FTER HIGH BLOOD PRESSURE IN PREGNANCY - Survey for women
Chronic Hypertension only -TYP	E OF CARE RECEIVED DURING PREGNANCY
Questions marked with a green as continue.	terisk (*) simply mean that they must be answered in order to
17. If a healthcare provider did sp	eak to you about your future health risks, when did this occur?
Before birth	6 months to 1 year
Immediately after birth	1 year and over
Within first 6 weeks	I cannot remember
6 weeks to 6 months	
hypertension or preeclampsia exp	
During pregnancy/at birth	12 months after birth 24 months after birth
* 19. As a result of your pregnancy below after your baby was born?  Cardiologist	affected by blood pressure problems, were you referred to any of the (tick all that apply)
Renal (kidney) Physician	Nutritionist for dietary adjustment
General Practitioner	I cannot remember
Other (please specify)	

20. During your progr	ancios ovo	or the last	· 2 voare (	20 wook	e progna	acy and o	(or) which	blood pro	ecuro
20. During your pregr problem were you dia			. 3 years (	∠u week	s pregnai	icy and ov	zer), wnich	blood pre	ssure
	Gestatio Hyperter		Preeclamp	рі	o blood pre oblem diag this pregna	nosed	nnot rememb	er Not a	pplicable
First Pregnancy									
Second Pregnancy									
Third Pregnancy									
Any comments?									
22. At what point in ti	ma wara wa	u diagna	anda (Ch	0000 0 11	nost occur	rata tima f	romo)		
22. At what point in ti						During or after	No diagnosis of blood pressure problem		
22. At what point in ti	me were yo 20-28 weeks	ou diagno 28-34 weeks	sed? (Ch 34-37 weeks	oose a n 37-40 weeks	nost accu 40-42 weeks	During or	No diagnosis of blood pressure problem this	I cannot remember	
22. At what point in til	20-28	28-34	34-37	37-40	40-42	During or after giving	No diagnosis of blood pressure problem this		
	20-28	28-34	34-37	37-40	40-42 weeks	During or after giving birth	No diagnosis of blood pressure problem this pregnancy		
First Pregnancy	20-28	28-34	34-37	37-40	40-42 weeks	During or after giving birth	No diagnosis of blood pressure problem this pregnancy		
Second Pregnancy	20-28	28-34	34-37	37-40	40-42 weeks	During or after giving birth	No diagnosis of blood pressure problem this pregnancy		Not applica
First Pregnancy Second Pregnancy Third Pregnancy	20-28	28-34	34-37	37-40	40-42 weeks	During or after giving birth	No diagnosis of blood pressure problem this pregnancy		

ONG TERM HEALT	H RISKS AFT	ER HIGH BLo wor		SURE IN PRE	GNANCY -	Survey for
REGNANCY						
uestions marked wit ontinue.	h a green aster	isk (*) simply	mean that th	ey must be ans	wered in or	der to
<sup>c</sup> 23. Did you have a <i>p</i> problems?	lanned inductior	n of labour or <i>pl</i>	anned caesar	ean section due	to your bloo	d pressure
prosienie	Yes, planned induction of labour because of blood pressure issues in pregnancy	Yes, planned caesarean section because of blood pressure issues	Yes, planned caesarean for other reasons than blood pressure	No planned induction and no planned caesarean section	I cannot remember	Not applicable
First Pregnancy						
Second Pregnancy	0	0	0	0	0	0
Third Pregnancy						

#### LONG TERM HEALTH RISKS

This section is about some long term health risks that some women may experience after having had blood pressure problems in pregnancy.

For this section we would like you to think about the long-term health risks of a woman who has been diagnosed with high blood pressure in pregnancy.

Not everyone who experienced blood pressure problems in pregnancy will necessarily have health issues in the future. We would not want you to unnecessarily worry about any of these risks, therefore we will provide you with further information about long-term health after high blood pressure in pregnancy at the end of the survey.

