Postnatal cardiovascular risk after hypertensive disorder of pregnancy: Identifying knowledge needs and education recommendations for women and healthcare providers

Heike Roth BMid(Hons), GradCertAEd

A thesis submitted for the degree of Doctor of Philosophy (Midwifery)

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Certificate of original authorship

I, Heike Roth, declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Faculty of Health at the University of Technology, Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis. This document has not been submitted for qualifications at any other academic institution. This research is supported by the Australian Government Research Training Program.

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Statement of contributions to jointly authored works contained in this thesis

The systematic review of the literature and all results from this thesis have been submitted for publication in peer-reviewed journals. Below is a description of the contributions made to the papers by the co-authors. I take full responsibility for the accuracy of the findings presented in these publications and this thesis. All authors have given permission for the publications to be incorporated into this PhD.

Thesis format

This is a thesis by compilation and consists of seven chapters, five of which are papers; Chapter Two to Chapter Six. Chapters Two, Three, and Five are papers that have been published in peer reviewed journals during my PhD candidature. Chapters Four and Six are currently under peer review. Publication details for each chapter are outlined below, together with a statement of contribution and percentage contribution for each author. All authors have provided permission for the papers to be included in this thesis.

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Roth H, Henry A, Homer CSE. Assessing the knowledge gap of women and healthcare providers concerning cardiovascular risk after hypertensive disorders of pregnancy (oral presentation). *Australian College of Midwives National Conference,* Canberra, Australian Capital Territory, Australia.

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Glossary of terms

AAPEC	Australian Action on Preeclampsia
ACM	Australian College of Midwives
CH	Chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia
CVD	Cardiovascular disease
CSANZ	The Cardiac Society of Australia and New Zealand
DRANZCOG	Diplomate of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (General Practitioner with Obstetrics/Gynaecology Diploma)
FRANZCOG	Fellow of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (Specialist obstetrician/gynaecologist).
GDM	Gestational diabetes mellitus
GH	Gestational hypertension
GP	General practitioner
HCP	Healthcare provider
HDP	Hypertensive disorders of pregnancy
HELLP	Haemolysis, elevated liver enzymes, low platelet count syndrome
IHD	Ischaemic heart disease
ISSHP	International Society for the Study of Hypertension in Pregnancy
IUGR	Intrauterine growth restriction
NICU	Neonatal Intensive Care Unit
NSW	New South Wales
P4 Study	Postpartum physiology, psychology and paediatric follow-up study
PE	Preeclampsia
PVD	Peripheral vascular disease
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
SESLHD	South Eastern Sydney Local Health District
SOMANZ	Society of Obstetric Medicine of Australia New Zealand

Abstract

Background

Women with a history of hypertensive disorder of pregnancy (HDP) are at significantly increased risk of future cardiovascular disease compared to women with no HDP pregnancies. Recent findings suggest this information is not transferred sufficiently to women, and how best to do this, including how to equip healthcare providers (HCP) for the knowledge transfer process, is not known. The aim of this study was to (i) identify knowledge and knowledge gaps of Australian women and HCPs regarding health risks after HDP and (ii) to explore their education preferences.

Method

A sequential explanatory mixed method design was undertaken. After a scoping review of relevant literature, data were collected from two cohorts: women and HCPs. Quantitative data on knowledge related to health after HDP were collected using online surveys. Qualitative data were collected through interviews and analysed using framework analysis.

Findings

The scoping review identified that published literature reflected a lack of, or insufficient knowledge amongst HCP and women regarding CVD risks after HDP. The surveys (266 women and 492 HCPs) found that women's and HCP level of knowledge about health post-HDP was similar. Knowledge was highest in both groups regarding risk of recurrent hypertensive disorders in future pregnancies and future chronic hypertension, and lowest/greatest knowledge gaps regarding risks after gestational hypertension versus preeclampsia, and increased risk of Type 2 diabetes. Only one-third of participants in each cohort were aware that risks start within 10 years after the HDP affected pregnancy.

In the qualitative component (13 women and 20 HCPs), women's preference included early post-HDP birth risk counselling about long-term and modifiable risk factors from their HCPs accompanied with evidence-based, print or web-based information. HCPs wanted access to similar material to assist in their risk discussions with women. HCPs expressed a preference for multi-disciplinary education, preferably endorsed or facilitated by professional colleges and health organisations. Both groups were in favour of structured long-term follow-up, including reminder systems, to facilitate the transition from hospital to community health and align with international and local societies' hypertension guidelines.

Conclusion

Important knowledge gaps in women and healthcare providers were found regarding health after HDP in the Australian context. Women and healthcare providers want more information about long-term and modifiable risk factors post-HDP. Recommendations are made to enable a more structured transition from hospital to community health post-HDP, including automated alerts to remind women about key points of follow-up.

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Chapter 1: Introduction

Hypertensive disorders of pregnancy (HDP) affect approximately 5-10% of pregnancies (Centre for Epidemiology and Evidence 2018; Duley 2009), and include preeclampsia (PE), gestational hypertension (GH) and chronic hypertension (CH). As well as being a major cause of short-term maternal and fetal morbidity and mortality (Riise et al. 2018; Theilen et al. 2016), HDP have been shown to significantly increase women's future cardiovascular and metabolic risk profile (Brown, Best, et al. 2013; Giorgione et al. 2021; McDonald et al. 2008; Naghavi et al. 2017; Oliver-Williams et al. 2019; Payne et al. 2016; Riise et al. 2018; Theilen et al. 2016; Wu et al. 2017).

Globally, cardiovascular disease (CVD) is one of the leading causes of death in women (Roth et al. 2018). For women who have experienced an HDP, the risk is 2-3 times higher compared with those who did not (Brown, Best, et al. 2013; McDonald et al. 2008; Theilen et al. 2016). However, even if HDP cases were halved, the increased CVD and metabolic disorder risk associated with past HDP will remain a major public health problem well into the future (Rolnik et al. 2017). A further key element, adding to the magnitude of concern, is that the onset of these HDP-associated CVD risks and deaths occur prematurely, within 10 years of an affected pregnancy (Wu et al. 2017) with the risk continuing lifelong (Theilen et al. 2016).

Guidelines for best, evidence-based care of this group of women in the postnatal period and beyond are non-specific as evidence around effective risk reduction for this particular group of women is minimal (Brown, Magee, et al. 2018; Lowe et al. 2015). In addition, it is often likely that many women do not understand their risk factors as these may not be explained in detail nor may women be given a clear treatment plan for the future (Burgess & Founds 2016; Cain et al. 2016; Leslie & Briggs 2016). It remains questionable whether women would seek preventative medical consultations or follow recommended lifestyle changes to reduce their risk factors. Women may also not be aware of signs and symptoms of CVD such as myocardial infarction or stroke. In addition to a probable knowledge gap amongst women (Brown, Bell, et al. 2013; Hird et al. 2017; Hutchesson et al. 2018; Seely et al. 2013; Skurnik et al. 2016; Traylor et al.

2016; Viana Pinto et al. 2014), studies have described knowledge gaps in healthcare providers (HCP) as well (Adekanle et al. 2015; Heidrich et al. 2013; MacDonald et al. 2007; Wilkins-Haug et al. 2015; Young, Hacker & Rana 2012). Many of these areas that are unknown or uncertain will be explored in this PhD which aims to (i) identify knowledge and knowledge gaps of women and healthcare providers (HCP) in Australia with regards to health risks after HDP and (ii) to explore their education preferences in order to develop recommendations to best address these findings within the Australian healthcare setting.

This introductory chapter will define the various forms of HDP and the link between HDP and future health risks for women and their children will be explained. An overview of setting and context of this study will be illustrated. Guidelines providing recommendations for long-term follow-up after HDP will be introduced as well as current national incentives to address women's health post-HDP. The aims and objectives of this study will be presented and an overview of the structure of the thesis provided. A COVID-19 statement has been included as per submission requirements stated by the University of Technology Sydney.

Definition of hypertensive disorders of pregnancy

HDP include chronic hypertension (CH), gestational hypertension (GH) and preeclampsia (PE) (Brown, Magee, et al. 2018; Lowe et al. 2015). As a collective, these disorders complicate approximately 5-10% of all pregnancies (Duley 2009), individually PE represents about 2-4% (Payne et al. 2016) GH about 3% (Payne et al. 2016), and CH approximately 0.5-2% (Lowe et al. 2015). In Australia, this represents over 15,000 pregnancies per year (Davis, Roberts, Henry, et al. 2016; Duley 2009). CH in particular is increasingly frequent due to increasing pre-disposing factors in the maternity population, particularly being overweight, obesity and older age (Centre for Epidemiology and Evidence 2018; Payne et al. 2016). HDP leads to over 40,000 maternal deaths globally every year, and 1 in 8 women experience major short-term PE complications (Centre for Epidemiology and Evidence 2018; von Dadelszen & Magee 2016; von Dadelszen et al. 2011). HDP is reported as a direct cause of death in 0.3 per 100,000 Australian women (Australian Institute of Health and Welfare 2018a) and is responsible for one in 40 Australian stillbirths and neonatal deaths (Australian Institute for Health and Welfare 2020; von Dadelszen & Magee 2016), while globally a baby dies every minute due to PE. HDP also has significant long-term consequences and intergenerational effects. For the mother, lifelong increased cardiometabolic disease risks include at least a doubling in the risk of myocardial infarction, stroke, and type 2 diabetes, three of the top 10 killers of Australian women (Brown, Best, et al. 2013; Naghavi et al. 2017; Riise et al. 2018; Theilen et al. 2016; Wu et al. 2017). For children of HDP-affected pregnancies, there is a substantial increase in childhood mental health and developmental disorders (Dachew et al. 2018; Lahti-Pulkkinen et al. 2020), while increased blood pressure (BP) and weight (which in turn predisposes them to cardiometabolic disease) occur as early as 5 years of age (Alsnes et al. 2017; Davis et al. 2012; Fraser et al. 2013).

There are multiple classification frameworks available to advise best practice of HDP diagnosis, management during pregnancy and long-term considerations. The International Society for the Study of Hypertension in Pregnancy (ISSHP) provides an international perspective and since this study will be conducted in Australia, the *Society of Obstetric Medicine of Australia and New Zealand* (SOMANZ) framework will be also be used as a key reference (Lowe et al. 2015).

CH is defined by a blood pressure greater than or equal to 140mmHg systolic and/or 90mmHg diastolic confirmed before pregnancy or before 20 completed weeks of gestation. White coat hypertension needs to be excluded. Pre-existing hypertension is a strong risk factor for the development of preeclampsia (Lowe et al. 2015).

GH is characterised by the new onset of hypertension after 20 weeks gestation without any maternal or fetal features of preeclampsia (Lowe et al. 2015). Unless it progresses to PE, which occurs in 25-60% of cases, GH is associated with few adverse pregnancy outcomes (Lowe et al. 2015). However, like PE it is also associated with long-term cardiovascular sequelae (Lowe et al. 2015).

PE is a multisystem disorder, and as defined by ISSHP (Brown, Magee, et al. 2018) and SOMANZ (Lowe et al. 2015) is new-onset hypertension at or after 20 weeks gestation with at least one of (a) proteinuria (b) maternal organ dysfunction (acute kidney injury, liver involvement, neurological complications, haematological complications) (c) uteroplacental dysfunction (e.g. fetal growth restriction, abnormal Doppler (Lowe et al. 2015). PE is a major cause of poor pregnancy outcome, including maternal death or major morbidity due to, for example, stroke, renal failure or hepatic impairment. Fetal death or morbidity are further complications of PE (Mol et al. 2016). Maternal vascular dysfunction, chronic immune system activation, renal dysfunction and for the growing baby, intrauterine growth restriction (IUGR) are common clinical manifestations (Mol et al. 2016). Table 1 illustrates the various body systems involved with PE and how the disorder is manifested in these.

Table 1: Body systems and the clinical manifestations of preeclampsia*

Affected organ	Manifestation
Renal	Significant proteinuria – a spot urine protein/creatinine ratio ≥ 30 mg/mmol
	Serum or plasma creatinine >90 μmol/L
	Oliguria: <80 mL/4 h (Urate is not included as a diagnostic feature)
Haematological	Thrombocytopenia <100,000/ μL
	Haemolysis: schistocytes or red cell fragments on blood film, raised bilirubin, raised lactate dehydrogenase >600 mIU/L, decreased haptoglobin
	Disseminated Intravascular Dissemination (DIC)
Liver	Raised serum transaminases
	Severe epigastric and/or right upper quadrant pain
Neurological	Convulsions (eclampsia)
	Hyperreflexia with sustained clonus
	Persistent, new headache
	Persistent visual disturbances (photopsia, scotomata, cortical blindness, posterior reversible encephalopathy syndrome and retinal vasospasm)
	Stroke
Lungs	Pulmonary oedema
Placenta/fetus	Fetal growth restriction

* adapted from SOMANZ Guidelines (Lowe et al. 2015)

Preeclampsia pathogenesis is still incompletely understood, however Figure 1 summarises the current 2-stage hypothesis. In the first stage, immune, genetic and/or pre-existing disease factors contribute to a defective placentation. Then in the second stage an abnormal inflammation response, elevated cytokines and vascular manifestations result in maternal and/or fetal signs of PE. Pathophysiology may differ in early-onset (<34 weeks gestation) versus later PE, with excessive physiological placentation theorised to result in late onset of PE. The consequences of endothelial cell activation appear to be consistent amongst all women who develop preeclampsia. There is, however, a variable impact on multiple organ systems. Disease severity generally correlates with the degree and number of organ dysfunctions (Magee et al. 2014).

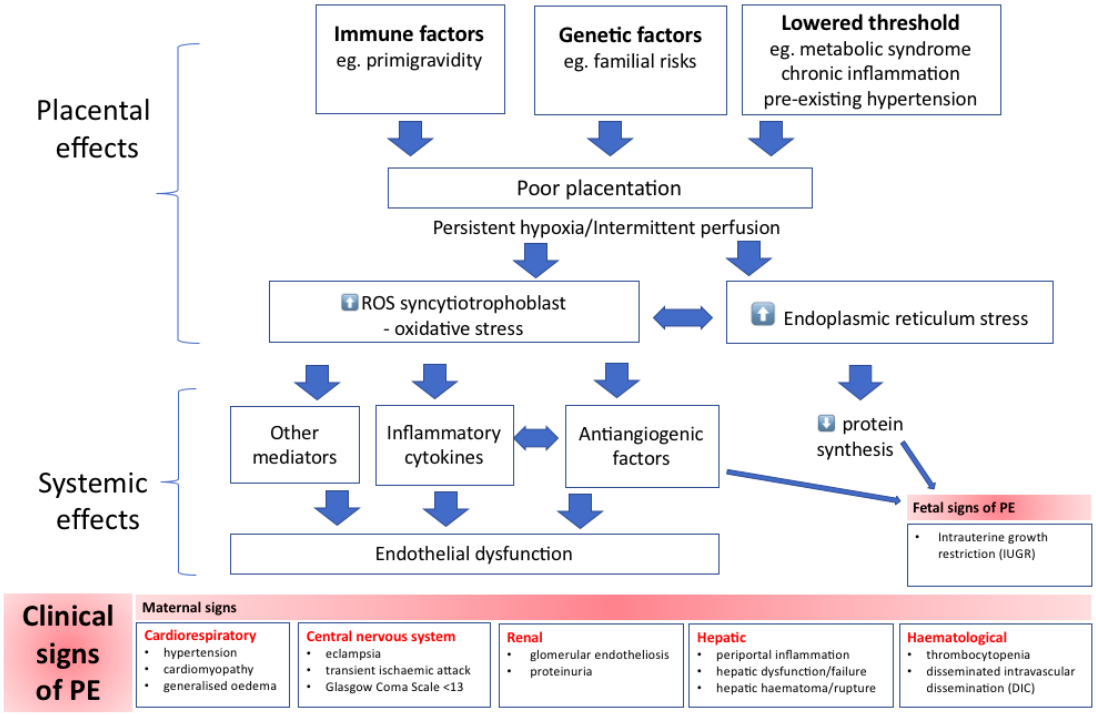

Figure 1: The origins, effects and clinical signs of preeclampsia - Adapted from Magee et al. (2014)

Preeclampsia is a top 5 cause of direct maternal mortality in Australia and globally, with over 40,000 mothers and 500,000 infant deaths worldwide attributed annually to PE (von Dadelszen & Magee 2016). It is also a major cause of severe illness in pregnancy: even in high-income countries, including Australia, 1 in 8 affected women will have a serious pregnancy/immediate postpartum complication such as renal failure, pulmonary oedema, liver impairment, or neurological dysfunction (von Dadelszen et al. 2011).

Whilst GH and CH have fewer immediate pregnancy complications, both progress to PE in at least one in four cases (Brown, Magee, et al. 2018) and, like PE, are associated with other important pregnancy complications, including gestational diabetes (Bryson et al. 2003; Oliver-Williams et al. 2019).

The link between HDP and future health risks

Within the context of HDP, pregnancy has been likened to a metabolic and vascular ‘stress test’ for women, predicting their future disease susceptibility (Craici, Wagner & Garovic 2008; Oliver-Williams et al. 2019). Systematic reviews as well as meta-analyses have shown that there is a significant increase of risks for women who have been diagnosed with HDP, that extends beyond the pregnancy and are independently associated with increased lifetime CVD and other chronic disease risks (Brown, Best, et al. 2013; Theilen et al. 2016). To clarify, the relative increased risk is present and events begin to occur (despite a small absolute risk of event) within 10 years of affected pregnancy. The risks continue lifelong, increasing in absolute frequency with time due to the greatly rising absolute risk of CVD with age. However, relative risk compared to women of the same age, the relative risk does not rise markedly (Brown, Best, et al. 2013; Theilen et al. 2016).

After HDP, women not only have a 3-4 times increased risk of CH (Brown, Best, et al. 2013), but 2-3 times increased risk of CVD (myocardial infarction, stroke, cardiovascular death), five times the rate of chronic renal disease, and a doubling of type 2 diabetes (Brown, Best, et al. 2013; Hirst et al. 2019; Khashan et al. 2019; Naghavi et al. 2017; Riise et al. 2018; Theilen et al. 2016). There is also an increasing body of recent research linking PE and GH with other major chronic diseases including chronic kidney disease, end-stage kidney disease, and Type 2 diabetes mellitus. The risk of type 2 diabetes is present even if the woman did not have gestational diabetes during her HDP pregnancy (Barrett et al. 2020; Khashan et al. 2019; Pace et al. 2017; Timpka et al. 2018). Other risks for women post-HDP include postpartum depression, anxiety, and post-traumatic stress disorder (Caropreso et al. 2020; Porcel et al. 2013;

Roberts, Davis & Homer 2019).

These long-term, adverse maternal health outcomes after HDP, as well as being of importance to individuals, may represent a further strain on public health. Heart disease and stroke are two of the three leading causes of death in Australian women (Australian Bureau of Statistics 2018b). The incidence of death by stroke or ischemic heart disease are 2-2.5 times higher in women who were diagnosed with preeclampsia than those who experienced a normotensive pregnancy (Brown, Best, et al. 2013; McDonald et al. 2008; Riise et al. 2018; Theilen et al. 2016; Wu et al. 2017). PE carries a risk of premature death, as the women that were studied were 8-20 years post pregnancy, with an average age of less than 56 years (McDonald et al. 2008; Tooher et al. 2013; Wu et al. 2017). With HDP-associated CVD risk increasing within 10 years of an affected pregnancy (Wu et al. 2017) and continuing lifelong (Theilen et al. 2016), the risk is therefore at least as high or even higher than traditional CVD risk factors, such as smoking and obesity (Appelman et al. 2015).

In 2007 (Bellamy et al.) the first systematic review and meta-analysis on PE and the risk of CVD and cancer in later life was published. This study included prospective and retrospective cohort studies, which provided a dataset of 3,488,160 women of which 198,252 were affected by preeclampsia. Regarding CVD and cancer, 29,495 episodes were identified. The study found that after PE, women have an increased risk of CVD. The relative risk of the various conditions are itemised in Table 2 below. The conclusion of this initial systematic review suggests that an obstetric history of PE should be considered when screening for CVD risk. Since then, further studies have confirmed findings regarding the long-term health impact of PE and have provided insight into the potential health sequalae post GH (Oliver-Williams et al. 2019).

Table 2: Relative risk (95% confidence interval) of cardiovascular disease after preeclampsia (Bellamy et al. 2007)

Condition	**RR**	**Range**	**Weighted mean follow-up**
Hypertension	3.70	2.70 to 5.05	After 14.1 years
Ischaemic heart disease	2.16	1.86 to 2.52	After 11.7 years
Stroke	1.81	1.45 to 2.27	After 10.4 years
Venous thromboembolism	1.79	1.37 to 2.33	After 4.7 years
Cancer incl. breast cancer	1.04 (no increased risk)	0.78 to 1.39	After 17 years
Overall mortality after preeclampsia	1.49	1.05 to 2.14	After 14.5 years

A further systematic review and meta-analysis was published around the same time by McDonald et al. (2008). Their focus was on cardiovascular sequalae of preeclampsia and eclampsia. This review included case-control and cohort studies which examined cardiac, cerebrovascular or peripheral arterial disease as well as cardiovascular mortality >6 weeks postpartum. This included women with and without history of preeclampsia or eclampsia. The results are itemised in the below Table 3. As with Bellamy et al. (2007), the McDonald et al. (2008) study concluded with the findings that women with a history of preeclampsia have a significant increased risk of early CVD as well as mortality.

Table 3: Relative risk (95% confidence interval) of cardiovascular disease after preeclampsia/eclampsia (McDonald et al. 2008)

Condition	**Relative Risk** (95% confidence interval)	**Range**
Cardiac disease in case control groups	2.47	1.22-5.01
Cardiac disease in cohort studies	2.33	1.95-2.78
Cerebrovascular disease	2.03	1.54-2.67
Peripheral arterial disease	1.87	0.94-3.73
Cardiovascular mortality	2.29	1.73-3.04

Then followed a further systematic review and meta-analysis on CVD risk in women with PE which was published in 2013 (Brown, Best, et al. 2013). The study confirmed similar findings from earlier studies detailed above. The conclusion states that women with a history of preeclampsia bear a doubling of odds of future cardiovascular or cerebrovascular events compared to unaffected women. Table 4 illustrates the findings.