\* 24. FOR WOMEN WITH HISTORY OF BLOOD PRESSURE PROBLEMS IN PREGNANCY:

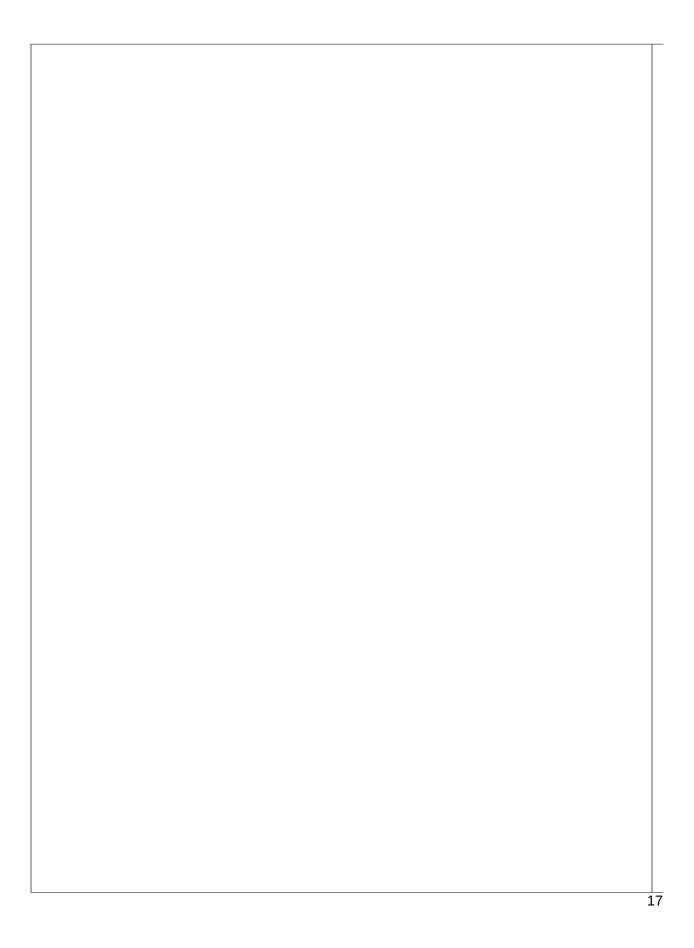
Compare yourself to a woman who has NOT had blood pressure problems in pregnancy.

Do you think you have a lower/same/higher chance of getting the following:

	woman without blood pressure in pregnancy	woman without blood pressure in pregnancy	woman without blood pressure in pregnancy	Not sure/I do not know
High blood pressure later in life				0
Diabetes				
Kidney disease				
Breast cancer				$\bigcirc$
Heart attack				
High blood pressure in another pregnancy		$\bigcirc$		$\bigcirc$
Stroke				
Heart disease				
Seizures				
Vascular Disease				

If you are concerned by any of the above potentially affecting you, information is available at the end of the survey where risks are explained.

r this section we would lik ood pressure in pregnancy	=	long term health risks of	a woman who has been o	diagnosed with high
25. FOR WOMEN WI	THOUT HISTORY OF	BLOOD PRESSURE	PROBLEMS IN PRE	GNANCY:
Compare yourself to a	a woman who HAS ha	d blood pressure prob	olems in pregnancy.	
Do you think you have	e a lower/same/higher	chance of getting the	following:	
	Less chance than a woman with blood pressure in pregnancy	Same chance as a woman with blood pressure in pregnancy	Higher chance than a woman with blood pressure in pregnancy	Not sure/I do not kno
High blood pressure later in life				
Diabetes				
Kidney disease				
Breast cancer				
Heart attack				
High blood pressure in another pregnancy	$\bigcirc$			$\bigcirc$
Stroke				
Heart disease	$\circ$	$\circ$	$\bigcirc$	
Seizures				
Vascular Disease	$\bigcirc$	$\bigcirc$		
26. How many years a symptoms of the pote	ntial risks may start to	appear?		ous signs and
< 10 years after pregi	nancy	> 20 ye	ars after pregnancy	
10-15 years after pre	-	Not sur	e/do not know	
16-20 years after pre				
Other (please specify	)			