Table 4: Cardiovascular disease risk in women with preeclampsia (Brown, Best, et al. 2013)

Condition	**Relative Risk** (95% confidence interval)	**Range**
Fatal or diagnosed cardiovascular disease	2.28	1.87- 2.78
Cerebrovascular disease	1.76	1.43-2.21
Hypertension	3.13	2.51-3.89

The most recent systematic review prior to the commencement of this PhD, conducted in 2017 (Wu et al.) studied the future risk of heart failure, coronary heart disease, composite CVD, death because of coronary heart or CVD, stroke, and stroke death after PE. The review included 22 studies with over 6.4 million women including over 25 8,000 women with PE. The meta-analysis, adjusted for possible confounders, showed that PE was independently associated with a number of future increased risks: future heart failure, coronary heart disease, CVD death and stroke. These are summarised in Table 5 and relative risk indicated.

Table 5: Cardiovascular disease risk in women with preeclampsia (Wu et al. 2017)

Condition	**Relative Risk** (95% confidence interval)	**Range**
Future heart failure	4.19	2.09-8.38
Coronary heart disease	2.50	1.43-4.37
CVD death	2.21	1.83-2.66
Stroke	1.81	1.29-2.55

After adjusting for age, PE continued to be associated with an increased risk of future coronary heart disease, heart failure, and stroke (RR, 3.89; 95% CI, 1.83-8.26). Further adjustment for confounders such as body mass index (RR, 3.16; 95% CI, 1.41-7.07), and diabetes mellitus (RR, 4.19; 95% CI, 2.09-8.38) also showed persistent increased future risk. The study therefore further highlighted the importance of lifelong monitoring of CVD risk factors in women post PE.

Regarding CVD sequelae post-GH versus post-PE, evidence has also been accumulating. An American study in 2016, of 60,000 women who were diagnosed with GH (post-PE risks analysed separately), found that these women were at a 2-3-fold higher risk of mortality from stroke and ischemic heart disease (Theilen et al. 2016). This suggests that GH is not a benign, short-term disease, and like PE has increased risks of long-term CVD.

For women with CH, high blood pressure is long-established as one of the most important risk factors for CVD (Fuchs & Whelton 2020; Roth et al. 2018). Large cohort studies have demonstrated that, in general, CH is an important risk factor for coronary heart disease and stroke heart failure, atrial fibrillation, chronic kidney disease, heart valve diseases, aortic syndromes, and dementia (Lewington et al. 2002). CH in pregnancy is becoming more frequent due to more women being overweight, obese and experiencing pregnancy at an older age (Centre for Epidemiology and Evidence 2018; Payne et al. 2016).

The focus of this thesis is thus on post PE/GH knowledge given women with CH already have higher risk of CVD, and as per general adult guidelines for CVD prevention should be receiving regular medical follow-up (The Royal Australian College of General Practitioners 2018).Specific additional advice regarding future lifestyle and optimisation of risk factors in subsequent pregnancies may also be beneficial for women with CH, particularly for women who are obese, have other cardiovascular risk factors, secondary hypertension or end-organ disease (Lowe et al. 2015).

It is important to elucidate whether HDP itself increases the future risk of CVD or whether it serves as a marker for women at risk. Results from Romundstad et.al (2010) suggest that the positive association of PE and GH with post-pregnancy cardiovascular risk factors may be due largely to shared pre-pregnancy risk factors rather than reflecting a direct influence of the HDP. Garovic et.al (2010) aimed to assess the association of hypertension in pregnancy and future CVD. They conclude that hypertension in pregnancy may be an independent risk factor for subsequent diagnoses of hypertension and stroke (Garovic et al. 2010). Regardless of the source of the risk, the future increased risk of CVD remains and is often not addressed with women due to the translation gap that underpins the rationale for this study.

More recently, since the commencement of the PhD, Oliver-Williams et al. (2019) published a systematic review and meta-analysis of studies quantifying association between GH and cardiovascular events in women. A total of 11 studies, including 3 209 836 women (74 066 with GH), examined the risk of cardiovascular events in primiparous women affected by GH. Risk assessed included overall CVD, CHD, heart failure, any stroke, myocardial infarction (MI), thromboembolic events, angina, other circulatory disease, and a combined outcome of acute MI and acute cerebral stroke. GH in the first pregnancy was associated with a greater risk of overall CVD and coronary heart disease but not stroke or thromboembolic events (Table 6).

Table 6: Cardiovascular disease risk in women with gestational hypertension at index pregnancy (Oliver-Williams et al. 2019)

Condition	**Relative Risk** (95% confidence interval)	**Range**
Overall CVD	1.45	1.17-1.80
Coronary heart disease	1.46	1.23-1.73
Thromboembolic events	0.88 (no increased risk)	0.73-1.07
Stroke	1.26 (no increased risk)	0.96-1.65

Women with one or more pregnancies affected by GH were at greater risk of CVD, coronary heart disease and heart failure but not stroke (Table 7). These results further underscore the contribution of GH, not only PE, to CVD risk.

Table 7: Cardiovascular disease risk in women with gestational hypertension for one or more pregnancies (Oliver-Williams et al. 2019)

Condition	**Relative Risk** (95% confidence interval)	**Range**
Overall CVD	1.81	1.42-2.31
Coronary heart disease	1.83	1.33-2.51
Heart failure	1.77	1.47-2.13
Stroke	1.50 (no increased risk)	0.75-2.99

Findings from a large population study in the Australian setting showed that CVD risks are further increased for women who experience early onset of HDP, with women who give birth under 34 weeks gestation due to HDP having five-fold ongoing increased CVD risk (Arnott et al. 2020). When risk factors were combined, the risk was cumulative, whereby a woman who is a smoker and experiences early-onset HDP can result in a hazard ratio for CVD of 23.5 at 10 years postpartum (Arnott et al. 2020). This finding highlights the importance of early detection through targeted assessment and intervention in the early post-partum period (Arnott et al. 2020).

Giorgione et al. (2021) conducted a systematic review to estimate the incidence of hypertension in the first 2 years after HDP. A meta-analysis to calculate the odds ratio with a 95% CI and a sub-group analysis excluding women with CH were performed. The authors report that the risk of hypertension in the HDP group was significantly higher in the first 6 months following delivery (OR 18.33; 95% CI 1.35–249.48) than at 6–12 months (OR 4.36; 95% CI 2.81–6.76) or between 1–2 years postpartum (OR 7.24; 95% CI 4.44–11.80). A sub-group analysis demonstrated a similar increase in the risk of developing hypertension postpartum after HDP (OR 5.75; 95% CI 3.92–8.44) and PE (OR 6.83; 95% CI 4.25–10.96). Their findings indicate that the risk of hypertension after HDP is highest in the early postpartum period. This suggests that early postpartum diagnosis and intervention is indicated in order to improve maternal cardiovascular health.

Studies suggest that subsequent lifestyle education and intervention may be of help to reduce or even correct the future cardiovascular risk profile (Berks et al. 2013; Lui, Jeyaram & Henry 2019). Engaging women of childbearing age who may be motivated by a complication in pregnancy may be valuable from a public health perspective, given the prevalence and importance of CVD in women, and the central role of the woman as caregiver to children, spouses and other family members (Newstead, von Dadelszen & Magee 2007).

Health impact on children born to mothers with HDP

Research on issues for children of pregnancies affected by HDP is still ongoing, and potential impacts seem less clear than the health risks for mothers. It is also quite difficult to separate out effects on children that may go along with the woman having had an HDP pregnancy (such as baby being born premature or small) with longer-term effects that are due to the HDP itself. However on average, children of pregnancies affected by HDP tend to have higher blood pressure and weight by their teenage years than children of uncomplicated pregnancies, which predisposes them to issues such as diabetes and heart disease as adults (Davis et al. 2012).

Since this thesis started, a number of additional studies have been published that highlight increased risk of adverse cardiometabolic events, mental health concerns and neurodevelopmental disorders in children born to mothers with HDP. A recent study (Kurbasic et al. 2019) found that children born to mothers with a history of HDP are on an adverse cardiometabolic trajectory and need to be included in health prevention initiatives in the maternal post-pregnancy period. The children had increased relative risk of hypertension and also higher mean body mass index, systolic blood pressure, diastolic blood pressure, and poorer 2-hour 75 g oral glucose tolerance test result at 40 years of age.

There may also be some increase in behavioural and mental health issues in children of pregnancies affected by HDP (Dachew et al. 2018; Lahti-Pulkkinen et al. 2020). Lahti-Pulkkinen et al. (2020) highlight the adverse intergenerational consequences of maternal PE on offspring mental health. They concluded that maternal HDP, especially PE, predict increased offspring hazard of any childhood mental disorder. These effects were reported to be independent of parental mental disorders, paternal hypertensive disorders and several other covariates, independent of and additive with maternal overweight/obesity and diabetes mellitus disorders, and partially mediated by preterm and small for gestational age babies and Neonatal Intensive Care Unit (NICU) admission.

A systematic review and meta-analysis (Maher et al. 2018) looked at the association of HDP with the risk of neurodevelopmental disorders in the children. HDP is associated with a small yet statistically significant increase in the odds of autism spectrum disorder and attention-deficit/hyperactivity disorder in children compared with no exposure. Exposure to HDP may be associated with an increase in the risk of autism spectrum disorder and attention-deficit/hyperactivity disorder. Dachew et al. (2018) conducted a systematic review and meta-analysis, which showed an association of PE to increased risk of schizophrenia in the offspring. Further findings were reported on the effect of HDP and other mental and behavioural disorders, however these were inconclusive.

Perak et al. (2021) examined the associations between maternal gestational cardiovascular health and offspring cardiovascular health in a multinational cohort. Their findings established that there was a significant association between better maternal cardiovascular health at 28 weeks gestation and better offspring cardiovascular health at ages 10 to 14 years. Greater surveillance of infants exposed to HDP may allow early intervention and in turn improve neurodevelopmental and general health outcomes.

Knowing health risks and the impact this has on change in behaviour

Whilst awareness about a health condition and mitigation options are important, it needs to be challenged whether this knowledge then leads to action and eventually to improved outcomes. Actively engaging with the knowledge of risk and ways to mitigate risk may present challenge on individual, professional, structural and social levels.

When addressing disease prevention in general and also post HDP more specifically, the woman and healthcare provider share responsibility to transform this knowledge into action. This encompasses individual and professional aspects where both, the woman and the healthcare provider need to have knowledge and work in partnership for screening and treatment to occur (Hird et al. 2017; Keely 2012). It is however, up to the individual, the woman, to make follow-up appointments, attend them and action the advice provided by HCP (Bick et al. 2020). Furthermore, at a professional level, the coordination of various healthcare services to assist women achieve best health outcomes is important (Davies et al. 2009; Starfield, Shi & Macinko 2005; Trankle et al. 2019).

Perception of risk is an individually driven element that is key when exploring ways to address risk. Women may perceive risk based on personal experience and associational meanings (Street et al. 2009). Research has shown that women with a family history of CVD disease had greater awareness of future CVD risk. However, despite risk counseling women without a family history of CVD did not perceive the risk to apply to them (Brown, Bell, et al. 2013). Risk perception of HDP recurrence and future CVD due to HDP was also higher in women who experienced PE with severe features (Traylor et al. 2016), further indicating that many other HDP affected women may not identify with the increased risk. Similarly, in a study conducted on risk perception among women with a history of gestational diabetes mellitus (Kim et al. 2007), women usually did not perceive themselves to be at elevated risk, despite understanding the association between the disorder and postpartum diabetes.

Appropriate coordination and access to post-HDP care may be challenged as a result of a lack of overarching policy or organisation of primary healthcare services (Department of Health 2019). The various levels at which primary health care services are administered in Australia (state and federal) and funding arrangements (public and private) need to be considered when measuring translation of knowledge into action and improved health outcome.

Intervention data specific to the HDP population remain scarce. However, evidence regarding lifestyle behaviour change intervention after HDP reports an expected reduction of future CVD risk by approximately 10% (Berks et al. 2013; Timpka et al. 2017). A number of observational studies suggest postpartum follow-up clinics may be of benefit (Celi et al. 2019; Janmohamed et al. 2015; Nowik, Pudwell & Smith 2016) although rates on women not attending were reported to be as high as 25% with attendance lower in the socially disadvantaged women. A recent internet-based radomised controlled trial of lifestyle behaviour change interventions after preeclampsia

(Rich-Edwards et al. 2019), involved predominantly women of high education status. The study found that improved knowledge regarding lifestyle behaviour change increased women's confidence to engage in lifestyle behaviour change.

Looking at disease prevention from a more general perspective, evidence has repeatedly suggested that health knowledge of the person at risk and understanding of preventive action is key in prevention. For example, better knowledge in patients' general knowledge about coronary has shown to significantly improve adherence to lifestyle changes and medication (Alm-Roijer et al. 2006). Similarly, in for patients with rheumatoid arthritis, educational programs about cardiovascular disease were suggested as a preventive measure made available at the time of diagnosis (Boo et al. 2017). In a recent study addressing cardiovascular risk among older adults, Liu et al. (2020) concluded that independent factors of higher cardiovascular risk levels included lower CVD knowledge, older age, lower income, and lower educational level.
Lack of risk knowledge may be detrimental turn into insufficient preventative behaviours and suboptimal patient outcomes. Research on the broader topic of public CVD knowledge and its risk factors suggests that effective educational interventions, that are sensitive to the perceptions, attitudes, and abilities of targeted individuals are key in developing preventive behaviours and improving health outcomes (Awad & Al-Nafisi 2014). Optimally, in order to achieve sustainable benefits for most patients, these should be flexible, culturally safe and integrated with the patient's primary healthcare provider (Briffa et al. 2009).

In the context of women's health and their underlying biological mechanisms that contribute to sex-specific differences in health outcomes, prevention treatment, and access to care for women are key to decrease the global CVD burden in women (Vogel et al. 2021).

Maternity care in Australia - the context for this study

The study has its origins and anchor within St George Hospital in New South Wales, the most populous state in Australia. The initial pre-survey group interviews as well as the healthcare provider (HCP) survey validation was conducted on site. However, as per sample description the distribution of the survey included women and healthcare providers across Australia.

The Australian healthcare system

The Australian healthcare system provides a wide range of services. General practitioners (GPs) as well as emergency departments are the main portal to other health services, including specialist consultations. For most people with illnesses, primary health care (such as GPs and midwives) is their first point of access. The setting includes general practices and community health centres as well as home. Medical specialists work in a chosen area of medicine, such as cardiology and obstetrics/gynaecology and work in the private sector or in private or public hospitals. It is usual practice for a person seeking specialist care to be referred by their GP. Hospital services in Australia are provided by both the public and private sectors. The Australian, state and territory, and local governments share responsibility for running the health system. While some aspects of the Australian healthcare system are the same nationwide other aspects vary depending on the location, with variances between states, cities and rural and remote areas. For example, access to the various healthcare providers varies depending on location (Department of Health 2019).

Births in Australia

A total of 305,832 births were registered in Australia in 2019 resulting in a total fertility rate (TFR) of 1.66 babies per woman. The fertility rate of Australian women aged 35 years and over continues to rise, however the rate is falling in most other age groups according to the latest figures from the Australian Bureau of Statistics. In the past 30 years, the fertility rate of women aged 35-39 has more than doubled, and for women aged 40-44 it has tripled. In contrast, teenage fertility nearly halved during this period (Australian Bureau of Statistics 2019).

Australia is a very multi-cultural country. The most recent data from the Australian Census (2016) reported over 300 languages spoken in Australian homes. More than one-fifth (21%) of Australians spoke a language other than English at home. The top 5 languages spoken at home as a proportion of all languages spoken in Australia in 2016 were: English 72.7%, Mandarin 2.5%, Arabic 1.4%, Vietnamese 1.2% and Cantonese

1.2% (Australian Bureau of Statistics 2016). Aboriginal and Torres Strait Islander population represents 2.8% of the Australian population (Australian Bureau of Statistics 2016). Of mothers who gave birth in 2016 (to report on data collected in the same year as the Australian Census data), 26% were born in a main, non-English-speaking country, compared with 23% of women of reproductive age in the population. The proportion of mothers born in a main, non-English-speaking country has increased from 17% in 2006 (Australian Institute of Health and Welfare 2018b).

Given the relationship between HDP and future increased risk of CVD, it is important to review the incidence of HDP and the highest-ranking causes of death in women in Australia. In Australia, up to 30,000 pregnant women per year develop HDP, with 10,000 of these attributed to PE, and 15,000-18,000 to GH (Davis, Roberts, Henry, et al. 2016; Duley 2009).

National and international recommendations

It is well established epidemiologically that HDP are associated with an increased risk of CVD in later life. National and international guidelines recognise this increased risk but due to a lack of research in this area regarding postpartum care and early intervention to prevent CVD after HDP, few details are provided on how to best risk stratify or when and how to monitor these women. A recent review of guidelines addressing women with HDP summarised current guidelines and identified gaps regarding health recommendations for follow-up post-HDP (Gamble et al. 2019). Sixteen included guidelines, published between 2010 and 2018, mentioned the follow-up of women with HDP. Only half provided some level of recommendation for follow-up beyond the immediate post-partum period. The future risk of CVD to women post-HDP was recognised in these guidelines and they provided detailed recommendations for the management of these conditions during pregnancy and in the immediate post-partum period. The included guidelines recommended that women and primary care clinicians were made aware of their future health risk and some suggest yearly BP monitoring, at least five-yearly review of renal functions, urinalysis and lipid profile testing concurrent with lifestyle modifications and control of other CVD risk factors. The review states that the included guidelines used a combination of meta-analyses, cohort studies and expert opinions to inform their recommendations. Their conclusion highlights a need for further research around risk reducing strategies for women post-HDP.

As per Magee's (2014) review of the quality of evidence at the time included key international guidelines dating from 2006 until 2012, the recommendations were reportedly based on predominantly low-grade quality of evidence. The recommendation that had the highest quality of evidence supporting it was that women who are overweight need to be encouraged to attain a healthier body mass index to decrease risk in future pregnancies as well as for their long-term health (Magee et al. 2014). Going on this example, one can conclude that the recommendations made at present are not based on the highest possible quality evidence but rather on cohort and case control studies with good to fair evidence to recommend the clinical preventive action (Magee et al. 2014). The Australasian guidelines (Australia and New Zealand) (Lowe et al. 2015), the American (American College of Obstetricians and Gynecologists 2013) and World Health Organization guidelines (World Health Organization 2011) have been deemed very practical, however the evidence supporting these documents is not graded (Magee et al. 2014). The National Institute for Health and Care Excellence Guidelines (The National Institute for Health and Care Excellence 2010) have graded recommendations, however on the topic care beyond 6 weeks postpartum of HDP pregnancy, the recommendation simply advises to refer to community follow-up. This continues to show no specific actions as to how the woman should be followed up.

The ISSHP guidelines (Brown, Magee, et al. 2018) suggest that all women should be reviewed at three months post-partum to ensure that blood pressure, urinalysis, and any other previous abnormalities have normalised. Further investigations and/or appropriate referral is recommended if proteinuria or hypertension persist. Another recommendation made by ISSHP is to encourage post-HDP women to achieve pre-pregnancy weight over 12 months and to limit inter-pregnancy weight gain by adapting to/maintaining a healthy lifestyle. This includes exercise, eating well and aiming for ideal body weight. In addition, an annual medical review is advised life-long (Brown, Magee, et al. 2018).

Further research needs to be conducted to inform practices that reflect on evidence. As it currently stands, extrapolations are also made from other fields of research and are then applied to HDP management. A recent Canadian study testing exercise on well women during pregnancy revealed that increased moderate-to-vigorous physical activity might be beneficial for reflex control of blood pressure during pregnancy (Sobierajski et al. 2018). Recommendations for women who have experienced HDP continue to extrapolate from other populations, such as the aforementioned Canadian study (Sobierajski et al. 2018) to make recommendations.

Health events that occur during pregnancy may present a glimpse into the future and identify potential future risk factors. These risk factors may then provide, in conjunction with further research on effective risk reduction methods, a unique opportunity to plan future screening and preventative health recommendations by primary HCP (Williams 2012). Research suggests that pregnancy outcomes such as HDP may serve as a means to identify women who may require increased medical surveillance and preventive measures for later CVD (Ben-Ami et al. 2010). Despite the evidence of increased risk of CVD in women with a history of HDP, follow-up of these women varies and may be insufficient (Berks et al. 2013; Fleming, Steinberg & Poon 2018; Nijdam et al. 2009). If the risk of PE proves independent of established risk factors for CVD, affected women would be eligible for preventive therapies at an earlier age than usual (Bellamy et al. 2007).

A collaborative paper published by the American Heart Association and the American College of Obstetricians and Gynecologists (Brown, Warner, et al. 2018) addressed the need to improve quality and equitable healthcare gaps for women. In the United States of America (USA), the majority of women consider their primary health care practitioner to be their obstetrician/gynaecologist, so the combination of efforts was seen as opportune. Through a collaborative approach it is hoped that optimal prevention strategies begin many years before clinical CVD is apparent. Whilst a combined effort is a positive move to improve education and prevention, the publication mainly describes general CVD risk factors and general recommendations for CVD prevention in women. Postnatal specific recommendations are limited to the suggestion that this time proves to be opportune to discuss CVD reduction methods. These methods are weight-loss and following a healthy diet as these can have a positive effect on all CVD risk factors and reproductive outcomes. Therefore, the recommendations were not based on any new evidence on actual treatment post-HDP but limited to general risk reduction (Brown, Magee, et al. 2018).

Lowe et al. (2015), from the Society of Obstetric Medicine of Australia and New Zealand (SOMANZ), recommend that there is follow-up beyond the usual 6 weeks postnatal consultation with regards to pregnancy-related changes and also to determine the need for ongoing care. Particular focus is recommended on the investigation and management of renal disease. The guidelines suggest caution and regular consultation in particular for women who have had essential (chronic) hypertension and those whose blood pressure have not normalised by six weeks postpartum. Women who are obese, have pre-existing cardiovascular risk factors or end organ disease may require advice on lifestyle changes and minimisation of risk factors for subsequent pregnancies. Although this finding is included in the general conclusion of numerous research papers, the suggestions are not specific and lack clear instruction for HCPs to follow. This widens the potential of diverse interpretation and hence also application. The research to provide proof of more specific actions is yet to be undertaken (Lowe et al. 2015).

Further reports of post PE/ Haemolysis, elevated liver enzymes, low platelet count (HELLP) syndrome assessment clinics have lent insight into their potential positive influence on early, post-pregnancy lifestyle changes. Janmohamed et al. (2015) conducted a study which evaluated changes in weight and cardiovascular risk factors in participants, after six months of attendance at a hospital-based clinic. Over the study period, 21 women were seen for a minimum of six months of follow-up. The women were attended by a team comprised of a dietician, pharmacist, obstetrician and a nurse practitioner. Within the timeframe, improvement in weight and body mass index was noted, however deemed statistically non-significant. Physical activity improved significantly, from 14% of women participating in physical activity before pregnancy to 76% at a mean of 4.4 months postpartum. This study demonstrated the early benefits of a longitudinal interdisciplinary intervention with counselling about lifestyle modifications in view of CVD risk reduction. A noteworthy aspect of this study is that initially 104 women were scheduled to attend the clinic for their initial consult. Over the duration of the study, 83 women (80%) progressively dropped out by not presenting to their follow-up appointment. This in itself was an interesting observation and the researchers deducted that a reason may have been the lack of information given to women on their CVD risk and importance of attending this follow-up clinic. Other low uptake rationale given was that women may have had a baby in the NICU, competing family demands, scheduling difficulties and the need for in-person attendance to the clinic.

Current Australian initiatives

There are a number of initiatives, programs and organisations in Australia who are working in this important space. The Heart Foundation (The Australian Heart Foundation 2019) is an Australian charity, dedicated to improving heart health of Australians. Their aim is to minimise premature morbidity or mortality due to heart disease. Their goal is to help Australians have access to quality healthcare and ensure risk factors are well managed and CVD is well treated. Their focus is on early detection, recognition of symptoms and improved emergency care and treatment for heart attack and heart failure. An inter-professional initiative in 2018 led by the Heart Foundation and Ministry of Health resulted in the production of an information flyer for women and one for healthcare providers, summarising women’s health risks post-HDP and listing the recommendations for post-HDP care. These remain available for women and healthcare providers to access via the Australian Heart Foundation (The Australian Heart Foundation 2019).

An Australian organisation called “Know her Heart” (2017) is committed to working with women to raise awareness of heart related diseases and aim to decrease Australian deaths from these by 50% by 2025. Supported by a number of respectable organisations, “Know Her Heart” is a health promotion charity and registered not-for-profit organisation that aims to provide women with information on the risks of heart disease. Online awareness campaigns and general publicity tailored to events such as Valentine’s Day are aimed to improve knowledge on general cardiovascular health in women. The organisation is supported by charities such as the Heart Foundation. This platform could provide another avenue to explore in the spread of information in Australia.

Australian Action on Pre-eclampsia (AAPEC) is a voluntary consumer organisation incorporated in Victoria that provides support and information to women and their families who have experienced PE (Australian Action on Preeclampsia 2020). AAPEC aims to educate, inform and advise the public and healthcare providers about the prevalence, nature and risks of PE and eclampsia. They furthermore campaign for greater awareness and action to improve methods of detection and treatment and promote research addressing the disorder. In order to raise awareness, the organisation operates a network of regional support groups as well as information seminars and workshops for the general public and healthcare providers.

In addition to the health messaging and promotion by these organisations, research is being conducted in Australian clinical areas in order to address the gaps identified in the evidence and to establish best practice follow-up recommendations for women post-HDP (Brown et al. 2020; Henry et al. 2020).

Standard postpartum practice for women after HDP

In Australia, most women with a history of mild-moderate HDP who are not on medication at the time of discharge from maternity care are generally referred to their GP for a six-week postnatal check-up (Lowe et al. 2015). The only referral they have is an automated birth and neonatal summary given to the woman by the maternity service to hand on to the GP. These women may not be informed of their increased risk of developing CVD or diabetes in the future. In cases where this information is conveyed verbally on the postnatal ward, women may not remember or acknowledge the importance of the information due the focus being on the birth, care of the baby, the impact of interrupted sleep and other priorities or interferences. Women who have chosen a private obstetrician or independently practising midwife as maternity care provider will be referred back the obstetrician/midwife for the six-week postpartum check (Australian College of Midwives 2021). The transmission of the information is clinician dependent and the obstetrician/GP/midwife may or may not have knowledge of the full extent of the HDP health impact and best-practice regarding post-HDP follow-up.

If women have experienced severe HDP or remain on medications beyond their hospital stay, they often receive a more structured follow-up. This may involve a risk discussion with the women regarding the HDP implications on future health (topics would vary, and they are not standardised), a referral letter to their nominated GP may address management of medication and possibly recommendations relating to mitigation for recurrence at subsequent pregnancy. The content may depend on the medical officer writing the referral, resulting in great diversity of standard postnatal care (Australian College of Midwives 2021; Lowe et al. 2015).

The gap identified

At commencement of this study, there was therefore a large body of epidemiological evidence (as outlined in this chapter) suggesting the importance of PE and GH to women's future health, in particular increased CVD, Type 2 diabetes and renal disease risks. Despite available international (Brown, Magee, et al. 2018) and local (Lowe et al. 2015) guidelines, lack of evidence and of clear guidance on how to provide information to women who have experienced HDP was evident. Initial literature search also suggested an overall lack of awareness, in women and HCP, of the extent of health risk post-HDP, and lack of evidence-based guidance addressing what post-HDP education for women and HCP should look like (Adekanle et al. 2015; Brown, Best, et al. 2013; Heidrich et al. 2013; Hird et al. 2017; Hutchesson et al. 2018; MacDonald et al. 2007; Seely et al. 2013; Skurnik et al. 2016; Traylor et al. 2016; Viana Pinto et al. 2014; Wilkins-Haug et al. 2015; Young, Hacker & Rana 2012). These findings then guided the development of the PhD aims and objectives.

The aims and objectives of this study

Aims

This study aims to (i) identify knowledge and knowledge gaps of women and healthcare providers in Australia with regards to health risks after hypertensive disorders of pregnancy and (ii) to explore their education preferences in order to develop recommendations to best address these findings within the Australian healthcare setting. This includes women who have experienced HDP, general practitioners, obstetricians, midwives and cardiologists. The findings from this study will contribute towards improving immediate and long-term postnatal care and care between pregnancies by improving knowledge and improving access to knowledge for women and their healthcare providers. The impact of knowledge may assist in reducing transgenerational risk of CVD.

Pregnancy is an opportune time for screening of medical and psychosocial conditions that may be accentuated by the changed physiology of pregnancy. These changes may affect women's pregnancies and potentially also their postnatal lives. Knowing about women's history and risk may not only guide the pregnancy healthcare providers to address the pregnancy related risks with the women, but also direct the women towards the most appropriate follow-up pathway in the medium to long-term postnatal time. The study will also aim to explore the type of information women would like access, given their future increased risk of CVD and explore the HCP's preferences for education on the topic. The aims and objectives are summarised below to assist in the understanding of the intended study.

Objectives

There were four objectives. These were:

1. To conduct a scoping review of the literature addressing knowledge gaps of women and healthcare providers with regards to CVD risk after HDP.
2. Using the results from our scoping review on women's and HCP knowledge about long-term health after HDP we aim to co-design and face validate a survey with:
    (i) women who have had a lived experience of HDP
    (ii) healthcare providers
3. To explore current knowledge and identify knowledge gaps on the topic of long-term health after HDP amongst:
    (i) women in Australia (comparing knowledge of women with a lived experience of HDP and women without HDP or other major health concerns)
    (ii) targeted healthcare providers practicing in Australia, including general practitioners, midwives, obstetricians and cardiologists.
4. To elicit preferred educational content, format and access regarding health after

HDP, as a basis for creating tailored information and health advice for:

(i) women who have had a lived experience of HDP
(ii) targeted healthcare providers practicing in Australia, including general practitioners, midwives, obstetricians and cardiologists.

Structure of the thesis

The thesis, a PhD by compilation, includes five first-author publications which are presented in Chapters two to six. There is some repetition between the five chapters, since the publications address a similar background at the beginning of each paper in order to allow the individual manuscripts to stand alone and provide context.

Several methods have been used in this PhD in order to achieve the above objectives. Each paper has a methods section that is appropriate to the objective of each paper and as such, there is no separate methods chapter. Figure 2 outlines the sequential explanatory mixed methods design used in with the corresponding chapters in the thesis.

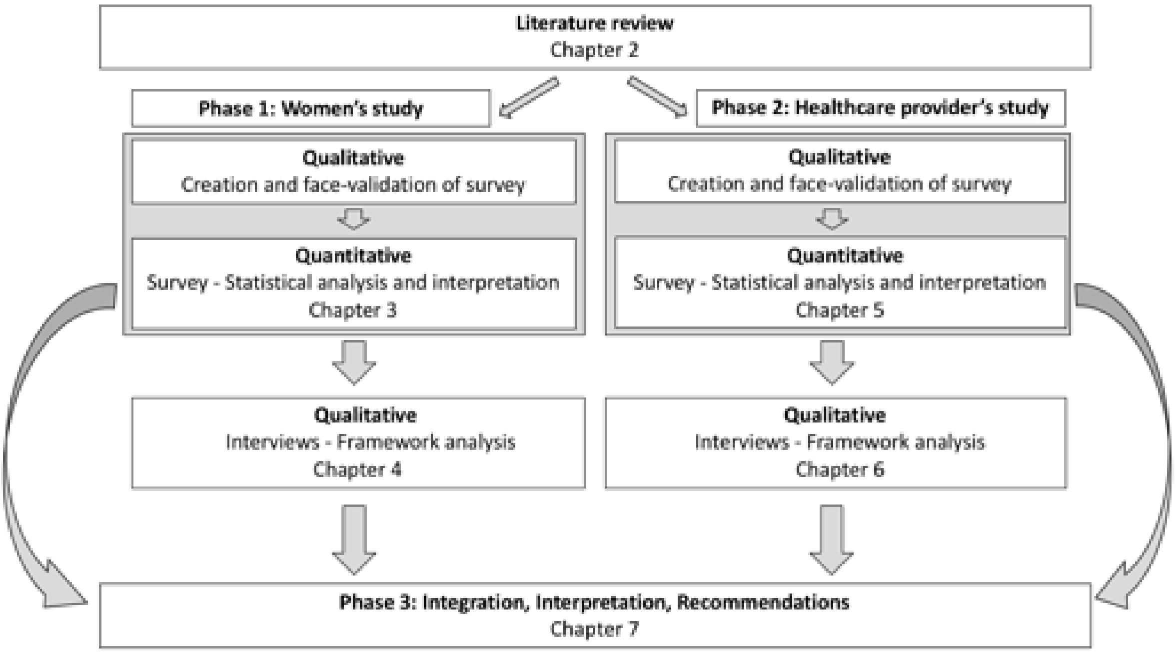

Figure 2: Outline of the sequential explanatory mixed methods research design used in the thesis with corresponding chapters in thesis.

Table 8 summarises the structure of the thesis in relation to the objectives and below, a brief description of the chapters.

Table 8: Thesis structure and publications linked to research objectives

Chapter	Title	Objective
1	Introduction	-
2	Assessing Knowledge Gaps of Women and Healthcare Providers Concerning Cardiovascular Risk After Hypertensive Disorders of Pregnancy - A Scoping Review	1
3	Assessing Australian women's knowledge and knowledge preferences about long-term health after hypertensive disorders of pregnancy: a survey study.	2(i), 3(i), 4(i)
4	Exploring education preferences of Australian women regarding long-term health after hypertensive disorders of pregnancy: a qualitative study	4(i)
5	Assessing knowledge of healthcare providers concerning cardiovascular risk after hypertensive disorders of pregnancy: an Australian national survey	2(ii), 3(ii)
6	Exploring education preferences of Australian healthcare providers regarding long-term health after hypertensive disorders of pregnancy: a qualitative study	4(ii)
7	Discussion, recommendations and conclusions	-

Chapter One has provided a definition of HDP and its pathophysiology, its impact on future health risks and implications on women's health within a greater context of health are explained. The aim and objectives of this study are summarised.

Chapter Two provides insight into the current situation, as well as the enablers and barriers to knowledge acquisition and transmission. This paper is a scoping review which summarised literature which explored what women and healthcare providers know about cardiovascular risks after HDP. It also identified the aspects of care that can were seen as enablers and barriers to knowledge and action on knowledge. This is a published paper.

> Roth H, LeMarquand G, Henry A, Homer CSE. Assessing Knowledge Gaps of Women and Healthcare Providers Concerning Cardiovascular Risk After Hypertensive Disorders of Pregnancy - A Scoping Review. *Frontiers in Cardiovascular Medicine*. 2019;6(178).

Chapter Three reports findings from a national survey which explored Australian women's current knowledge on the topic of long-term CVD health after HDP and elicited women's preferred educational content and format regarding health after HDP. This is a published paper.

> Roth H, Homer CSE, LeMarquand G, Roberts L, Hanley L, Brown M. Henry A. Assessing Australian women's knowledge and knowledge preferences about long-term health after hypertensive disorders of pregnancy: a survey study. *BMJ Open* 2020;10(12):e042920 doi: 10.1136/bmjopen-2020-042920.

Chapter Four reports on findings from post-survey interviews that were conducted with women with a history of HDP. The chapter explored women's preferred content, format and access to education regarding long-term health after HDP. This is a paper that is currently under review with BMC Women's Health.

> Roth H, Henry A, Roberts L, Hanley L, Homer CSE. Exploring education preferences of Australian women regarding long-term health after hypertensive disorders of pregnancy: a qualitative study (under review with *BMC Women's Health* since March 2021; revisions made and submitted 9 June 2021).

Chapter Five reports findings from a national survey which explored Australian healthcare provider's current knowledge and practice regarding long-term cardiovascular health after HDP. This is a published paper.

> Roth H, Homer CSE, Arnott C, Roberts L, Brown M, Henry A. Assessing knowledge of healthcare providers concerning cardiovascular risk after hypertensive disorders of pregnancy: an Australian national survey. *BMC Pregnancy and Childbirth.* 2020;20(1):717.

Chapter Six reports on findings from post-survey interviews, exploring healthcare provider's preferred content, format and access to education regarding long-term health after HDP. Manuscript submitted to Health Professions Education 24 June 2021.

> Roth H, Morcos V, Roberts L, Homer CSE, Henry A. Exploring education preferences of Australian healthcare providers regarding long-term health after hypertensive disorders of pregnancy: a qualitative study (submitted to *Health Professions Education* 24 June 2021).

Chapter Seven integrates and discusses the key findings of the chapters in the context of long-term health after HDP and the greater impact on women's health. With reference to the evidence found as part of the research undertaken as part of this degree, I propose education recommendations for women post-HDP and for HCP that are suitable for general use in the Australian healthcare setting and provide recommendations for future research.

Tables and Figures are included in each chapter, numbered in the order of appearance with numbering recommenced at commencement of each chapter.

Appendices include copies of the Human Research Ethics Committee (HREC), Prince of Wales Research Governance Ethics approval letter, Site Specific Approval for St George Hospital in the SESLHD and Honorary Research Associate approval letters and the University of Technology Sydney Ratification approval letter. The Appendices also include the supplementary materials that were submitted as part of the individual publications. Appendices are numbered continuously throughout the thesis.

Ethical considerations

This project required human research ethical approvals. The central location in which this project is conducted is the South Eastern Sydney Local Health District (SESLHD), therefore the main human research ethical approval was sought from Prince of Wales Research Governance. Site specific Approval was sought for St George Hospital in the SESLHD. A further requirement was for the researcher to obtain University Ethics ratification as the researcher was a Ph.D. candidate, enrolled at UTS and the project was conducted under supervision from supervisors affiliated to UTS.

Ethical approval was provided by the Prince of Wales Research Governance under HREC 18/POWH/326 (Appendix 1). The Site Specific Application (SSA) for St George Hospital in the SESLHD was approved under 18/G/213 (Appendix 2). The ratification for the University of Technology Sydney has also been obtained under ETH18-3061 (Appendix 3).

Doing a PhD through the COVID-19 era

The year 2020 has been a year of many challenges and these have caused some unavoidable delays to the progression of my thesis. The COVID-19 pandemic meant that there was high anxiety in the community and the health sector at the very time I had planned to recruit participants for interviews. It would have been inappropriate at that time to approach women who had recently given birth and hospital staff given all the concerns and COVID-19 related planning underway. I did not want to come across as insensitive towards the targeted group, given the current pandemic required substantial adjustments in health services and people's personal lives. Interviews would have possibly been a further burden and workload which the healthcare providers may not have engaged with. My principal supervisor, Distinguished Professor Caroline Homer and my co-supervisor, Associate Professor Amanda Henry advised me to delay contacting participants at this time.

The process of lock-down, university closures, physical distancing and an inability to meet face to face also created delays. Prior to March 2020, I was working closely with my supervisor Associate Professor Amanda Henry undertaking my statistical analysis and this required attending St George Hospital where she works to sit with her and do the analysis. From the middle of March 2020 this was not possible as Amanda was on the frontline of the health services as an obstetrician at the hospital. I have also pivoted my work to focus on the COVID-19 response and that has been distracting. My primary supervisor, Professor Caroline Homer also pivoted her work to focus on the COVID-19 response. My family at home was also affected by the lockdown and school closures impacted on my children and my ability to focus on my PhD.

I was able to re-commence data collection once the pandemic planning had established but essentially had lost approximately three to four months of time. Invitations to participate in the interviews were eventually sent in April 2020 when it was thought that the timing may be more appropriate. At that point we had a better idea of where Australia stood within the pandemic effect and plans had been put into place within health services. Therefore, the initially unknown impact had somewhat stabilised and I felt that, despite it not being optimal timing, I had to proceed with my data collection.

The invitations featured a preamble to acknowledge COVID19 and its effect on the participant's personal and professional lives so as not to come across as insensitive with such invitation during the pandemic. I was able to recruit some participants (with an initial invitation and a further reminder two weeks later), however had hoped to recruit more in this process. As the participants were voluntarily sourced from a preceding survey it was expected that the response rate to interview invitations was double of the numbers actually recruited.

As a full time PhD candidate and to meet project completion requirements with the necessary research quality and integrity, I requested to be considered for an RTPS extension of 6 months. The extension was granted and greatly assisted me to continue the study as necessary.

Summary of chapter

Chapter One has provided insight into HDP and its long-term impact on future health. The literature on how increased risk is translated into practice is discussed and shows there is scarce evidence around the assessment of knowledge in the key stakeholders such as women who have experienced GH or PE as well as HCP such as general practitioners, cardiologists, obstetricians and midwives. Evidence around consensus on how the high-risk women's future health could optimally be planned is scarce. This may be due to the fact that no significant studies have explored various risk reducing interventions. Once a knowledge gap is identified, targeted education can be developed in consultation with stakeholders and distributed in view of improving health knowledge in women and HCP. The study was outlined and a thesis structure displayed. Chapter Two will present a scoping review which examined what women and HCP know about cardiovascular risks after HDP, discuss aspects of care that can be seen as enablers and barriers to knowledge and action on knowledge as well as identify gaps that this thesis will address.

Chapter 2: Assessing knowledge gaps of women and healthcare providers concerning cardiovascular risk after hypertensive disorders of pregnancy- A scoping review

Context

Chapter Two is the first of the five papers published or prepared for publication within the scope of this thesis. It illustrates the literature review process and findings regarding existing research that addresses the topic of post-HDP health knowledge amongst women and healthcare providers. This published paper relates to objective 1: To conduct a scoping review of the literature addressing knowledge gaps of women and healthcare providers with regards to CVD risk after HDP.

Publication details

This paper was published in Cardiovascular Epidemiology and Prevention which is a section of the journal Frontiers in Cardiovascular Medicine in 2019. The journal publishes peer-reviewed, clinical research papers that are of international interest. The journal specifications required English (US) spelling to be used. The accepted manuscript is reproduced in this chapter with permission under the Creative Commons Attribution Non-Commercial license (CC BY-NC 4.0) (and adapted to match the English [Australian] spelling used within this thesis).

Roth H, LeMarquand G, Henry A, Homer CSE. Assessing Knowledge Gaps of Women and Healthcare Providers Concerning Cardiovascular Risk After Hypertensive Disorders of Pregnancy—A Scoping Review. *Frontiers in Cardiovascular Medicine*. 2019;6(178).

Abstract

Background: A history of a hypertensive disorder of pregnancy (HDP) at least doubles a woman's risk of cardiovascular disease (CVD). The risk increases within 10 years after HDP and continues for life, making long-term health after HDP of major public health importance. Understanding knowledge gaps in health care professionals and women regarding cardiovascular health after HDP is an important component in addressing these risks.

Objectives: The primary aim was to examine what women and healthcare providers (HCP) know about cardiovascular risks after HDP. The secondary aims were to identify enablers and barriers to knowledge and action on knowledge.

Methods: A scoping review was conducted. This was a narrative synthesis, using PRISMA-ScR guidelines, of English-language full text articles that included assessment of knowledge of women, and/or HCPs, on long-term cardiovascular risk after HDP. The databases Embase, Medline, Scopus, ProQuest, Cochrane and PsycInfo were searched from 01 January 2005 – 31 May 2019.

Results: Twelve studies were included, six addressing women's knowledge, five addressing HCP knowledge and one addressing both. The studies included 402 women and 1215 HCPs from seven countries. Regarding women's knowledge, six of seven studies found women had limited or no knowledge about the link between HDP and CVD. Where women were aware of the link, the majority had sourced their own information, rather than obtaining it through their HCP. In five of six studies, HCPs also mostly had limited knowledge about HDP-CVD links. Primary enablers for HCP acquisition of knowledge and counselling were the availability and knowledge of guidelines. Where comparisons between HCP groups were made, obstetricians had greater knowledge than family physicians, internal medical specialists, or midwives.

Conclusion: There was a low level of knowledge amongst HCP and women about increased CVD risk after HDP. Where women had higher levels of knowledge, the information was often obtained informally rather than from HCPs. There were variations in knowledge of HCPs, with obstetricians generally more aware than other professions. Further country and context-specific research on current status of women's and HCP knowledge is therefore necessary when creating educational strategies to address knowledge gaps after HDP.