LONG TERM HEALTH RISKS AFTER HIG	SH BLOOD PRESSURE IN PREGNANCY - Survey for
	women
* 27. How many years after blood pressure pro	oblems in pregnancy do you think the various signs and
symptoms of the potential risks may start to a	
< 10 years after pregnancy	> 20 years after pregnancy
10-15 years after pregnancy	Not sure/do not know
16-20 years after pregnancy	I don't think I will get any of these as I maintain a healthy lifestyle
Other (please specify)	
Cuter (piecase specify)	
I CASE OF DISTRESS	
	on of this survey, please contact your GP or the Principal Investigator of this
tudy, Dr Amanda Henry on 02 91132315 or Amanda.henry	y1@health.nsw.gov.au
or more information on this tonic places visit The Australia	on Lloort Foundation on the following links
for more information on this topic please visit The Australia	
ttps://www.heartfoundation.org.au/your-heart/women-and-	-heart-disease/womens-stories

### TYPE OF CARE RECEIVED DURING PREGNANCY WHERE A BLOOD PRESSURE PROBLEM WAS DIAGNOSED

Questions marked with a green asterisk (\*) simply mean that they must be answered in order to continue.

It is quite likely that some of the following questions may bring back some memories or bring rise to emotions that you find difficult to deal with. Please contact the Principal Investigator, Dr Amanda Henry on 02 91132315 or via email Amanda.henry1@health.nsw.gov.au if you would like to discuss these concerns. For medical assistance you can consult your General Practitioner.

* 28. Have you ever been admitted to a 'High Depende blood pressure problem in pregnancy?	ncy Unit' or 'Intensive Care Unit' as a result of your
Yes	
No	
I am not sure	
I cannot remember	
* 29. Have any of your babies been admitted to 'Neona Care Nursery' as a result of your blood pressure prob Yes No	tal Intensive Care', 'High Dependancy Unit' or 'Special lem in pregnancy?
30. After your baby was born have you had any of the	following? (select all that apply)
Blood pressure measurement in hospital	Consultation with a renal (kidney) specialist
Blood pressure measurement with my GP	Consultation with an obstetric medicine specialist (doctor who specialises in complications of pregnancy like high blood
Consultation with an obstetrician	pressure)
	I cannot remember
Other (please specify)	

ncreased risk of high blood pressure	Risk of hypertensive disease in your next pregnancy
Increased risk of kidney problems	I was told to eat a healthy diet, do some exercise and
Increased risk of stroke	normally
Increased risk of heart attack	No risks were discussed  I cannot remember
Increased risk of vascular disease	T cannot remember
Other (please specify)	

LONG TERM HEALTH RISKS A	AFTER HIGH BLOOD PRE women	SSURE IN PREGNANCY -	Survey for
TYPE OF CARE RECEIVED DU WAS DIAGNOSED	JRING PREGNANCY WHE	EN A BLOOD PRESSURE	PROBLEM
Questions marked with a green as	sterisk (*) simply mean that	they must be answered in o	der to
continue.			
32. If a healthcare provider did sp	peak to you about your future	health risks, when did this occ	cur?
Before birth	6 mo	onths to 1 year	
Immediately after birth	1 yea	ar and over	
Within first 6 weeks	I can	nnot remember	
6 weeks to 6 months			
* 33. When would be a good time the hypertension or preeclampsia ex		ong term health risks in your ge	estational
During pregnancy/at birth	12 months after birth	24 months after birth	
* 34. As a result of your pregnancy below after your baby was born?		roblems, were you referred to	any of the
Cardiologist	Fitne	ess centre for exercise	
Renal (kidney) Physician	Nutri	itionist for dietary adjustment	
General Practitioner	I can	nnot remember	
Other (please specify)			