Introduction

Preeclampsia (PE) is a multi-system disorder unique to human pregnancy characterised by hypertension and involvement of one or more other organ systems and/or the fetus (Lowe et al. 2015). PE is well recognised as a major cause of poor pregnancy outcome. It is one of the top three causes of maternal mortality and severe morbidity in both high and low resource countries, leading directly to over 50,000 maternal deaths globally per year (Ghulmiyyah & Sibai 2012). For babies, up to one in five premature births occur following their mothers having preeclamptic pregnancies (Duley 2009).

In addition to the short-term impacts, long-term adverse maternal health outcomes after PE and other hypertensive disorders of pregnancy (HDP) may be an even greater burden of disease. Cardiovascular disease (CVD), the leading cause of death in women globally (Roth et al. 2018), is 2-2.5 times higher for women who have experienced PE at some stage in their life compared with those who had normotensive (normal blood pressure) pregnancies (Brown, Magee, et al. 2018; McDonald et al. 2008; Theilen et al. 2016). This risk of premature death is present 8-20 years after the affected pregnancy (Egeland et al. 2018; McDonald et al. 2008; Neiger 2017). Gestational Hypertension (GH), new-onset hypertension without any other complications during pregnancy, has little association with adverse pregnancy outcomes (Lowe et al. 2015), however is associated with long-term cardiovascular sequelae (Riise et al. 2018; Theilen et al. 2016). Together with essential hypertension (EH), which indicates pre-existing increased cardiovascular risk, these HDP conditions complicate approximately 10% of pregnancies (Duley 2009).

Peak cardiovascular health organisations, such as the American Heart Foundation, now recommend healthcare providers (HCP) ask women about their HDP history when assessing their cardiovascular health and risk factors. The International Society for the Study of Hypertension in Pregnancy (ISSHP) recommendations (Brown, Magee, et al. 2018) address the postpartum management of HDP and recommend a review at 3 months to ensure screening tests are within normal range or alternatively ensure appropriate referral occurs. ISSHP also recommends informing women of their long-term CVD risk, adoption of a healthy lifestyle with maintenance of an ideal weight and regular aerobic exercise, and regular follow-up with a general practitioner to monitor blood pressure and periodic measurement of fasting lipids and blood sugar.

Despite these recommendations, clinicians may not be aware of the association between HDP and CVD, suggesting that women are not given appropriate information about health after HDP (Brown, Bell, et al. 2013; Hird et al. 2017; Seely et al. 2013; Skurnik et al. 2016; Traylor et al. 2016; Viana Pinto et al. 2014). Several studies conclude that both HCP and women should be provided with information regarding the link between HDP and later CVD (Burgess & Founds 2016; Cain et al. 2016; Leslie & Briggs 2016). Therefore, the primary aim of this paper was to undertake a scoping review to examine what women and HCP know about cardiovascular risks after HDP. Secondary aims were to identify the aspects of care that can be seen as enablers and barriers to knowledge and action on knowledge.

Methods

A scoping review of published literature on knowledge of women and/or HCP about CVD risk after PE or GH was undertaken. Scoping reviews follow a systematic approach to identify main concepts, evidence and knowledge gaps on a specific topic (Tricco et al. 2018). This methodology was appropriate given our interest in the broad topic of knowledge on health after HDP and the likely heterogeneous nature of the body of literature. This scoping review adheres to PRISMA-ScR guidelines (Tricco et al. 2018) (Appendix 4) and the CASP (Critical Appraisal Skills Program (CASP) 2018) qualitative checklist was also used to assess quality in the of included qualitative literature (Appendix 5). Narrative synthesis was applied to analyse the included literature.

We searched multiple Databases including Embase, Medline, Scopus, ProQuest, Cochrane and PsycInfo. The year of publication was limited to 1st January 2005 to 31st May 2019. Key words descriptors, Medical Subject Headings as well as MeSH terms were (but not limited to): “Health Knowledge, Attitudes, Practice”, “Education*”, “Communication Barriers”, “Risk perception”, “Enablers”, “Knowledge”, “Knowledge gap”, “Knowledge sharing”, “Pre?eclampsia”, “gestational hypertension”,

“Hypertension, Pregnancy-Induced”, “future cardiovascular disease”, “long?term cardiovascular risk” (Appendix 6).

Key words were developed and separated into search categories. One was knowledge/education/risk perception, another was PE/GH/HDP and a third was long-term CVD risk. Database searches were accompanied by hand searching reference lists and citations of all included studies to identify any additional, relevant studies.

Papers were included (Table 1) if they were original research addressing knowledge assessments, communication and awareness of long-term increased CVD risk after PE (including HELLP and eclampsia) or GH, full-text, available in English and if published during the selected timeframe. The date limit was applied as most initial cohort studies showing increased risk of CVD after PE were not published until the early 2000s, and the first risk meta-analysis was not published until 2007 (Bellamy et al.). Studies of any methodology (qualitative/quantitative/mixed methods), sample size and type were eligible for inclusion.

Papers were excluded (Table 1) if they were a conference or research abstract only, a review article without novel research, or items (e.g. study protocol or trial registration) that pertained to planned or in-progress research without published results. Where abstracts matched our search criteria and topic but with no details on study method and results and no full-text associated publications were found, authors were contacted for further details. However, this did not yield further inclusions by the cut-off of 31st May 2019.

Research that concerned CH only (without superimposed PE) was excluded, as CH is recognised by HCP as conveying increased CVD risk. Additionally, papers with focus only on the application of lifestyle recommendations to reduce the CVD risk after experiencing a pregnancy with a hypertensive disorder were excluded.

Table 1: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Studies assessing women's knowledge on increased CVD risk after HDP (PE, HELLP and Eclampsia, GH, CH with superimposed PE)	Studies assessing CH in pregnancy only
Full text available with detailed results	Only abstract is available e.g. conference
Qualitative and quantitative studies, all methods, sample type and size	Reviews, trial registrations
Papers available in English language	Papers only available in other language than English
Original research	Papers without novel research
All years of publication	Studies on application of lifestyle modifications to reduce CVD risk

All articles were independently reviewed for inclusion by two reviewers who read the title, abstract and full text. Discussion between the two reviewers resolved discrepancies. After summarising the included papers, the papers were split into two categories: women's knowledge, and HCP's knowledge.

The Critical Appraisal Skills Programme (CASP) (Critical Appraisal Skills Program (CASP) 2018) tool was used to assess quality of the included literature. Although this is a tool designed to assist in systematic review inclusions, this quality appraisal tool was helpful in the systematic approach to enquire and reason about the studies eligible within the boundaries of the inclusion/exclusion criteria. The CASP checklist addresses three areas when appraising literature to be included in a review, these are validity, results and clinical relevance.

Results

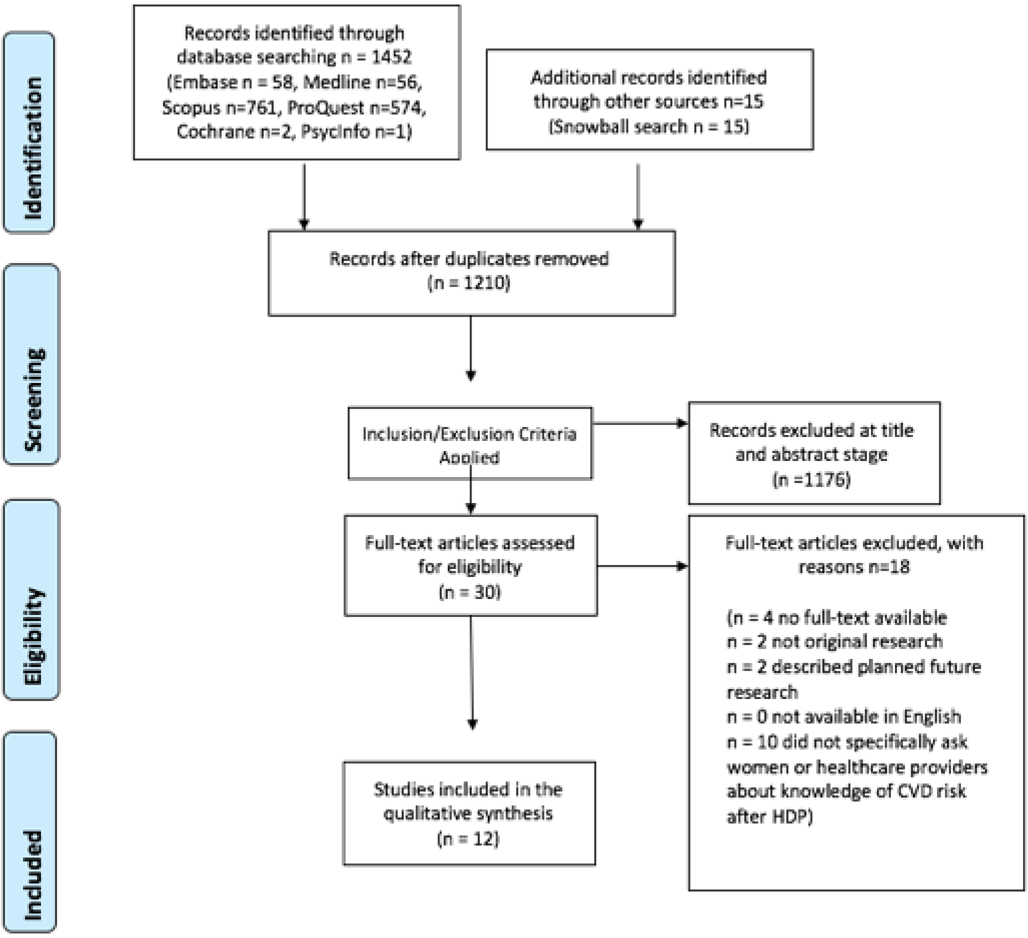

Figure 1: PRISMA Flowchart of screening and selection process

Of 1467 identified articles, 12 studies met inclusion criteria (Figure 1). Appendix 7 summarises the characteristics of the studies included. Out of the 12 studies, six addressed women's knowledge (Brown, Bell, et al. 2013; Hutchesson et al. 2018; Seely et al. 2013; Skurnik et al. 2016; Traylor et al. 2016; Viana Pinto et al. 2014), five addressed HCP knowledge (Adekanle et al. 2015; Heidrich et al. 2013; MacDonald et al. 2007; Wilkins-Haug et al. 2015; Young, Hacker & Rana 2012) and one addressed both women and HCP (Hird et al. 2017). The studies include eight quantitative (surveys, chart reviews) (Adekanle et al. 2015; Heidrich et al. 2013; Hutchesson et al. 2018; MacDonald et al. 2007; Traylor et al. 2016; Viana Pinto et al. 2014; Wilkins-Haug et al. 2015; Young, Hacker & Rana 2012) and four qualitative studies (Brown, Bell, et al. 2013; Hird et al. 2017; Seely et al. 2013; Skurnik et al. 2016) (focus group, group interview, semi-structured interviews). Of the qualitative studies, most were assessed as moderate to high quality on CASP criteria and details are itemised in Appendix 5. In total, the studies collected information from 402 women and 1215 HCP.

Five studies were conducted in the United States of America (USA) (Seely et al. 2013; Skurnik et al. 2016; Traylor et al. 2016; Wilkins-Haug et al. 2015; Young, Hacker & Rana 2012) two from Canada (Hird et al. 2017; MacDonald et al. 2007) one each from Australia (Hutchesson et al. 2018), Germany (Heidrich et al. 2013), Nigeria (Adekanle et al. 2015), Portugal (Viana Pinto et al. 2014) and the United Kingdom (UK) (Brown, Bell, et al. 2013).

The included studies displayed various levels of focus on knowledge assessment of CVD after HDP. Eleven conducted surveys or interviews exploring the women's or HCP's knowledge specifically and more extensively. One study's focus was on exploring general follow-up of women with a history of PE and women's knowledge of CVD risk factors in general but did include a single question regarding women's knowledge on the link between PE and future CVD (Viana Pinto et al. 2014).

Women's knowledge

Seven (including the study addressing both women and HCP) studies addressed women's knowledge (Brown, Bell, et al. 2013; Hird et al. 2017; Hutchesson et al. 2018; Seely et al. 2013; Skurnik et al. 2016; Traylor et al. 2016; Viana Pinto et al. 2014). Three were quantitative (Hutchesson et al. 2018; Traylor et al. 2016; Viana Pinto et al. 2014) and four were qualitative studies (Brown, Bell, et al. 2013; Hird et al. 2017; Seely et al. 2013; Skurnik et al. 2016). Six studies focused on the exploration of women's knowledge (Brown, Bell, et al. 2013; Hird et al. 2017; MacDonald et al. 2007; Seely et al. 2013; Skurnik et al. 2016; Traylor et al. 2016) while one (within a study with a different main focus) included a question about whether counselling of HDP link to CVD had occurred (Viana Pinto et al. 2014).

Six out of the seven studies found that women had limited or no knowledge about the link between HDP and CVD. In the USA, Seely et al. (2013) found that in 20 women after PE, the “majority” were not aware of their HDP CVD risks. In another study in the USA, of 14 women found that 10 out of the 14 women (71%) were unaware of the link between PE and CVD (Skurnik et al. 2016). A survey of 78 women in Portugal found that nearly 70% were not counselled on the link between PE and CVD (Viana Pinto et al. 2014). There was some evidence that women’s knowledge of future CVD risk perception differed according to the type of severity of their HDP. A study of 146 women in the USA (of which 52% were without severe features, 28% PE had severe features such as HELLP and Eclampsia and 20% had CH alone) found that CVD risk awareness was higher in those with severe PE (65%) and CH (75%) than those with PE without severe features (43%) (Seely et al. 2013; Traylor et al. 2016). In Canada, Hird et al. (2017) reported that the five women in their study were either not at all informed or partially informed. When informed this was limited to two out of five women finding out about potential recurrence of PE in a subsequent pregnancy. Four of the five women were not advised to have any follow-up blood tests. Only one out of the five women was advised about her CVD risk. In the UK, Brown et al. (2013) found that five of their 12 participants could not recall the HDP-CVD risk being raised with their HCP. Of those who were counselled of their risk, it was found that especially those women without a family history of CVD did not perceive the risk to apply to them. The one exception was the Australian study by Hutchesson et al. (2018), where close to two thirds of 127 women with a recent history of PE (≤2 years post PE) had higher knowledge about certain aspects of future CVD risk (96% answered ‘true’ for future risk of hypertension and 66% answered ‘true’ for future risk of stroke).

Women’s knowledge in the early postpartum period versus later

There were conflicting findings regarding whether women in the first few years after HDP had higher knowledge about future CVD risk than those 5 years or more post-pregnancy. In Australia, Hutchesson et al. (2018) found 67% of women with recent PE (≤2 years) were aware of future CVD risk. However, in the USA a focus group study of women who had PE less than 5 years ago, the majority of the 20 women did not know of their future CVD risk until they attended the focus groups (Seely et al. 2013). There were similar findings in another focus group study of 14 women (Skurnik et al. 2016) where most (10/14) of women were unaware of the link between PE and future CVD.

Sources of knowledge, enablers and barriers to knowledge acquisition in women

Three of the seven studies explored sources of knowledge acquisition by the women (Hird et al. 2017; Hutchesson et al. 2018; Skurnik et al. 2016). These showed that women in general wanted information on their HDP and to understand more about its link to future CVD. For example, in Brown et al. (2013) all 12 women interviewed with a history of PE wanted to receive more information on PE and future implications on health. Enablers and barriers to women's knowledge acquisition were also addressed by most of the studies.

Of the seven studies that enquired about women's perceptions of being given information, major themes were that women did not receive information, or felt they received insufficient information, from their HCP about risks after HDP. For those who were aware of long-term risks prior to being surveyed or interviewed, this knowledge had often been self-acquired. Hutchesson et al. (2018) undertook a cross-sectional survey with women who had a recent PE diagnosis to examine their knowledge about whether they were at greater risk of developing a list of health complications. The participants (n=127) displayed high awareness about being at greater risk of developing hypertension later in life (98%) and being more susceptible to stroke and CVD (67%). However, 60% of the 'aware' participants reported that they gained knowledge by doing their own research, while only 25% heard about their long-term risk from their obstetrician, about 13% from their general practitioner and 6% from their midwife. Despite most participants (about 95%) having had their blood pressure measured, a lower proportion reported serum cholesterol and/or glucose screening (about 41%), and fewer had received advice on various lifestyle risk factors (ranging from 2% for smoking and about 30% for weight management, exercise and healthy eating).

The one study addressing both women's and HCP's knowledge assessed how relationships between risk, pregnancy, and women's health are understood and acted upon. Five women were interviewed, and they reported being either minimally or not informed around diagnosis about long-term CVD risk after PE. Recurrence of PE in a subsequent pregnancy was addressed with two of the five interviewees. Only one was tested and counselled at six weeks postpartum. Women were unsure whether their pregnancy history was transmitted to their family physician. Women did not always trust the skills and knowledge base as well as the decisions made by their care givers. Finally, participants had made extensive efforts to source information relating to their condition from places like the internet, online discussion boards, magazines and even television series (Hird et al. 2017).

One of the qualitative studies in the UK showed that women with a family history of CVD disease had greater awareness of future CVD risk (Brown, Bell, et al. 2013). Of the 12 women interviewed, seven had family history of CVD (Brown, Bell, et al. 2013). Women without traditional risk factors found it hard to envisage themselves as being at risk and did not see the relevance of such information. The authors noted timing of discussions as an important element to consider when communicating about postpartum risk, taking into account situational factors of new motherhood, and when women are ready to consider their own health as well as their baby's, to engage successfully with this group of women. (Brown, Bell, et al. 2013). A study conducted in Portugal of 78 women with either history of PE or CH and superimposed PE showed that addressing of risk after PE by HCP predominantly did not happen (54 no versus 24 yes) (Viana Pinto et al. 2014).

Healthcare provider's knowledge

The studies about health providers' knowledge varied in the screening questions and detail of knowledge inquiry. Six studies addressed HCP's knowledge (including the study which addressed both groups) (Adekanle et al. 2015; Heidrich et al. 2013; Hird et al. 2017; MacDonald et al. 2007; Wilkins-Haug et al. 2015; Young, Hacker & Rana 2012). The studies assessed knowledge with varying depth, therefore the results display different aspects of knowledge.

A Canadian study with 554 participants (obstetrician/gynaecologist, midwives and family physicians (MacDonald et al. 2007) showed that almost two-thirds (64%) knew that women with a history of GH had a higher risk of developing hypertension in the future. About one-half of the clinicians were aware that women with a history of PE were at higher risk than nulliparous women to develop hypertension in the future. The study did not compare knowledge between the different HCP groups.

In one of the USA studies (Young, Hacker & Rana 2012), participants were asked about their typical counselling for CVD risk reduction. This showed that of 161 participants (118 internists/internal medicine physicians, 53 obstetricians) 95% of internists and 70% of obstetricians reported providing general CVD risk reduction counselling. When asked about knowledge of future cardiovascular risks in women with PE, the majority in both groups were incorrect or unsure about the risk of several future comorbidities associated with a history of PE. With the exception of risk of future hypertension, where only 6% internists and 17% of obstetricians answered incorrectly, the comorbidities that were surveyed yielded a significant knowledge gap. The other risks surveyed were future risk of ischemic heart disease (56% internists and 23% obstetricians answered incorrect/unsure), stroke (48% internists and 38% obstetricians answered incorrect/unsure) and a shorter life expectancy which displayed the highest percentage of incorrect/unsure answers (79% internists and 77% obstetricians). Only 5% of internists and 42% of obstetricians asked about PE as part of taking a woman's medical history. Of the doctors asking about a PE history, only a small group (9% of internists and 38% of obstetricians) provided counselling to women at risk. The findings suggested that clinicians are not aware of the association between adverse pregnancy outcomes such HDP and CVD (Young, Hacker & Rana 2012).

Wilkins-Haug (2015) undertook an anonymous survey in the USA. The survey was case-based, had 124 participants and explored obstetrician/gynaecologist versus internists' recognition of long-term CVD risk after PE. One aspect of the survey was to assess the participants' understanding of how pregnancy history may influence long-term cardio- vascular risk, where information was collected through a combination of direct query, multiple choice responses, case-based questions, and branch logic. The second aspect assessed their general knowledge of CVD risk. Overall, about 28% and 15% of internists and obstetricians respectively, indicated they would not obtain a pregnancy history when specifically assessing a patient's history for cardiovascular risk. When history of PE was obtained, internists were more likely to order fasting glucose test than gynaecologists (48% versus 21%).

In Germany, a survey about knowledge of the association between PE and long-term risks of CVD was distributed to a random sample of 500 obstetrician-gynaecologists with 121 participating. Overall, the doctors with better knowledge of existing guidelines had better understanding of risks and were more likely to offer counselling to women with a history of PE. More specifically, 87% of doctors knew of the association between PE and future hypertension, whilst 79% knew about the association with stroke risk. Although the majority of the respondents were aware of the increased CVD risk post PE, the awareness of existing guidelines on long-term follow-up care and counselling of affected women remained deficient. Only 45% of participants were aware of these guidelines, however knowledge was higher amongst these participants (Heidrich et al. 2013).

The only study in a low to middle income country (LMIC) was undertaken by Adekanle et al. (2015) in south western Nigeria. A survey was distributed to 146 healthcare professionals as part of a workshop at a teaching hospital. The majority (87%) were knowledgeable about future hypertension risk after PE and about ischemic heart disease (63%), stroke (69%) and kidney disease risk (73%). Forty-six percent counselled on CVD risk after hypertensive disorder. The doctors had better knowledge (78% overall) than both nurses (58%) and community healthcare workers (54%). However, the majority (64 %) were not aware that a shorter life expectancy is linked with PE, while only 38 (26%) asked about PE on routine visits and 46% counselled on cardiovascular risk.

Enablers and barriers to knowledge acquisition for healthcare providers

A Canadian study (MacDonald et al. 2007) identified weaknesses in knowledge base and communication amongst the maternity care providers and community health care (family physicians). There was a significant discrepancy when addressing the communication between the hospital to community handover after HDP. Of the participating maternity care providers, 83% stated that they informed the family physician with regards to the woman’s history after HDP. However, only 58% of the participating family physicians stated that they received HDP information about the women transitioning back into the community. Furthermore only 12% of family physicians stated that they were made aware that women post-HDP are at increased risk of CVD, despite 41% of maternity HCP claiming that this happened. This study suggests that effective identification and follow-up of women with HDP is not occurring.

A follow-up Canadian study assessed whether HCP shared information with women about their increased CVD risk (Hird et al. 2017). In this study of 8 healthcare practitioners, three of the eight did not inform women of increased risk more than 50% of the time. Interviews were undertaken to explore participants' perceptions of and attitudes towards the relationship between PE and CVD risk. Structural, practical, and ideological barriers were shown to impede knowledge sharing between HCP and women about the relationship between PE and CVD risk (Hird et al. 2017). Patient electronic records were not consistently available to all HCP, hence the community HCP are reliant on written records transferred to them. One obstetrician in Hird et al.'s study (Hird et al. 2017) relied on assumed knowledge of midwives and family physicians to link PE to long-term CVD risk. HCP reported filtering what they said and when about a certain situation. Some were cautious about the timing (e.g. in high stress situation) and others felt that if the women did not ask they would probably not want to know and hence the HCP would not address the topic.

Three of the six studies mentioned guidelines (Adekanle et al. 2015; Heidrich et al. 2013; Hird et al. 2017). In Adekanle et al. (2015) it is unclear which guideline participants are asked about. Their discussion refers to a national guideline, however declares that PE guidelines are institution based. Only 16% of participants were aware of a guideline, the authors suggest this number may reflect the medical practitioners as there was a smaller number of them. Heidrich et al. (2013) asked about awareness of current national guidelines which comment on follow-up of PE and future CVD risk management. Overall only 45% knew about these guidelines with significantly more knowledge in the group with guideline awareness. The group with guideline knowledge counselled women more frequently about long-term risks, more frequently assessed blood pressure, had better knowledge of the link between HDP and CVD and screened for family history of PE more frequently. The third study (Hird et al. 2017) found that the absence of clinical practice guidelines had a possible effect on the postpartum management of PE and CVD risks. The current guidelines' focus was more on the diagnosis and the intrapartum management of HDP.

Discussion

This scoping review found that, in most studies, women's and HCP's knowledge about the increased risk of CVD after HPD was low. The different studies explored differing aspects of knowledge. Some studies included one question about knowledge of the association of HDP and CVD, whereas other studies used further questions to differentiate amongst the various aspects of knowledge on this topic. Three studies used the term 'risk perception' which showed a distinction between basic factual knowledge versus how a woman at risk may perceive her own risk as true or not true. Issues with communication between different HCP (between hospital and community) as well as between HCP and women was identified, particularly when asking about pregnancy history when CVD risk assessing, transferring pregnancy history and risk factors to community HCP, and counselling women on the long-term CVD risk. Due to the diversity in explored aspects of knowledge within the included studies it is difficult to compare and contrast the studies themselves. A common ground however is found in their discussion of enablers and barriers to the acquisition of knowledge.

Women

Enablers to acquisition of and action on knowledge

There were a number of enabling features for knowledge acquisition. The internet and access to a variety of information via online communities and networks appeared to be an enabler for women. Where women displayed reasonably high aspects of knowledge, it was found that they had sourced this information by conducting their own research (Hird et al. 2017; Hutchesson et al. 2018). Women felt it was beneficial to receive information on how this risk could be reduced (Brown, Bell, et al. 2013).

Clarification on the extent to which a history of PE and GH are an independent factor for future CVD are considered helpful in the provision of effective communication (Brown, Bell, et al. 2013). Interestingly, risk perception of HDP recurrence and future CVD due to HDP was higher in women who had a family history of CVD and/or PE with severe features (Brown, Bell, et al. 2013; Traylor et al. 2016), further indicating that many other HDP affected women do not identify with the increased risk. They may not be aware that they could be affected in the future and are less likely to seek information as a result. Poor self-reporting of a PE and GH history may also accentuate the issue (Brown, Warner, et al. 2018; Carter et al. 2015; Coolman et al. 2010; Stuart et al. 2013).

Some women felt that having access to other women who have had a similar pregnancy experience with HDP may have been a supportive move towards risk reducing lifestyle changes. Access to community of women who have experienced HDP or similar support groups may be helpful in feeling less isolated, more informed and supported (Brown, Bell, et al. 2013; Seely et al. 2013; Skurnik et al. 2016). The thought of being able to support other women in similar situations was a motivator. The suggestion to have privacy maintained in this online community and a moderator who could validate medical information exchanged as well as keep the community's communication positive. In other areas of women's healthcare, including breastfeeding and polycystic ovarian syndrome, online community groups have been effective (Bridges, Howell & Schmied 2018; Holbrey & Coulson 2013) for women's emotional support and empowerment, so could be explored further for post-HDP women.
Online tracking of weight and blood pressure was deemed to be helpful in the application of knowledge with regards to lifestyle changes. Having support from family members when implementing lifestyle changes was deemed important and their family also benefiting from the healthy changes was a further motivator (Skurnik et al. 2016). Women felt that a reminder by their HCP to follow-up after HDP was needed to bring the mother's health back into mind after having given birth and transitioning to parenthood (Brown, Bell, et al. 2013).

Barriers to acquisition of and action on knowledge

A lack of knowledge from their HCP on the link between HDP and CVD was a barrier to women, as well as their poor insight into or lack of action towards risk reducing lifestyle changes. The lack of knowledge about the link is also a barrier for women to then act on possible modifiable CVD risks or to simply gain insight into and understanding of the HDP they experienced. Barriers to action for women were predominantly related to family and caregiving responsibilities, lack of knowledge, lack of appropriate and timely follow-up, remembering what type of follow-up and monitoring they needed, as well as poor recovery postpartum (Brown, Bell, et al. 2013; Seely et al. 2013). The amount and type of information given at any particular healthcare encounter was considered to be a barrier (Hird et al. 2017).

From the HCP perspective, HCPs felt some information needed to be repeated over multiple visits to be truly understood, and that limited consultation time required them to prioritise the type of information shared with women. Some only responded to questions raised by the women and withheld other information. In turn, women were not confident they are being given all the information they need postpartum to manage their risk (Hird et al. 2017). Transition from hospital-based obstetric care to primary community-based care was also a barrier for women (and a system level barrier) as was lack of health insurance (in the USA) (Seely et al. 2013).

Healthcare providers

Where comparisons between HCP groups were made, obstetricians had a higher level of knowledge than family physicians, internal medical specialists, midwives or community health workers (Adekanle et al. 2015; MacDonald et al. 2007; Young, Hacker & Rana 2012). Knowledge and application into practice was demonstrated when guidelines were available, and their existence was known (Heidrich et al. 2013).

There was only one study conducted in a LMIC (Adekanle et al. 2015). In this setting (Nigeria), knowledge was higher amongst doctors compared with "lower cadre" health workers (examples cited in the included paper include associate nurses, community health workers). Although different contextually, this statement could be applicable to high income countries where community-based HCP (such as general practitioners/family physicians/community nurses) are close to the community.

Enablers to acquisition of and action on knowledge

Implementation and knowledge of guidelines may provide an enabling environment for better knowledge and application of this knowledge (Heidrich et al. 2013; Young, Hacker & Rana 2012). An example of positive influence of the implementation of guidelines can be found in the Netherlands (Van Kesteren et al. 2015), where an increase in counselling following PE occurred. This is likely to reflect an increase in education of gynaecologists over time regarding cardiovascular risk, resulting in confidence addressing these concerns with the women in their care.

The type of specialty training in the HCP domain was a further enabler. When knowledge amongst professions was compared, obstetricians were more knowledgeable than family physicians and midwives for example (Adekanle et al. 2015; Wilkins-Haug et al. 2015; Young, Hacker & Rana 2012). This may be linked to the training, scope of practice as well as exposure to women with HDP that this medical specialty has. More generally, although potentially linked to specialty training, Wilkins-Haug et al. (2015) found that when there was better overall knowledge of CVD risk factors and screening knowledge, this was associated with greater knowledge of association of PE with later life CVD.

Barriers to acquisition of and action on knowledge

Poor communication between hospital and community HCP was mentioned in almost all HCP papers (Adekanle et al. 2015; MacDonald et al. 2007; Seely et al. 2013; Young, Hacker & Rana 2012). In areas where knowledge was high that this did not translate into action-taking on the reduction of long-term risk factors (Adekanle et al. 2015). There were also a number of examples of withholding or not sharing information from women during CVD counselling or post-HDP counselling (2007; 2012). Even when providers know about the association of PE with later CVD they did not apply this knowledge when counselling women. Further information on what a history of HDP means in terms of increased future risk and follow-up needed was perceived as not frequently shared by maternity specialists (MacDonald et al. 2007). Here too the gap between the information sharing by maternity HCP and information reception by community HCP was significant, (MacDonald et al. 2007) with participants' answers possibly reflecting the intention of communication rather than what actually occurs in daily practice.

Studies comparing latest clinical guidelines in different countries highlight the variations in clinical recommendations (most likely due to lack of high-level evidence base for what is effective post-HDP follow-up) and lack of cost effective follow-up. Some authors suggested further studies take place in order to inform practice guidelines and optimise prevention strategies (Schmidt, Christensen & Knudsen 2017). These include adjustment of general CVD guidelines to include taking a pregnancy history (Groenhof et al. 2017; Hauspurg et al. 2018; Zoet et al. 2015) and associating HDP with the increased risk of developing CVD.

A large amount of research exploring various aspects of women's increased CVD risk with a history of HDP have suggested that education as well as addressing modifiable risk factors could be targeted for improving the short- and long-term sequelae for women (Burgess & Founds 2016; Egeland et al. 2018). The literature shows that poor pregnancy history taking is common. Recent population research has found women are less likely than men to have their cardiovascular (CVD) risks (not including PE history) fully assessed, and less often have risks appropriately managed when they are assessed (Hyun et al. 2017). The gap may occur due to a number of potential barriers. Firstly, at individual and social levels, physicians may not be aware or familiar with existing guidelines on best practice in this matter. Secondly, physicians and women may have the old misconception of CVD being a man's disease. Furthermore, the misconception of senior physicians may have been passed on to the younger generation of physicians. In addition to financial, time and resource constraints, it is likely that women have been disadvantaged in receiving appropriate CVD risk factor assessment. When assessments do happen, women also are less likely than men to have their risks managed appropriately. Therefore, an increased rate of assessment and management of CVD risks are needed are needed in women generally, over and above specific management after HDP (Hyun et al. 2017).

Considering pregnancy history when assessing a woman's CVD risk may assist in targeted efforts to initiate risk-reduction strategies in women with a history of pregnancy complications and improve communication between women and HCP as well as communication between maternity (Hauspurg et al. 2018; Rich-Edwards et al. 2010) and minimise the need for women having to rely mainly on exploring resources online to educate themselves (Hutchesson et al. 2018).

Implications for practice

Overall, there appears to be a knowledge gap in women and HCP on the association of HDP and risk of CVD. This gap could be narrowed and the information about this topic needs to be distributed in a suitable, accessible and targeted way.

The study that reflected reasonably high knowledge levels and counselling of women reasoned that the participants were aware of the existence of guidelines on the topic and showed application of these in practice (Heidrich et al. 2013). Guidelines are available (Brown, Magee, et al. 2018) however their existence alone may prove to be insufficient. A potential education campaign of guideline awareness is one of the solutions, to encourage implementation of guidelines into practice.

Knowledge of HDP link to future CVD in both the HCP and women would be optimal in order to make progressive adjustments to potentially reduce the risk of future disease. Studies conducting research on lifestyle adjustments for women with a history of HDP have already been published in some countries. This shows attempts to reduce risk by applying the knowledge HCP and women have.

A specific follow-up clinic may be an effective method of prevention of future risk for women (Cusimano et al. 2014; Janmohamed et al. 2015) as knowledge alone about risk may not translate into motivation or changes to lifestyle in order to reduce risk (Bokslag et al. 2018). There are early benefits of counselling about lifestyle modifications in order to prevent CVD in women with recent PE. Channelling women into appropriate health centres once pregnancy care is completed may be an enabling approach (Cusimano et al. 2014; Janmohamed et al. 2015). Careful pregnancy screening and appropriate escalation to the right HCP, women’s risk profile can be identified and addressed. Appropriate referral offers opportunity to determine effective treatments that can prevent the progression of HDP and in turn reduce future CVD (Cusimano et al. 2014).

The gap identified in the Literature

This review has identified some gaps in the literature. The lack of evidence and hence of clear guidance on how to provide information to women who have experienced HDP identifies one of these gaps. More specific aspects of knowledge on the topic need to be assessed in women and HCP such as more specific knowledge of individual risk factors. Furthermore, higher numbers of women and HCP in a variety of countries and healthcare settings could be assessed and contribute to a more in-depth insight into knowledge levels and also on possible targeted knowledge enhancing strategies. Despite having gained insight into some of the enablers to knowledge acquisition and application, little evidence has been collected addressing what form education should take.

Strengths and limitations

Strengths of the review include the comprehensive search strategy and scoping review by two independent reviewers according to PRISMA-ScR criteria. It provides an up-to-date evidence-base of the literature on the topic of women's and HCP's knowledge of cardiovascular health after hypertensive pregnancy. Our scoping review looked at both perspectives (women and HCP) and contextualised these findings amongst a larger context of CVD screening and prevention, enablers and barriers as well as from a primary health perspective.

The included literature is limited to English language. The methods of the research we included are diverse and different aspects of knowledge were examined amongst different HCP. Women's medical conditions examined also slightly varied from one paper to another. Having included international literature, cultural health context with access to healthcare are different, this makes the findings more difficult to compare and contextualise. Knowledge is contextual, and knowledge of risk factors and risk reducing behaviour does not imply action on this knowledge. This aspect is hard to measure and by participation alone, this may already show a sign of bias to being receptive to knowledge and possibly motivated to make lifestyle changes. When planning knowledge transmission and action on health after HDP, it is important to consider the local context. This applies to the country's available health services, workforce and scope of follow-up care postpartum. Despite the different settings of the included studies, there were several common themes around knowledge gaps, barriers and enablers of acquisition of knowledge that were found in this review, including low knowledge among women and HCP of CVD after HDP, lack of communication of knowledge by HCP with higher knowledge (usually obstetricians) to HCP colleagues and women, and women's use of informal sources to gain knowledge. This suggests some generalisability regardless of context.

Conclusion

In general, there is a lack of knowledge amongst HCP and women regarding CVD risks after HDP. Where women had higher levels of knowledge, the information was often obtained informally rather than from HCP. Obstetricians were generally more aware than other professions of the HDP-CVD link, however did not necessarily communicate this knowledge to either women or other HCPs. Awareness of risk factors may provide, in conjunction with further research on effective risk reduction methods, a unique opportunity to plan future screening and preventative health recommendations by primary HCP, which currently appears to be insufficient in women with a history of HDP. Further country and context-specific research on current status of women's and HCP's knowledge is therefore necessary when creating educational strategies to address knowledge gaps after HDP.

Chapter 3: Assessing Australian women's knowledge and knowledge preferences about long-term health after hypertensive disorders of pregnancy: a survey study

Context

Chapter Two illustrated the literature review process conducted at the commencement of the study and informed aspects of the methodological processes for this thesis as well as to the broader discussion. Chapter Three reports on findings from a nationally distributed survey which (a) explored Australian women's current knowledge on the topic of long-term CVD health after HDP (b) elicited women's preferred educational content and format regarding health after HDP.

This published paper relates to the following overall objectives:
2(i) Using the results from our scoping review on women's and HCP knowledge about long-term health after HDP we aim to co-design and face validate a survey with women who have had a lived experience of HDP.
3(i) To explore current knowledge and identify knowledge gaps on the topic of long-term health after HDP amongst women in Australia (comparing knowledge of women with a lived experience of HDP and women without HDP or other major health concerns).
4(i) To elicit preferred educational content, format and access regarding health after HDP, as a basis for creating tailored information and health advice for women who have had a lived experience of HDP.

Publication details

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Roth H, Homer CSE, LeMarquand G, Roberts L, Hanley L, Brown M. Henry A. Assessing Australian women's knowledge and knowledge preferences about long-term health after hypertensive disorders of pregnancy: a survey study. BMJ Open 2020;10(12):e042920 doi: 10.1136/bmjopen-2020-042920

Abstract

Objective(s): To (a) assess women's current knowledge regarding long-term cardiovascular health after hypertensive disorders of pregnancy (b) elicit women's preferred educational content and format regarding health after hypertensive disorders of pregnancy.

Design and setting: A custom-created online survey exploring Australian women's knowledge about long-term health after hypertensive disorders of pregnancy, distributed through consumer groups and social media.

Participants: 266 women with (n=174) or without (n=92) a history of hypertensive disorders of pregnancy.

Primary and secondary outcome measures: 1) Proportion of women identifying long-term health risks after hypertensive disorder of pregnancy using a 10-point risk knowledge score with 0-4 'low', 4.1-7.0 'moderate' and 7.1-10 'high'. 2) Exploration of preferred content, format and distribution of educational material post hypertensive disorder of pregnancy.

Results: Knowledge scores about health after hypertensive disorder of pregnancy were moderate in groups with and without a history of the disorder. Knowledge was highest regarding risk of recurrent hypertensive disorders in a subsequent pregnancy, 'moderate' for chronic hypertension and heart attack, 'moderate' and 'low' regarding risk of heart disease and 'low' for diabetes and renal disease. Only 36% of all participants were aware that risks start within 10 years after the affected pregnancy. The majority of respondents with a history of HDP (76%) preferred receiving information about long-term health 0-6 months postpartum from a healthcare provider (80%), key organisations (60%), social media (47%) and brochures/flyers (43%).

Conclusion(s): Women's knowledge regarding health risks after hypertensive disorder of pregnancy was 'moderate', although with important disease-specific gaps such as increased risk of diabetes. Most women wanted to be informed about their long-term health from a healthcare provider.

Strengths and limitations of this study

- Consumer co-created survey exploring health knowledge after hypertensive pregnancy.
- For the first time survey results include findings from women with a history of gestational hypertension as well as from women without a history of hypertensive disorder of pregnancy.
- Recruitment from groups with potentially greater baseline knowledge may bias results, although substantive knowledge gaps still found.
- Although surveys were available in English, Arabic and Mandarin, there remains potential sub-optimal coverage of culturally and linguistically diverse groups.

Introduction

Hypertensive disorders of pregnancy (HDP) include chronic hypertension (CH), preeclampsia (PE) and gestational hypertension (GH) and complicate 5-10% of pregnancies (Duley 2009). PE is a multi-system disorder characterised by new-onset hypertension after 20 weeks' gestation and involvement of one or more other organ systems and/or the fetus (Brown, Magee, et al. 2018; Lowe et al. 2015). GH is new-onset hypertension after 20 weeks' gestation without any other complications. Apart from GH itself being considered an adverse pregnancy outcome and it carrying an increased risk of progression to PE (Brown, Magee, et al. 2018; Lowe et al. 2015) is not associated with adverse pregnancy outcomes. However, both conditions are associated with long-term cardiovascular and other chronic disease sequelae (Riise et al. 2018; Theilen et al. 2016). CH is defined as hypertension that is confirmed before pregnancy or before 20 completed weeks gestation, which may worsen during pregnancy and/or on which preeclampsia may be superimposed (Brown, Magee, et al. 2018). Globally, cardiovascular disease (CVD) is one of the leading causes of death in women (Roth et al. 2018), and for women who have experienced an HDP, it is 2-3 times higher compared with those who did not (Brown, Best, et al. 2013; McDonald et al. 2008; Theilen et al. 2016). This risk of premature death is present within 10 years after the affected pregnancy (Arnott et al. 2020; Egeland et al. 2018; McDonald et al. 2008) and remains after adjusting for the presence of other cardiovascular risk factors.

There is also an increasing body of recent research linking PE and GH with other major chronic diseases including chronic kidney disease, end-stage kidney disease, and Type 2 diabetes mellitus (Barrett et al. 2020; Khashan et al. 2019; Pace et al. 2017; Timpka et al. 2018).

Both Australian and international societies, including the Society of Obstetric Medicine of Australia and New Zealand (SOMANZ) and the International Society for the Study of Hypertension in Pregnancy (ISSHP), recommend that women and healthcare providers (HCP) are provided with information about HDP and later CVD (Brown, Magee, et al. 2018; Lowe et al. 2015). This includes recommending that women have a clinical review several months postpartum, and regular general practitioner (GP) follow-up to monitor blood pressure, fasting lipids and blood sugar (Brown, Magee, et al. 2018). Adopting a healthy lifestyle with maintenance of an ideal weight and regular aerobic exercise is emphasised (Brown, Magee, et al. 2018; Lowe et al. 2015). The aims of this study were to (a) explore Australian women's current knowledge on the topic of long-term CVD health after any HDP, not just PE and (b) elicit women's preferred educational content and format regarding health after HDP, as a basis for creating tailored information and health advice for women after HDP.

Method

A national survey of women with and without a history of HDP was conducted, using a custom-created, face-validated online survey. Ethical approval was provided by the relevant Human Research Ethics Committee (HREC 18/POWH/326, REGIS 2019/PID05668).

Patient and Public Involvement

As a validated instrument to assess women's knowledge was unavailable, a survey was custom designed. Initially, women with a history of HDP, comprising nine volunteers from the *Postpartum physiology, psychology and paediatric follow up study (P4 Study)* (Davis, Roberts, Mangos, et al. 2016) and Australian Action on Preeclampsia (AAPEC), were invited to take part in group interviews which addressed the possible content and design of the survey, tested the survey for face validity and provided feedback for improvement. The topics discussed during the interviews were sourced from findings from a scoping literature review (Roth et al. 2019) and further complemented by questions specifically exploring the Australian context for women experiencing HDP. Nine women participated in the face-validation process and commented on content, language, flow, survey structure including length, whether the introduction and the risk profile proposed for the end of the survey were informative as well as using appropriate language. Following feedback and integration of suggestions from the women, the survey was modified until consensus over a final version was achieved among study investigators, including the consumer representative (LH). The survey was made available in English, Arabic and Mandarin.