EDUCATION
In this section we would like to find out about your preferred ways of getting information about long term health after gestational hypertension and preeclampsia.
Questions marked with a green asterisk (*) simply mean that they must be answered in order to continue.
* 35. After experiencing gestational hypertension or preeclampsia what do you want to know about your long term health? (select all that apply)
Risk reduction for subsequent pregnancies
Reducing risk behaviours (eg. diet, exercise, smoking cessation)
Statistics (eg. increased risk)
At what point does the risk increase
Signs and Symptoms
Where to find information
How to discuss the matter with my healthcare provider
Impact on my children from the pregnancy affected by blood pressure problems
Other (please specify)
* 36. How do you want to receive the information? (select all that apply).
Key organisations addressing heart health (e.g. The Australian Heart Foundation or Her Heart)
Social Media channels (e.g. Instagram, Facebook, Twitter)
Brochures/Flyers
Medical Professionals
Podcasts/Media
Online videos
Other (please specify)

37. Is there any	thing else you would	like to tell us?		

#### POST-SURVEY OPTIONS AND SUMMARY OF RISK PROFILE

#### Some further things we would like you to consider:

38. We would like to have your opinion on what you think would be appropriate education material to improve women's knowledge. We would also like to know how the education could best be distributed to women. Would you like to participate in a **focus group** (one off - 2hrs max at St George Hospital, Sydney) or a **telephone interview** (one off 30 mins max)? By involving 'consumers', meaning women like you, the education package will have added value.

If you are interested in participate in either, you can leave your details here.

•		
Name		
Email Address		
Phone Number		
39. Please leave your not be used for any otl	email address to <b>receive results</b> from this her purpose.	study (in approx. 1 year). Your details wil
Email Address		

#### IN CASE OF DISTRESS

If you experience any distress caused due to the completion of this survey, please contact your GP or the Principal Investigator of this study, Dr Amanda Henry on 02 91132315 or Amanda.henry1@health.nsw.gov.au

For more information on this topic please visit The Australian Heart Foundation on the following link: https://www.heartfoundation.org.au/your-heart/women-and-heart-disease/womens-stories

### RISK PROFILE - LONG TERM RISKS AFTER BLOOD PRESSURE PROBLEMS IN PREGNANCY EXPLAINED

You may like to take a screenshot of the risk profile so you can refer back to it whenever you need to.

#### **RISK PROFILE**

Although most women will experience good long-term health after having high blood pressure in pregnancy, there are, unfortunately, some long term health risks associated with having had high blood pressure in pregnancy.

Women who have had high blood pressure during pregnancy are about 3 to 4 times more likely to develop chronic hypertension than women who did not have a blood pressure problems in pregnancy. They are also about twice as likely to get diabetes in later life, even if they did not have diabetes during pregnancy.

Blood pressure diseases are also more likely to happen in the next pregnancy to women who have already had a previous blood pressure problems in pregnancy compared to women who have not. Therefore, if they have had a pregnancy with blood pressure problems, it is important to be seen early in their next pregnancy. There are treatments that can decrease the chance of recurring problems.

Women are also more likely to get various forms of cardiovascular disease (heart disease, stroke, vascular disease) if they have had gestational hypertension, preeclampsia and/or chronic hypertension. All of these cardiovascular problems are about twice as likely to eventually happen to a woman who has had blood pressure problems in pregnancy compared to a woman who has not. This still means most women will not have heart disease or diabetes after having high blood pressure in pregnancy, especially if they can avoid risk factors like smoking or excessive weight gain, and maintain a healthy diet and exercise.

Kidney problems are about 5 to 10 times more common after preeclampsia in particular. Although the relative risk of developing kidney problems is substantially higher after preeclampsia, the absolute risk of long-term kidney disease is still low. Unless the woman already had a kidney problem, well over 90% of women after preeclampsia and gestational hypertension will not have a kidney problem.

Fortunately, although seizures may occur as a result of preeclampsia during pregnancy, women have no higher long term risk of seizures compared to women who did not have a complicated pregnancy. There is no increased risk of getting cancer (e.g. breast cancer, leukaemia) after having high blood pressure in pregnancy.

For all the long term health risks, these start to go up within 10 years after an affected pregnancy and are ongoing after that. Therefore, it is recommended that women attend regular blood pressure checks with their GP and discuss any changes they can make to improve their general health. For more general information about heart health and managing health risks, please visit the National Heart Foundation website: https://www.heartfoundation.org.au/your-heart/know-your-risks

THANK YOU FOR YOUR PARTICIPATION