Data collection

The final survey was targeted at women in Australia, 18 years and older with a history of pregnancy in the last 3 years. Women who were currently pregnant were requested to only complete the survey if they had no major issues in their current pregnancy. Women not currently pregnant with pregnancy in the preceding three years were eligible either if they had experienced HDP (CH, GH or PE) or a pregnancy without any serious complications. The online survey, using SurveyMonkey^{TM}, was open from July to August 2019. Survey distribution occurred through the P4 study participants, organisations such as AAPEC, maternity consumer groups as well as via the project's consumer representative and social media (Facebook and Twitter) including multicultural networks in order to reach Arabic and Mandarin speaking communities. A targeted convenience sample was selected. Prior to acknowledging their voluntary participation at the commencement of the survey, women were presented with an introductory letter outlining the details of the study (Appendix 8). Commencement of the survey was then taken as consent to participate.

The data collection instrument

The survey for women (Appendix 8) explored demographic details, assessed obstetric history, history of HDP and other medical history including family history. The survey was tailored to women's self-reported HDP history (GH, PE, CH with or without worsening in pregnancy or superimposed PE, no hypertension history), with women given definitions of HDP conditions early in the survey to aid their self-report. Questions focused on knowledge of risk after pregnancy, provision of care and education following birth and what information and education women would like to receive. Women with a history of GH, PE or CH were asked to classify their perceived risk (based on their own lived HDP sub-type) of experiencing various long-term health outcomes as greater, less than or equal to that of a woman with a normotensive pregnancy. Women who experienced a normotensive pregnancy were also asked to classify whether they believed women who had had HDP were at greater, lesser, or equal risk. The survey included two 'distractor' conditions not known to have an increased risk after HDP (breast cancer and seizures) to elicit negative answers and ascertain whether women could identify what they were not at increased risk of after HDP as well as what they were at risk of. At survey completion, women were provided with a correct risk profile summary and a link to further information.

Data analysis

Quantitative survey analysis was undertaken using SPSS Version 25 (SPSS Statistics for Windows, Armonk, NY). Demographic data and responses to individual questions were analysed descriptively. To examine difference in knowledge levels amongst the targeted subgroups, (GH, PE, CH in pregnancy, no hypertension history) responses regarding HDP and future health risks were compared using Chi-squared testing or likelihood ratio for categorical data (as appropriate to subgroup sample size) and one-way ANOVA testing for continuous data. A *p* value of <0.05 was considered statistically significant.

A knowledge score was created for the risk matrix whereby one (1) point was allocated to the correct answer, 0 for the incorrect answer, 0 for 'I do not know' and 0 for no answer/left blank. A mean knowledge score for each condition/health outcome was calculated and a scale of 'low', 'moderate' and 'high' knowledge was established. The ranking classifications were chosen based on the data distribution and were divided into three score categories. For each individual condition/health outcome's mean score, 'low knowledge' equated to a mean of 0.00-0.40, 'moderate knowledge' was 0.41-0.70 and 'high knowledge' a mean of 0.71-1.00. An overall mean score out of 10 (as there were 10 conditions) was calculated for the HDP and non-HDP groups (i.e. the HDP group's knowledge regarding their long-term health risks and the non-HDP group's knowledge regarding the long-term health risks of HDP women). This overall score was classified as 'low' 'moderate' or 'high' using the same mean ranges as were used for the individual conditions. Categorical analysis for proportions of each knowledge group ('high', 'moderate' and 'low') was also conducted to provide a further perspective.

Results

In total, 308 survey responses were received (Figure 1). Forty-two were excluded: 40 for discontinuing the survey and not answering the question asking about their perception of lower/same/higher risk with regards to 10 health conditions, and two with 'CH only' (no worsening hypertension or superimposed PE in pregnancy) who were excluded due to small numbers. Of 266 included responses, 174 (65%) women had a lived experience of any HDP (will be known as HDP for reporting purposes) and 92 (35%) did not (will be known as non-HDP for reporting purposes). The HDP group consisted of 15 women with GH only (9%), 143 women with PE only (82%) and 16 women with CH plus superimposed pregnancy hypertension or PE (9%; will be known as CH). Of the HDP group, 123 (71%) had their most recent experience with HDP less than three years prior (32% <1 year prior and 39% 1-3 years prior).

Most respondents were in the 26-35 or 36-45 year age groups (91%), 89% were of Caucasian ethnicity, 90% pursued education beyond secondary school and 96% were in a relationship (Table 1). HDP women were more likely to be Caucasian, to have a history of diabetes, renal problems, be overweight and to have at least one additional cardiovascular risk factor than non-HDP women (Appendix 9), and less likely to be university-educated. Half of all participants were sourced through social media (50%), with most of the remainder (45%) recruited via the P4 study (8% of HDP women, 46% of non-HDP women) and AAPEC (35% of HDP women).

Table 1: Respondent demographics

	Total N(%)	GH %	PE %	CH %	Total HDP N (%)	Total Non HDP N(%)	P value HDP vs non HDP
Total N	**266**	**15**	**143**	**16**	**174**	**92**	
AGE							
18-25	12 (5)	13	6	-	10 (6)	2 (2)	0.16
26-35	117 (44)	33	48	50	81 (47)	36 (39)	0.25
36-45	126 (47)	53	42	50	76 (44)	50 (54)	0.10
45+	10 (3)	-	5	-	7 (4)	3 (3)	0.75
Prefer not to answer	1 (0)	-	-	-	-	1 (1)	-
ETHNICITY							
Caucasian	236 (89)	93	97	81	165 (95)	71 (77)	<0.001
Asian	23 (9)	7	2	6	5 (3)	18 (20)	<0.001
Other[1]	7 (3)	-	1	13	4 (2)	3 (8)	0.65
HIGHEST EDUCATIONAL ATTAINMENT							
Secondary School	25 (9)	7	14	13	23 (13)	2 (2)	0.003
Diploma/Trade*	69 (26)	33	33	50	60 (35)	9 (10)	<0.001
University Degree	171 (64)	60	52	38	90 (52)	81 (88)	<0.001
Prefer not to answer	1 (0)	-	1	-	1 (1)	-	-
RELATIONSHIP STATUS							
In a relationship	254 (96)	100	93	88	162 (93)	92 (100)	0.001
Not in a relationship	11 (4)	-	6	13	11 (6)	0 (1)	
Prefer not to answer	1 (0)	-	1	-	1 (1)	-	-
RECRUITED TO SURVEY VIA							
P4 Newsletter	56 (21)	13	8	6	14 (8)	42 (46)	<0.001
AAPEC	62 (23)	7	40	19	61 (35)	1 (1)	<0.001
Social Media	134 (50)	80	52	69	97 (56)	37 (40)	0.02
Other [2]	14 (5)	-	1	6	2 (1)	12 (13)	<0.001

* Diploma or Trade certificate

[1] Other: Indigenous Australian (n=1), Polynesian or Maori (n=2), mixed ethnicity (n=4).

[2] Other: Friend (n=11), ACM (n=1), Clinic (n=1), Maternity Consumer group other than AAPEC (n=1).

PE = preeclampsia GH = gestational hypertension CH = chronic hypertension, worsening in pregnancy and/or superimposed preeclampsia P4= Postpartum Physiology, Psychology, and Paediatric Study AAPEC= Australian Action on Pre-eclampsia ACM= Australian College of Midwives.

Table 2: Means of risk factor knowledge of women listed by type of HDP

	GH n=15	PE n=143	CH n=16	HDP n=174	Non HDP n=92	P Value HDP vs non HDP
Chronic Hypertension	0.53	0.78	0.81	0.76	0.62	0.02
Diabetes	0.27	0.24	0.31	0.25	0.35	0.12
Renal Disease	0.27	0.54	0.69	0.53	0.21	<0.001
Heart Attack	0.53	0.69	0.75	0.68	0.52	0.01
Repeat HDP	0.87	0.90	0.94	0.90	0.71	<0.001
Stroke	0.47	0.62	0.81	0.63	0.53	0.14
Heart Disease	0.47	0.69	0.75	0.68	0.50	0.005
PVD	0.33	0.50	0.50	0.32	0.45	<0.001
*Breast Cancer**	0.20	0.52	0.31	0.47	0.65	0.004
*Seizures**	0.27	0.29	0.13	0.27	0.44	0.01
OVERALL MEAN KNOWLEDGE SCORE (OUT OF 10)	**4.2**	**5.8**	**6.0**	**5.6**	**5.2**	0.21

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy, PVD= Peripheral Vascular Disease

* Breast cancer and seizures are distractors within the survey. These were included despite being conditions that women after HDP are not at greater risk of.

MEAN SCORE		
🟥	LOW	0-0.40
🟧	MODERATE	0.41-0.70
🟩	HIGH	0.71-1

Average knowledge scores are shown in Table 2 and detailed results on which these scores are based are shown in Appendix 10. Overall knowledge of the 10 conditions in the survey was ‘moderate’ for both groups (5.6/10 amongst HDP and 5.2/10 amongst non-HDP, p=0.21), with 33% in both groups having “high” overall knowledge and 32% and 40% respectively having “low” overall knowledge (Appendix 11). Women with a history of HDP had ‘high’ knowledge with regards to recurrence of HDP in a subsequent pregnancy (0.90) and risk of future CH (0.76). The same group had ‘moderate’ knowledge regarding increased chance of conditions such as heart attack (0.68), heart disease (0.68) and stroke (0.63). Women without HDP history had ‘high’ knowledge (0.71) for HDP recurrence in a subsequent pregnancy. The same group of women had moderate knowledge of CH (0.62) and stroke (0.53). Lowest knowledge across both groups was around the risk of future diabetes (0.25 HDP group and 0.35 for non-HDP group). Further ‘low’ scoring conditions were peripheral vascular disease (PVD) and renal disease. For most conditions HDP women had significantly higher knowledge than the non-HDP group. However, the non-HDP group were more likely to correctly identify that the risk of the two ‘distractor’ conditions, seizures or breast cancer, were equal for both groups.

Appendix 12 shows knowledge score breakdown by time since pregnancy. In the subgroup of HDP women who experienced PE (n=143), average knowledge was similar amongst women who experienced HDP within the last three years (5.8/10), compared to those who experienced HDP more than three years ago (5.7/10). Of the HDP women, only 32% were aware that the cardiovascular conditions may start manifesting within 10 years after an affected pregnancy, compared with 45% of women in the non-HDP group (p=0.036). About a third in each group (30% HDP, 36% non-HDP) were unsure about timing of risk rise/when health conditions manifest (Appendix 13).

Women with HDP history were asked about their personal experience of risk discussion with HCP (Table 3 represents summary of collective HDP data, Appendix 14 provides all findings by HDP sub-group). The most frequent discussions about future health were regarding HDP in subsequent pregnancies (45%), risk of CH (43%), and ‘No discussion’ (37%). Risk discussions were no more likely to have occurred in women with HDP less than 3 years ago or over 3 years ago. There were also no statistically significant differences found between HDP subgroups about whether future risks were discussed, or what types of risk were discussed.

Table 3: Proportion of conditions discussed when addressing future risk (multiple answers collected) within and over 3 years since last HDP (summary of collective HDP data)*

	Total n = 174 N (%)		Overall Total n = 174 N (%)	P value < 3 yrs vs >3 yrs
	<3yrs	**>3yrs**		
HDP next pregnancy	55 (45)	24 (47)	79 (45)	0.78
Chronic Hypertension	55 (45)	19 (37)	74 (43)	0.37
No discussion	**45 (37)**	**19 (37)**	**64 (37)**	**0.93**
Lifestyle changes	32 (26)	8 (16)	40 (23)	0.14
Heart Attack	22 (18)	7 (14)	29 (17)	0.50
Renal Disease	23 (19)	4 (8)	27 (16)	0.07
Stroke	20 (16)	6 (12)	26 (15)	0.45
Peripheral vascular disease	16 (13)	5 (10)	21 (12)	0.56
Cannot remember	6 (5)	2 (4)	8 (5)	0.78

*Table represents frequency of each option; percentages add to over 100% as women were asked to select any/all that applied. PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

When asked about preferences of the timing of a future risk discussion, the majority (76%) of women wanted a discussion 0-6 months postpartum. The topics most women with HDP wished to discuss (Table 4) are ‘impact on my children from the pregnancy affected by HDP’ (73%), ‘signs and symptoms of the conditions’ (67%), ‘when does risk rise’ (54%) and ‘risk reduction for subsequent pregnancy’ (54%). HDP women’s preference for receiving information on long-term health after HDP is via a medical professional (80%), through key organisations such as The Australian Heart Foundation (60%) and social media (47%).

Table 4: HDP women's preferences for content and distribution of information/education on future risk after HDP (multiple answers collected) in order of preference

	GH %	PE %	CH %	Total HDP N (%)
Total N	**15**	**143**	**16**	**174**
Preference of Discussion Topics*				
Impact on my children from the pregnancy affected by HDP	73	80	63	136 (73)
Signs and Symptoms of the conditions	80	71	69	124 (67)
Risk reduction for subsequent pregnancy	40	62	44	101 (54)
When does the risk rise	40	61	50	101 (54)
Statistics	40	60	38	98 (53)
Reducing risk behaviours (diet, exercise, smoking cessation)	40	56	31	91 (49)
Where to find information	40	51	13	81 (44)
How to discuss the matter with my healthcare provider	27	40	25	65 (35)
Preference of Distribution*				
Medical professionals	73	82	75	140 (80)
Key organisations	53	61	63	105 (60)
Social Media	40	51	19	82 (47)
Brochures/Flyers	40	45	31	75 (43)
Online Videos	20	24	25	42 (24)
Podcast/Media	13	23	25	39 (22)

*Table represents frequency of each option; percentages add to over 100% as women were asked to select any/all that applied. PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy.

Discussion

This study found overall, 'moderate' knowledge of health conditions after HDP amongst both HDP and non-HDP women. Amongst women with a history of HDP, highest knowledge was identified with regards to future risk of hypertension and repeat HDP in subsequent pregnancies. Conversely, knowledge of future risk of diabetes was low, as was knowledge of the "distractor" conditions among HDP women particularly. Diabetes as a future risk factor post-HDP has previously not been reported on in studies of women's knowledge, and our findings suggest this is an important knowledge gap to address.

Other novel aspects of our study are inclusion of women who had a history of GH as well as those with a history of PE, and assessing knowledge of non-HDP women's knowledge. Women after HDP had somewhat higher knowledge of most health risks than the non-HDP group, however non-HDP group also had better knowledge of some aspects such as timing of risk increase. However, both groups' knowledge of the early increase in risk was low, adding further concern and reason to address the knowledge gap. When looking at the proportion of participants scoring "high", these were equal between the HDP (33%) and non-HDP groups (33%), whilst proportions scoring "low" were similar enough (32% HDP versus 40% non-HDP) to not to show statistical significance. Our scoping review in 2019 (Roth et al.) identified that post-HDP, women have insufficient knowledge of their long-term risks. By including non-HDP women we wanted to explore whether knowledge was similar between the groups, which if so would suggest HDP women are not receiving tailored, targeted information and/or any information received is not translated into knowledge of personal risk after HDP. Given women after HDP were not markedly more knowledgeable about their health risks than unaffected women, the research-to-practice translational gap is further highlighted and suggests women with a lived experience of HDP remain underinformed about their increased CVD risk.

A further important finding was that many HDP women were not made aware of future health risks, with 37% of HDP women reporting to have had 'no discussion' about their increased long-term risk. Women with more recent HDP were no more likely than women with HDP>3 years ago to report having risks discussed, which is concerning. This finding suggests risk discussions may not have improved in recent years despite updated guidelines emphasising long-term health (Brown, Magee, et al. 2018; Lowe et al. 2015), and that the extensive evidence regarding long-term implications for women after HDP continues to be lost in the translation of research to practice. We are exploring reasons for this (e.g. lack of evidence base in guidelines, lack of provider knowledge of guidelines, siloed healthcare with insufficient handover from maternity care team to primary care) in our broader work.

Women's knowledge after GH has not been previously reported as far as we are aware even though GH has similar frequency and similar future CVD risk as PE (Theilen et al.

2017; Theilen et al. 2016). Although only 9% of our sample were GH, this group had somewhat lower knowledge than the PE and CH groups regarding conditions after HDP (although mostly not reaching statistical significance). Over half reported receiving no discussion of health risks after GH. Despite the small number of women with a history of GH (n=15) contributing to the study, this suggests potential substantive knowledge gaps after GH to address in both women and HCP.

International studies exploring women's knowledge have predominantly reported limited or no knowledge about the link between HDP and CVD (Roth et al. 2019) though our study found overall, 'moderate' knowledge of health conditions after HDP. The two conditions associated with highest knowledge were repeat HDP and risk of future hypertension. Findings were similar in Traylor et al.'s (Traylor et al. 2016) survey conducted in the United States of America (USA), where 146 women post-HDP were included (PE n=76, PE with severe features n=41, CH=29). Future hypertension and repeat HDP were correctly identified by women as risk factors, however this knowledge was mainly reflected in the group of women who had experienced PE with severe features. In the United Kingdom (UK), Brown et al. (2013) (n=12 women attending postnatal follow-up clinic) also found that women are aware of repeat HDP risks, however despite postnatal risk counselling, perception of hypertension and CVD risk was mainly associated with participants who had a family history of CVD. More recently in Australia, Hutchesson et al. (2018) surveyed 127 women with PE in the two years prior, finding very high knowledge about future hypertension risk (96%, higher than our post-PE findings) and most were aware of stroke (67%) and CVD (66%) risks (similar to our findings). Over a third of women after PE had 'no discussion' about future risk in our study. Hutchesson et al. (2018) reported over one third of their participants remained unaware of increased CVD risks, which is similar to our findings. Similarities may be explained by the fact that major source of PE participants for both, the Hutchesson et al. (2018) survey and ours was the patient support/advocacy group AAPEC. Recruitment from this advocacy group may also explain a higher post-PE knowledge than other studies have reported.

Our study findings resonate with those from similarly targeted women in Canada, Portugal, UK, the USA and a previous Australian study, all conducted between 2013 and 2017 (Roth et al. 2019). Therefore, from a global perspective, these findings reinforce a persistent and concerning, research to consumer gap. With international guidelines, including ISSHP (Brown, Magee, et al. 2018), specifically targeted to assist HCPs providing care to women on an international scale to better manage and address health after HDP, this practice gap of knowledge transmission to women would be expected to narrow.

Education preferences

Content

Women mostly wanted educational materials to address HDP impact on their children, signs and symptoms of conditions they are at higher risk of, the timing of when their risks rise, and how to best reduce risk of recurrent HDP. Similar preferences were expressed by the women included in Seely et al.'s (2013) focus group of 20 women after PE, with the key concern being the impact the PE pregnancy may have had on the health of their children. More recently, a UK-based study (Ho et al. 2020), involving women with a history of HDP and healthcare providers (HCP), identified research priorities regarding HDP. The top-ranking priority identified was the long-term physical and mental health consequences of HDP for the woman, baby and family. Other 'uncertainties' expressed by participants regarding their lived experience of HDP included topics such as diagnosis and management in pregnancy, prevention of future complications, short and long-term consequences of HDP for the woman and the baby, prevention of recurrent HDP as well as educational needs of HCPs and support for women and their families. Our study, with focus on women in Australia, suggests that similar uncertainties may benefit from being addressed, hence validating the importance of our findings.

Format of education and access

Our study identified that women mostly wanted to receive information about long-term health after HDP from medical professionals. Key organisations who are experts on the topic, via social media and through information brochures were other acceptable avenues of access to information. This is in contrast to Skurnik et al's (2016) focus group of 14 women after PE, whose preferences for educational materials about the link between CVD and PE were via pamphlets available in doctor's offices as well as via online communities and topical blogs. However, Hird et al's (2017) participants also expressed preference for HCP as their information source, including wanting HCP to guide them towards reliable online/external information sources rather than encounter irrelevant or potentially inaccurate information due to their self-initiated search. Hutchesson et al. (2018) report that high knowledge amongst participants was mainly due to the women's own research rather than receiving all possible, relevant information from their HCP. Overall, existing studies including ours would suggest that although women are very open to the use of online sources or information packs, their HCP are seen as central to closing their knowledge gaps.

Time of risk discussion

An important element to consider when communicating about risk with women who have experienced GH or PE is the timing of these discussions, as situational factors of being a new mother may alter when women are most receptive to follow-up. In our study, three-quarters of the women preferred this to occur in the first six months after birth. As well as being their preference, this also aligns with the potential benefits of early intervention and would allow for addressing knowledge gaps found in this study around how soon the risk rises after HDP. Addressing future risk early but not immediately is also supported by Brown et al.'s study of women after PE, where participants suggested that six months postpartum was the timeframe where they felt they had transitioned into a more comfortable stage of parenting and were able to focus more on themselves again (Brown, Bell, et al. 2013).

Strengths and limitations

The survey was co-created via a formalised process of seeking input and feedback on the usability, language and content from women who have previously experienced HDP. Although face-validation is a subjective process, involving consumers with a history of HDP gives added value to the survey.

Our knowledge score is both a strength, as it allows for a summary of findings across all the conditions and risks, and a limitation, as assigning cut-points for knowledge ranking is an arbitrary designation. Having included the distractor conditions (breast cancer and seizures) may also have altered the overall score. Whilst women are more likely to experience seizures during a pregnancy complicated by HDP compared to non-HDP women, the long-term risk of seizures is similar for both groups. Similarly, the association of HDP and future increased risk of cancer (including breast cancer) has been examined in a systematic review and meta-analysis, however proven not to be associated with increased future risks after HDP (Bellamy et al. 2007). Distractor inclusion may well have lowered overall knowledge score, for example women believing that after HDP they are at more risk of ongoing seizures since this is a risk during PE-affected pregnancy. However, we believe inclusion of distractors and assessment of women's response to them is valid, as it is important for women to not incorrectly believe they are at increased risk of more conditions than they are, as well as having knowledge of their increased cardiovascular risk. The addition of women with a history of GH as well as women without any history of HDP, is also a strength to add broader perspective on this topic.

Limitations include demographic make-up of respondents, with HDP participants predominantly English speaking and Caucasian (95%) despite the survey being available in Arabic and Mandarin as well as English. The non-HDP group (20% Asian background) had similar background demographics of Australian reproductive-aged women (Australian Bureau of Statistics 2019), and as HDP is more prevalent amongst the Caucasian population (Al-Rubaie et al. 2019), the sample in the context of ethnic background actually is proportionally likely close to representative of Australian HDP and non-HDP women. However, it would have been preferable to also gain insight from more culturally and linguistically diverse groups in order to understand their knowledge base and address their needs within this context.

In the survey, women were asked to select their HDP history which was then used to group them for analysis. Women's diagnosis of HDP is by self-report is a limitation, as some bias may be introduced through inaccurate self-report of diagnosis. The broad geographical range and anonymous nature of the survey precluded any verification of diagnosis. However, women were provided with definitions of the various HDP conditions at the start of the survey to aid them in their self-report. Another limitation is where participants were recruited from, with close to half either drawn from the P4 study (an Australian post-HDP research study) or consumer group AAPEC. Therefore, there may be knowledge bias in the sample (i.e. a more knowledgeable group of participants than the overall HDP or non-HDP population). The women's level of active engagement in pursuing further information on their long-term risks as well as their level of motivation to participate in this study, further contributes to knowledge bias. The number of respondents in all included HDP subgroups are a small proportion of the total number of women experiencing HDP, which suggests volunteer bias and this affects generalisability. However, non-representative, specialised samples of women can be noted within most research addressing women's knowledge on long-term health after HDP (Roth et al. 2019). As even this group with potentially greater baseline knowledge had substantive knowledge gaps, our study highlights the need for interventions to improve knowledge of health after HDP.

Implications

Close to two decades worth of data have been collected (Brown, Magee, et al. 2018) since research on the link between HDP and increased CVD risk emerged in the early 2000s, with the first systematic review published in 2007 (Bellamy et al. 2007). It could be expected that this knowledge, by now, would have been translated into practice and shared with HDP women, however our findings suggest that this is still not the case. This study is valuable from the public health perspective, given the wider context of prevalence and importance of CVD in women. Findings from this study and the broader study it is embedded in, will contribute towards the development, application and evaluation of educational materials for women and HCP. These future projects will address persistent knowledge-to-practice-gaps regarding improving women's cardiovascular health after HDP. Given the prevalence and impact of both HDP and CVD, this is valuable for women's health, and public health more broadly.

Guidelines such as ISSHP (Brown, Magee, et al. 2018) and SOMANZ (Lowe et al. 2015) suggest regular follow-up after HDP as well as counselling women with regards to their individual long-term CVD risk. Although available to the public, these are not designed for women. Compiling suitable information for women would be an important step towards closing the knowledge gap. It is important to establish preferred content, presentation and timing of education for post-HDP health for women as we have in this study, to maximise the chance that women will engage with and benefit from education.

Conclusion

This Australian survey of women’s knowledge of risks after HDP, found varying knowledge from the targeted groups. Despite ‘high’ knowledge being demonstrated regarding some risks, overall significant knowledge gaps were identified for certain conditions, particularly diabetes, and for knowledge about the relatively early timing of when health risks increase after HDP. Identifying these gaps are important in planning tailored education for women, and to improve early intervention for modifiable CVD risks in women after HDP. Addressing these women’s preferences for content and to have this delivered by their HCP may further lead to enhanced counselling, management and improved women’s health trajectories.

Chapter 4: Exploring education preferences of Australian women regarding long-term health after hypertensive disorders of pregnancy: a qualitative perspective

Context

Chapter Three reported on findings from a nationally distributed survey assessing women's knowledge about health post-HDP and explored women's education preferences. Chapter Four will now address the findings from the post-survey interviews conducted with women who participated in the survey. The interviews focused on providing rationale and insight from survey findings and explored preferred education content, format and access. This published paper relates to objective 4(i): To elicit preferred educational content, format and access regarding health after HDP, as a basis for creating tailored information and health advice for women who have had a lived experience of HDP.

Publication details

This paper was initially submitted for review to BMC Women's Health in March 2021. It has been peer reviewed twice, with revisions requested, and a revised manuscript was submitted 2 August 2021. I am awaiting feedback from the editorial office. This manuscript is submitted with a request for an Open Publication and its reproduction, once accepted, be permitted under the Creative Commons Attribution Non-Commercial license (CC BY-NC 4.0).

Roth H, Henry A, Roberts L, Hanley L, Homer CSE. Exploring education preferences of Australian women regarding long-term health after hypertensive disorders of pregnancy: a qualitative study (under review with *BMC Women's Health* since March 2021)

Abstract

Background: Hypertensive disorders of pregnancy (HDP) affect 5-10% of pregnant women. Long-term health issues for these women include 2-3 times the risk of heart attacks, stroke and diabetes, starting within 10 years after pregnancy, making long-term health after HDP of major public health importance. Recent studies suggest this knowledge is not being transferred sufficiently to women and how best to transmit this information is not known. This study explored women's preferred content, format and access to education regarding long-term health after HDP.

Methods: This was a qualitative study and framework analysis was undertaken. Women with a history of HDP who had participated in a survey on long-term health after HDP were invited to participate in this study. During telephone interviews women were asked about preferences and priorities concerning knowledge acquisition around long-term health after HDP.

Results: Thirteen women were interviewed. They indicated that they wanted more detailed information about long-term and modifiable risk factors. Their preference was to receive risk counselling from their healthcare provider (HCP) early after giving birth along with evidence-based, print or web-based information to take home. All women suggested more structured postnatal follow-up, with automated reminders for key appointments. Automated reminders should detail rationale for follow-up, recommended tests and discussion topics to be addressed at the appointment.

Conclusion: Our findings show that most participants wanted information soon after birth with all women wanting information within 12 months post birth, complemented with detailed take-home evidence. Participants indicated preference for structured follow-up via their HCP with automated alerts about the appointment and recommended tests. This evidence can be used to guide the development of education programs for women on health after HDP which may enhance knowledge, preventive health management and more generally improve women's health trajectories.

Summary

The known

- Hypertensive disorders of pregnancy (HDP) are linked to increased future health risks

- Studies show that health implications are not sufficiently conveyed to women post-HDP
- Research suggests that risk discussions between healthcare providers and women are suboptimal

The new

- This paper identifies women's preferences for information regarding content, format and access
- To adequately address their future health, women's mental health post-HDP needs to be considered

The implication

- These findings can be used to inform future education and information for women.

Introduction

Hypertensive disorders of pregnancy (HDP), including preeclampsia (PE), gestational hypertension (GH), and chronic hypertension (CH), affect 5-10% of pregnant women globally (Payne et al. 2016). GH, new-onset hypertension only after 20 weeks of pregnancy, may progress to PE but otherwise has good short-term outcomes. CH (hypertension diagnosed pre-pregnancy or in the first half of pregnancy) also may progress to PE, and as a traditional cardiovascular disease (CVD) risk factor already denotes a woman at high longer-term CVD risk. HDP, particularly the multi-system disorder preeclampsia (Lowe et al. 2015), are a major cause of poor pregnancy outcome leading globally to over 50 000 maternal deaths and 400,000 perinatal deaths each year (Duley 2009; Ghulmiyyah & Sibai 2012). Additionally, HDP are associated with substantial longer-term maternal disease. Ischaemic heart disease and stroke, two leading causes of death in women globally, (Naghavi et al. 2017) are 2-2.5 times higher after preeclampsia compared to normotensive pregnancies (Brown, Best, et al. 2013; McDonald et al. 2008; Theilen et al. 2016), with risks of Type 2 diabetes and renal disease also increased (Giorgione et al. 2021). Risks are present within 5-10 years of an affected pregnancy (Arnott et al. 2020; McDonald et al. 2008; Wu et al. 2017) and continue lifelong (Theilen et al. 2016). GH is also associated with long-term cardiovascular sequelae (Oliver-Williams et al. 2019; Riise et al. 2018; Theilen et al.

2016), while as CH is a traditional cardiovascular disease (CVD) risk factor, it already identifies woman as being at higher CVD risk.

Studies conducted globally have found that women have poor knowledge of their increased CVD risks after HDP (Roth et al. 2019). Healthcare providers (HCP) often lack the necessary knowledge (Roth, Homer, Arnott, et al. 2020; Roth et al. 2019) and when postnatal follow-up care is scheduled, women often do not attend (Cusimano et al. 2014). Many women have poor insight into risk-reducing lifestyle changes and may not engage in making changes, due to family and caregiving responsibilities, lack of knowledge, lack of appropriate and timely follow up, and higher cost of healthier diet (Brown, Bell, et al. 2013; Hoedjes et al. 2012; Robbins et al. 2011; Seely et al. 2013). Transition from hospital-based to community-based care with general practitioners (GP) is an additional system-level barrier to appropriate post-HDP follow-up, as is lack of health insurance (Seely, Tsigas & Rich-Edwards 2015).

There is limited understanding of the extent to which HCP conduct appropriate assessment and whether preventive management occurs after HDP. Research suggests women are less likely than men to have their CVD risks fully assessed, or appropriately managed when they are diagnosed (Hyun et al. 2017). Although international professional associations, including the American Heart Association, recommend asking women about preeclampsia/HDP during CVD risk assessment (Young, Hacker & Rana 2012), this has not been formalised in Australian guidelines (National Vascular Disease Prevention Alliance 2012).

As part of broader work on health after HDP, an online survey study assessing knowledge of long-term health and information needs of post-HDP Australian women (n=266) found that most post-HDP respondents (76%) wanted information 0-6 months postpartum, and from a HCP (80%), key organisations (60%), social media (47%) and brochures/flyers (43%) (Roth, Homer, LeMarquand, et al. 2020). However, there is limited understanding of women's preferences of how best to provide the information (Parfenova et al. 2020). This study explored women's preferred content, format and access to education regarding long-term health after HDP.

Method

Design

The study design was qualitative and used a framework approach to the analysis. Framework analysis is a data management method to facilitate interpretation of qualitative data (Furber 2010; Gale et al. 2013). The framework approach has been developed specifically for applied or policy-relevant qualitative research in which the objectives of the investigation are typically set in advance and shaped by the information requirements. It was considered suitable for analysis of our interview data, where comparisons within and between interviews generated themes. The matrix format was useful in the management of the data sets and it facilitated a structured overview of summarised data. The method has five phases that are interlinked, enabling understanding and interpretation of the data and moving from descriptive reporting to conceptual explanation of collected data.

Telephone interviews were chosen because eligible women were geographically diverse, and phone interviews offer greater flexibility in interview scheduling, reduced research costs and faster data collection (Shuy 2002). Participants have greater anonymity, which may encourage responses to sensitive questions (Novick 2008) and provide rich data for qualitative analysis (Cachia & Millward 2011).

Ethical approval was granted by South-Eastern Sydney Local Health District Human Research Ethics Committee (Ref: 18/POWH/326). The ratification for the University of Technology Sydney has also been obtained under ETH18-3061. We confirm that all methods were performed in accordance with the relevant guidelines and regulations associated with the ethics approvals by the above institutions. Informed consent was obtained from all the participants prior to the interview.

Context

Although geographically large, most Australians (71%) live in major cities of more than 100,000 and <10% in small towns (less than 10,000) or remote locations (Australian Bureau of Statistics 2018a). Australia has universal healthcare for citizens and permanent residents, with the federal government being responsible for outpatient facilities such as family doctor/GP while state governments are responsible for public hospitals (where almost all women give birth). Private healthcare is also widely available: approximately 25% of Australian births occur in a private hospital. There are both medically-led and midwifery-led models of care, although as with healthcare services generally these are more restricted in rural and remote regions (Department of Health 2019). Although some women see their GP for pregnancy care, most consult a different care provider for maternity care than their pre-pregnancy and ongoing health care (Council of Australian Governments: Health Council 2019; Department of Health 2019).

Participant recruitment

Participation was open to women who had taken part in a prior survey assessing knowledge of long-term health after HDP (Roth, Homer, LeMarquand, et al. 2020) which targeted Australian women who either experienced a recent HDP pregnancy or a pregnancy without any serious complications. The previously conducted survey consisted of a custom-created (consumer co-designed) online survey (available in English, Arabic and Mandarin) and was distributed through a targeted convenience sample approach to prior research study participants (Davis, Roberts, Henry, et al. 2016), organisations such as Australian Action on Preeclampsia (AAPEC), maternity consumer groups, through the project's consumer representative, and social media (Facebook and Twitter) including multicultural networks in order to reach Arabic and Mandarin speaking communities. The 266 participants with (n=174) or without (n=92) HDP history were given the option to leave contact details at survey conclusion if interested in follow-up interviews. A total of 61 women who provided their contacts were invited to participate in an interview, and 13 of them accepted the invitation. A study information sheet including consent items were emailed to participants prior to the interviews to allow for reading in their own time, without feeling pressured.

Data collection

Data collection involved semi-structured telephone interviews, all conducted in English by the same person (HR) from December 2019-January 2020. The interviews were audio recorded with verbal consent of participants and later transcribed. Before commencing interviews, the researcher introduced herself to participants and provided a brief summary of the results from the preceding survey study (Roth et al. 2019). Women had the opportunity to ask questions about the study information sheet and consent items. This provided a context for the questions. During the interview, women were asked about preferences and priorities concerning knowledge acquisition around long-term health after HDP (Appendix 15).

Data analysis

Interviews were transcribed verbatim, then analysed qualitatively using framework analysis (Furber 2010; Gale et al. 2013). The analysis was an iterative process that involved identifying and developing a thematic framework through an inductive approach (Furber 2010; Gale et al. 2013). The first author familiarised herself with the raw data by listening to the audio files, reading and re-reading interview transcripts and taking note of preliminary themes by which the data could be examined and referenced in relation to the research aims. These were then discussed and debated with other authors. A matrix developed in Microsoft Excel (V16.16.25 for Macintosh) was used to allocate categories to women's quotes. Relationships between themes were derived from the data, based on the original research aims and linked to previous quantitative findings (Furber 2010; Gale et al. 2013). There were no deviant categories identified from the data.

The authors include female HCP and a consumer. As a group we acknowledge our own personal values and positions, including our work within the Australian healthcare system and as recipients of maternity care, may impact on the research process and type of data collected (Burns et al. 2012).

Results

The 13 participants included 10 women with a history of PE, two women with a history of GH, one woman with CH and superimposed PE. The majority of the participants (n=12) were Caucasian while one was Aboriginal /Torres Strait Islander. All women who participated in the study had tertiary education, six were aged 26-35 years, another six were aged 36-45 years while one was older than 46 years. Eleven participants had experienced HDP in the three years preceding the interview. The distribution of participants in the study based on age group, ethnicity, education level, relationship status, and recency and type of HDP, HDP was similar to that of the preceding survey (Appendix 16). Average interview length was 28 minutes (range 16-36 minutes). Saturation was achieved after 8 interviews as most women were providing similar suggestions and comparable perceptions. However, all 13 women who had agreed to participate were interviewed to honour their commitment and contribution to the research.

The three main categories identified from the interviews were ‘Accessing evidence-based and comprehensive information’, ‘Transitioning care from hospital to community’ and ‘Fostering self-advocacy’ (Appendix 17).

Accessing evidence-based and comprehensive information

Women were asked about their current understanding of their CVD and diabetes risks. Their responses highlighted a lack of awareness regarding identification of these risks as well as limited knowledge about, or misinterpretation of, the potential risks for their context (post-HDP). Most women were also unsure what they could do to manage or mitigate their risks.

Women wanted post-HDP information to include HDP definitions and pathophysiology. They wanted to know their own long-term risks as well as their children’s risk, including a better understanding of how HDP leads to future health risks. Women also wanted explanations of how the various CVD and metabolic disorders affected the body and which signs and symptoms to seek medical assistance for.

Women wanted information on modifiable risk factors and how they could specifically address these. This included when and how their risks may manifest, what testing would be needed to identify and address these through early intervention, and instructions to assist them with recommended lifestyle changes and risk reduction. Timely information was important, and as stated by one woman:

> *The more important thing is actually getting at it at a time where it's timely for me, if I can change things about the way I live and those sorts of things, I don't want to find out 10 years later.*

It was also clear that processing the HDP pregnancy and birth takes time and needs to be accounted for, both as an important stand-alone issue, and in the context of knowledge transfer around longer-term health. Despite provision of context and interview questions clearly focusing on long-term health, most women repetitively referred back to their pregnancy and HDP diagnosis, birth and the immediate postnatal time, indicating a persistent focus on these events rather than their future health. One woman shared her post-PE experience:

> *... I was pretty blue, pretty dark time ... Sometimes just have to take two steps, one step forward, two steps backwards kind of thing. I think sleep deprivation doesn't help ... no one really knew what was going on with me. All the unknowns about it were quite shocking and then to find out afterwards that I have a chance of heart disease and things, is quite scary.*

Women wanted structured information accessible verbally, in print and as an electronic resource (smartphone application or a website). Most wanted the information to be specific and detailed but also relatable and easy to understand, addressing needs of women with disabilities (visual and auditory) and preferably catering for those from diverse linguistic and cultural backgrounds. Preference was expressed for highly visible and easy to find information, centralised through a website for example.

Participants’ preferred sources of information included women’s HCP, specialised organisations or targeted social media interest groups such as those focussed on premature birth or preeclampsia. Participants suggested push-notifications such as follow-up appointment reminders. Women wanted information through formal pathways, particularly their HCP, rather than relying on their own informal, self-guided internet searches:

> *I myself would like to access that directly through my doctor, as in my doctor giving that to me. I rely on them to give me that little bit of information when it comes to my medical future.*

A pamphlet or other print resource was mentioned by most women as being acceptable, especially for ‘take home’ information after the risk discussion with the HCP. Others wanted to access information electronically through a website with tailored information or to be emailed from their HCP. Women wanted their HCP risk discussion supplemented by links to reliable research articles or practical information. Women stated that smartphone applications would help ensure information was accessible.

Participants viewed social media as potentially facilitating access to information. Some women felt that accessing information through established organisations was also useful and trustworthy, with AAPEC and the Australian Heart Foundation via Facebook being specifically suggested. One woman suggested push notifications or health notices to women through targeted social media groups.

Transitioning care from hospital to community

Women wanted to know what their long-term medical follow-ups should include in terms of planning, blood tests and other investigations. Referral or clinical handover letters from the maternity HCP to the woman’s nominated community HCP, detailing pregnancy complications and required long-term follow-up, were suggested. Most women wanted follow-up reminders, likening it to the written and SMS reminders sent by Cervical Screening Registers or Gestational Diabetes Register. They found this format practical and said they were more likely to remember to make a follow-up appointment. Participants also reported that women would feel more involved and informed if there were details about the suggested appointment such as tests to be done or topics to be discussed, for example:

> *If you're developing those risks five to 10 years later, whether you then receive information from the either federal government or state government. Because I have gestational diabetes, I get a letter saying “you're at risk, make sure this year you get your blood tested”. Whether maybe the same type of communication could go out to the [future] hypertensive patient as well?*

The risk discussion needs to be timed such that the woman is able to focus on her own health rather than during the early transition to parenthood. Women who experience unexpected outcomes relating to their baby's birth may not be able to focus on their own health, short or long term, as this woman explained:

> *I think the timing is really important because when I had my follow up, my daughter was still in hospital. The information that I was processing at the time, probably wasn't great ... My daughter is one now and I kind of think, well now is the time I'm ready to process information about that [own long-term health].*

Some felt that their HCPs lacked knowledge about health after HDP and they were therefore unsure whether to trust their advice on addressing modifiable risks. One woman explained her doubts:

> *I don't feel ... I mean, I could be wrong, maybe she [GP] does know this. I really like her, and she has been on top of a lot of other stuff. But if she doesn't know, I'm 99% sure that she will never say to me, "I'm going to check your lipids," or "I'm going to check you for signs of whatever." If I don't bring it up, I don't think she will.*

The narratives showed that a more structured and pro-active referral approach from maternity to community would be useful. Most of the women felt that a structured transition system would enable them to gradually take ownership of the information and advocate for their own health.

Fostering self-advocacy

Taking ownership of their health and engaging in self-advocacy and accountability regarding their future health were seen as important. This enabled women to speak up regarding their health and actively seek knowledge to fill their self-perceived knowledge gaps. Although women wanted to, in a first instance, receive relevant health information from their HCP, they also recognised a degree of self-accountability for their long-term health, and that this may require additional effort to inform the GP of their medical history and to request tests. One woman described her approach to managing her own risk opportunistically:

> *It is then up to the patient to continue that post care with their GP ... when I go to the GP now and even if it's for, I had a fingernail infection. I'm like,*

> *"While I am here, he can take my blood pressure" ... I am so mindful to keep an eye on it now.*

Another woman described that the responsibility of sharing health related information when changing to a new GP lies with the woman:

> *... if you move doctors, that's a bit tricky as well, isn't it? Because you sometimes your file doesn't follow with you. It's up to you to tell your doctor.*

One woman felt that relaying important health information to her GP was similar to her alerting restaurant staff to the fact she is allergic to a certain food:

> *I think that would be more, a lot on my responsibility to a point to say to the GP. Like someone declaring they have a food allergy when going to a restaurant ... This is the first thing you need to say to the doctor, just say, I have history of hypertension, can you please check? If she can log on, and she goes here in my record, she'll see the details.*

When asked about how they accessed post-HDP information, the two most popular means were through the internet and participation in HDP research. Although women preferred to obtain this information via their HCP, these were considered enablers to knowledge acquisition. Most women explained they independently searched for information to get some, or a more comprehensive, understanding of their future health outlook after HDP. For example:

> *I more or less sort of inquired myself really. Because I think I was just googling. I mean the doctors just said high blood pressure and then that's all, it didn't really go any further than that ... I started googling and then I found out just through myself that yes it can be the cardiovascular heart disease, stroke...it would probably have been good that that was discussed.*

Women felt under informed and wanted more insight and understanding about their pregnancy diagnosis and the associated long-term health impact. This motivated their self-initiated pursuit of information and health advice. As a result, women expressed feelings of being ‘left to their own devices’. For some, participating in HDP studies was the only way they had accessed information regarding their health risks. For others, being aware of health-related family history was enabling to knowledge acquisition.

Promoting health via awareness campaigns or days such as ‘World Preeclampsia Day’ were seen as additional awareness raising and reminders about health after HDP.

Discussion

Women articulated their preferred content, format of, and access to, educational material relating to health after HDP. Three main categories were identified: ‘Accessing evidence-based and comprehensive information’, ‘Transitioning care from hospital to community’ and ‘Fostering self-advocacy’.

Experiencing HDP can mean unexpected pregnancy, birth and postnatal outcomes which makes receiving information difficult in the immediate time following such events. The finding suggests a need for appropriate guidance on the timing and format of information provision. Findings from the survey preceding these interviews showed that women preferred receiving information about long-term health 0-6 months postpartum, from a HCP, key organisations, social media and brochures/flyer (Roth, Homer, LeMarquand, et al. 2020). The interview findings support these results from the survey and identified additional reasons for these preferences. Participants requested more detailed information regarding their long-term health and how to address any modifiable risks, with their preferred information source being HCP consultation, supported by relevant print or online information for access whenever it suited them. These preferences are similar to findings from previous studies (Roth et al. 2019; Skurnik et al. 2016).

A study in the USA (Seely et al. 2013) reports similar findings regarding preferred educational content, such as effects on children and awareness of signs and symptoms of conditions women are at higher risk of, which suggests some common international needs and preferences. In addition, our preceding survey study (Roth, Homer, LeMarquand, et al. 2020) and Seely et al. (2021) found that in Australia and the USA respectively, women do not receive desired information from their HCPs and therefore resort to internet searches. Like this interview study and the preceding survey study (Roth, Homer, LeMarquand, et al. 2020), Seely et al. (2021) in the USA also found that women are not receiving desired information via their HCP and resort to web-based searches. Frustration regarding lack of available information post-HDP was expressed by women in both studies (Seely et al. 2021), with women emphasising a need for multiple information formats including print, online or mobile application.

In our study, as addressed under ‘Accessing evidence-based and comprehensive information’, women were clearly still affected by the unexpected outcomes of their HDP pregnancy and birth, and often focused on their immediate health and the next pregnancy rather than long-term effects of HDP. Similar to Brown et al.’s study on post-PE health (Brown, Bell, et al. 2013), the interviewer of our study had to ask participants to re-direct their focus on their long-term health whilst addressing the questions. Other studies have also found that psychological aspects of experiencing HDP are an important barrier when addressing post-HDP knowledge transmission (Dijkhuis et al. 2020; Hird et al. 2017; Hoedjes et al. 2012; Seely et al. 2021), and that women need to process the shock after experiencing severe PE before they can address lifestyle changes (Sandsæter et al. 2019). This suggests that psychological sequelae post-HDP need explicit acknowledgment by HCPs and in education materials in order to facilitate support-seeking among women if required before they can process and act on new, longer-term health information.

Women wanted more information delivered to them by their HCP. However, previous studies show that women’s post-HDP knowledge is low or inexistent (Roth, Homer, LeMarquand, et al. 2020; Roth et al. 2019), HCP have suboptimal knowledge (Roth, Homer, Arnott, et al. 2020; Roth et al. 2019), and that HCP address women’s direct questions but do not generally raise the topic of post-HDP risks (Hird et al. 2017). In view of improved preventive care, these patterns underscore a need for education in both, HCP and post-HDP women. Effective management of their own health may also be hindered if the woman’s knowledge and perception of risk is not in line with actual risk (Lewis, Robinson & Wilkinson 2003). However, in order to identify risk and establish a preventive approach, CVD primary prevention also requires accurate risk assessment by HCP (Davis & Duvernoy 2011). The findings suggest that in order to effectively communicate future health risks a number of elements relating to the woman as well as the relay of health information need to be considered. Both, this study and previously published research on the topic (Roth et al. 2019) demonstrate that factors affecting uptake and understanding of information such as the recency of a woman’s HDP, her health literacy and personal health beliefs need to taken into account. The manner in which health information is relayed, the language used to share it and the presentation are also important considerations for effective communication about future health risks (Ghosh & Ghosh 2005; Neuner-Jehle et al. 2011). In general health risk terms, when HCP present the individual risk rather than general population risk better results are obtained in proposed interventions, which requires the HCP to have effective communication skills, adequate knowledge and the ability to calculate this risk (Edwards et al. 2003; Haskard Zolnierek & Dimatteo 2009).

Strengths and weaknesses of the study

The interview data have been conducted as part of a broader program of work on women and HCP knowledge and educational needs post-HDP, which is an overall strength as it provides various perspectives and insights. Whilst the focus of the interviews was on gaining insight on women's educational preferences, our findings also highlight the importance of addressing psychologic sequelae post-HDP. Selection bias is likely, as only women who participated in the preceding online survey were invited to participate in the interviews. Half of the survey participants were recruited from ongoing studies relating to post-HDP research or consumer groups, so knowledge bias is also likely. The women's level of active engagement in pursuing further contribution to long-term risks as well as their level of motivation to participate in this study, further contribute to knowledge bias.

Although the distribution of women with CH, GH or PE from the preceding survey (Roth, Homer, LeMarquand, et al. 2020) was similar in the post-survey interviews, the findings may not be representative of all women in Australia. The interviewed women also had a clear understanding of which HDP they experienced, and by the time of the interview had at least some knowledge of their risk factors. If recruitment had been open to a wider population, the findings may have been more diverse in nature. This can be considered a strength given their lived experience and interest in contributing to positive change in this area of health. Despite the preceding online survey being available in Arabic and Mandarin as well as English, neither the survey nor the subsequent interview findings addressed in this paper were adequately reflective of Australia's cultural diversity. Considerations of the views of younger women (under 26 years of age) and those residing in different contexts (such as urban and rural areas) with different needs regarding post-HDP access to information and services could provide additional insights in preferences pertaining to educational materials. Once education is established it should be piloted to a culturally and age diverse group in order to then cater for a more proportionally balanced, post-HDP demographic.

Practice implications

Whilst many studies suggest that a first line of intervention to improve health outcomes in women is to inform them of their risk and their CVD screening and prevention options, few studies provide recommendations on what the education should look like (Roth et al. 2019; Seely et al. 2021). The findings from this interview study, combined with the preceding online survey findings, will be utilised in a planned local implementation pilot study, including website and app for women, educational material and website availability for their GP to assist with hospital-to-community transition postpartum, and reminder notifications for women to see their GP for post-HDP care. This study will contribute to positively address persistent knowledge-to-practice-gaps regarding improving women’s cardiovascular health after HDP. Women’s access to tailored, structured education may in turn contribute to informed choices women make regarding their lifestyle and follow-up care medium to long-term, potentially positively altering a women’s health trajectory.

Conclusion

Our findings show that women with a lived experience of HDP prefer to receive information from their HCP soon after birth, complemented with information to take home or access later. The participants suggest that ongoing structured follow-up via their HCP including automated reminders, alerting them to follow-up appointments and recommended tests to be conducted may improve knowledge levels and action on change. Psychologic sequelae post-HDP and especially after PE need to be acknowledged in post-HDP risk discussions and addressed in education materials as this will help women access further support as they negotiate their health journey post-HDP. Whilst information alone does not equate to action on change, it is an important ingredient in the approach for change.

Chapter 5: Assessing Knowledge of Healthcare Providers Concerning Cardiovascular Risk After Hypertensive Disorders of Pregnancy: an Australian national survey

Context

Chapter Three and Four report on the survey and interview findings from the Women's Study. Chapter Five and Six will report on survey and interview findings from the HCP study. This chapter will provide insight into the findings from the national survey, exploring HCP knowledge and consultation practices regarding post-HDP health.

This published paper relates to the following overall objectives:
2(ii) Using the results from our scoping review on women's and HCP knowledge about long-term health after HDP we aim to co-design and face validate a survey with healthcare providers.
3(ii) To explore current knowledge and identify knowledge gaps on the topic of long-term health after HDP amongst targeted healthcare providers practicing in Australia, including general practitioners, midwives, obstetricians and cardiologists.

Publication details

This paper was published in BMC Pregnancy and Childbirth which publishes peer-reviewed, multi-disciplinary research papers that are of international interest. The accepted manuscript is reproduced in this chapter with permission under the Creative Commons Attribution Non-Commercial license (CC BY-NC 4.0).

Roth H, Homer CSE, Arnott C, Roberts L, Brown M, Henry A. Assessing knowledge of healthcare providers concerning cardiovascular risk after hypertensive disorders of pregnancy: an Australian national survey. *BMC Pregnancy and Childbirth*. 2020;20(1):717.

Abstract

Background: Hypertensive disorders of pregnancy (HDP) affect 5–10% of pregnant women. Women after HDP have 2–3 times increased risk of heart attack, stroke and diabetes, as soon as 5–10 years after pregnancy. Australian healthcare providers' knowledge of cardiovascular disease (CVD) risks for women after HDP is unknown, and this study aimed to explore their current knowledge and practice regarding long-term cardiovascular health after HDP, as a precursor to producing targeted healthcare provider education on health after HDP.

Methods: A custom-created, face-validated online survey explored knowledge about long-term risks after HDP. Distribution occurred from February to July 2019 via professional colleges, key organisations and social media. The objective was to assess current knowledge and knowledge gaps amongst a group of healthcare providers (HCP) in Australia, regarding long-term cardiovascular health after hypertensive disorders of pregnancy (HDP), specifically gestational hypertension or preeclampsia.

Results: Of 492 respondents, 203 were midwives, 188 obstetricians, 75 general practitioners (GP), and 26 cardiologists. A risk knowledge score was computed with 0–6 considered low, 6.1–8.9 moderate and 9–12 high. Most participants (85%) were aware of increased CVD after preeclampsia and gestational hypertension (range 76% midwives to 100% cardiologists). There were significant differences in average knowledge scores regarding health after preeclampsia; high for cardiologists (9.3), moderate for GPs and obstetricians (8.2 and 7.6 respectively) and low for midwives (5.9). Average knowledge scores were somewhat lower for gestational hypertension (9.0 for cardiologists, 7.4 for obstetricians and GPs, 5.1 for midwives). Knowledge was highest regarding risk of chronic hypertension, moderate to high regarding risk of ischaemic heart disease, stroke and recurring HDP, and low for diabetes and peripheral vascular disease. Only 34% were aware that risks start < 10 years after the affected pregnancy.

Conclusion(s): Participants were aware there is increased cardiovascular risk after HDP, although less aware of risks after gestational hypertension and some specific risks including diabetes. Findings will inform the development of targeted education.

Background

Hypertensive disorders of pregnancy (HDP) includes preeclampsia (PE), gestational hypertension (GH) and pre-existing or chronic hypertension (CH) and complicates 5–10% of pregnancies (Duley 2009). PE is a multi-system disorder, characterised by hypertension and involvement of one or more other organ systems and/or the fetus (Brown, Magee, et al. 2018; Lowe et al. 2015). GH is new onset hypertension without any other complications during pregnancy and has little association with adverse pregnancy outcomes apart from increased risk of progression to PE (Brown, Magee, et al. 2018; Lowe et al. 2015). Both conditions are associated with long-term cardiovascular sequelae (Riise et al. 2018; Theilen et al. 2016). Cardiovascular disease (CVD), the leading cause of death in women globally (Roth et al. 2018), is up to two and a half times higher for women after HDP versus those with no HDP (Arnott et al. 2020; Brown, Best, et al. 2013; Riise et al. 2018; Theilen et al. 2016). This increased risk remains after adjusting for the presence of other cardiovascular risk factors and is present within 5–10 years after the affected pregnancy (Arnott et al. 2020; Egeland et al. 2018; Leon et al. 2019; McDonald et al. 2008; Wu et al. 2017)

Both Australian and international societies, including the Society of Obstetric Medicine of Australia and New Zealand (SOMANZ) and the International Society for the Study of Hypertension in Pregnancy (ISSHP), recommend women and healthcare providers (HCP) are provided with information about HDP and later CVD, and HCPs should ask women about their HDP history when assessing cardiovascular health and risk factors. This includes review at 3 months postpartum and regular follow-up with a GP to monitor blood pressure, fasting lipids and blood sugar (Brown, Magee, et al. 2018). Recommendations emphasise adoption of a healthy lifestyle with maintenance of an ideal weight and regular aerobic exercise (Brown, Magee, et al. 2018; Lowe et al. 2015). Despite existing evidence and recommendations, it is unknown whether Australian HCPs are aware of the association between HDP and CVD (Roth et al. 2019). The aim of this study was to explore Australian HCPs current knowledge and practice regarding long-term cardiovascular health after HDP, as a precursor to producing targeted HCP education on health after HDP.

Method

A national, multidisciplinary survey of HCPs was conducted, using a custom-created, face-validated online survey (Appendix 18). Ethical approval was provided by South-Eastern Sydney Human Research Ethics Committee (Ref: 18/POWH/326).

Face validation of the survey

As a validated instrument to assess HCP's knowledge and practice was unavailable, a survey was custom designed. The survey was initially compiled from a scoping literature review (Roth et al. 2019) and complemented by questions specifically exploring the Australian context. Twenty-one HCPs across eight professions (obstetricians, cardiologists, nephrologists, obstetric physicians, anaesthetists, general practitioners, midwives and community health nurses) participated in the face-validation process. These HCPs commented on content, language, flow, survey structure including length, whether the risk profile at survey conclusion was informative, and potential value of the survey data. The survey was modified until consensus over a final version was achieved.

Data Collection

The online survey, powered by SurveyMonkey (Survey Monkey Inc., San Mateo, USA), was open from 15 February until 4 August 2019. Survey distribution occurred through professional organisations, namely: The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) [targeted to DRANZCOG holders (General Practitioners with obstetrics and gynaecology diploma) and FRANZCOG (Fellow) members], the Australian College of Midwives (ACM), and the Cardiac Society of Australia and New Zealand (CSANZ). Additionally, distribution occurred via the study team's professional networks, as well as social media pathways such as Twitter and Facebook. The targeting of general practitioners/family doctors (GPs) with an obstetric diploma, and therefore specialised in maternity care and women's health, was a deliberate decision. With our survey identifying a 'best-case' knowledge scenario within this group of HCPs meant that we expected our sample to have higher overall knowledge on this topic, relative to all Australian HCPs in the included professions, setting an upper limit regarding future targeted education.

The survey collected demographic details and assessed HCPs general and specific knowledge of risk after HDP, and their practices around consultation and follow-up of women with a history of HDP. Early in the survey, HCPs were asked ‘Do you think that there is an increased risk of developing future cardiovascular disease after GH or PE?’. Those who answered ‘Neither GH or PE increase the long-term health risks’, were sent to the risk profile at the end of the survey so that detailed questions regarding risk were only being asked of those HCPs with some knowledge of CVD and HDP links. The HCPs were asked to classify the risk of women with a history of GH or PE, of various long-term health outcomes as ‘less than’, ‘equal to’ or ‘greater than’ that of a woman with a normotensive pregnancy. The survey included conditions that women are at increased risk of after HDP (CH, CVD, diabetes, renal disease) and also those with similar prevalence (breast cancer, leukaemia and seizures). Upon survey completion, HCPs were provided with a correct risk profile summary and a link to further information. Commencement of the survey was taken as consent to participate.

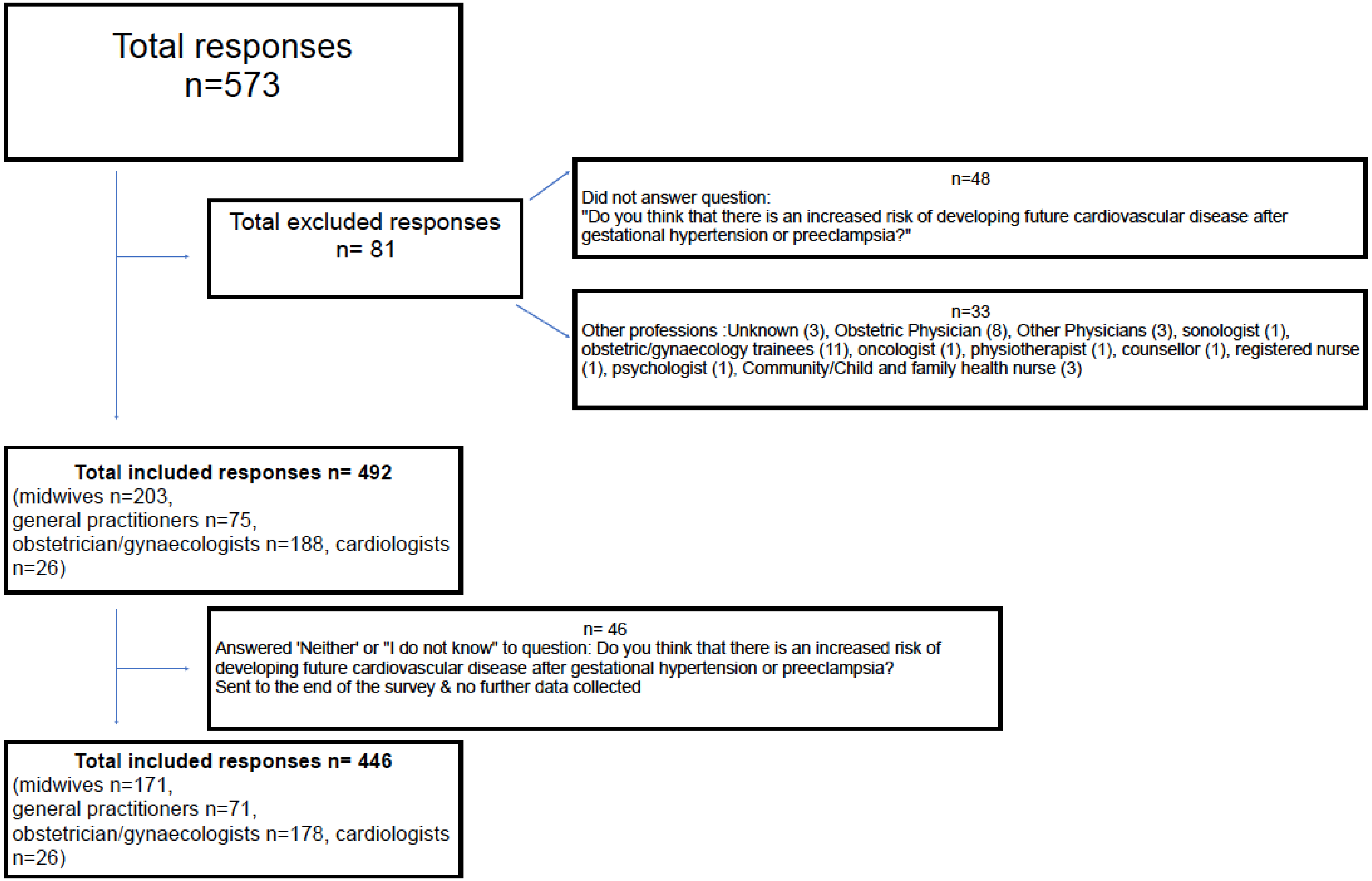
Data Analysis

Quantitative survey analysis was undertaken using SPSS Version 25 (SPSS Statistics for Windows, Armonk, NY). Demographic data and responses to individual questions were analysed descriptively. To examine difference in knowledge levels amongst the targeted HCP subgroups, (obstetricians, GPs, midwives, cardiologists) responses regarding HDP and future health risks were compared using Chi-squared testing for categorical data and one-way ANOVA for continuous data. A p-value of < 0.05 was considered statistically significant.

For ease of interpretation, a knowledge score was created for the GH and PE risk matrix, whereby 1 point was allocated to the correct answer, 0 for the incorrect answer, 0 for ‘I do not know’ and 0 for no answer/left blank. A mean score for each risk factor was calculated and a scale of ‘low’, ‘moderate’ and ‘high’ knowledge was established. The ranking classifications were chosen based on the data distribution. For individual risk mean scores, ‘low knowledge’ equated to a mean of 0.00–0.50, ‘moderate knowledge’ was 0.51–0.80 and ‘high knowledge’ a mean of 0.81–1.00. An overall mean score out of 12 (as there were 12 conditions) was given for GH and PE for each profession. A ‘low knowledge’ equated to a mean of 0–6 (50% or less correct answers), a mean of 6.1–8.9 was considered ‘moderate knowledge’, and a mean score of 9–12 was considered ‘high knowledge’.

Results

In total, 573 survey responses were received (Fig. 1). Eighty-one were excluded: 48 for not answering the key inclusion question ‘Do you think that there is an increased risk of developing future cardiovascular disease after GH or PE?’ and 33 for representing diverse professions that were not the target HCPs. Of 492 included responses 203 (41%) were from midwives, 75 (15%) GPs, 188 (38%) obstetrician/gynaecologists and 26 (5%) cardiologists. Of these, 446 provided responses to the detailed knowledge questions. Most respondents were female (82%) and approximately half had > 15 years’ experience in their profession, with the exception of cardiologists (70% 10 years or less in the profession). Almost all respondents (94%) see/treat women with a history of PE or GH, and the majority (78%) stated they routinely ask women about their pregnancy history including GH or PE (Table 1). Most respondents were aware of the increased CVD risk after both PE and GH (85%), while 6% thought only PE (4%) or GH (2%) increased risk, but not both (Table 2). The 9.3% who did not know (8.5%) or believed that neither GH nor PE (0.8%) carried a risk were directed to the end of the survey, with the remaining 446 respondents directed towards more in-depth knowledge questions.



Total responses
n=573

Total excluded responses
n= 81

n=48
Did not answer question:
"Do you think that there is an increased risk of developing future cardiovascular disease after gestational hypertension or preeclampsia?"

n=33
Other professions :Unknown (3), Obstetric Physician (8), Other Physicians (3), sonologist (1), obstetric/gynaecology trainees (11), oncologist (1), physiotherapist (1), counsellor (1), registered nurse (1), psychologist (1), Community/Child and family health nurse (3)

Total included responses n= 492
(midwives n=203,
general practitioners n=75,
obstetrician/gynaecologists n=188, cardiologists n=26)

n= 46
Answered 'Neither' or "I do not know" to question: Do you think that there is an increased risk of developing future cardiovascular disease after gestational hypertension or preeclampsia?
Sent to the end of the survey & no further data collected

Total included responses n= 446
(midwives n=171,
general practitioners n=71,
obstetrician/gynaecologists n=178, cardiologists n=26)

Figure 1: Survey inclusion

Table 1: Respondent demographics

	Midwives n(%)	GP n(%)	Obstetrician n(%)	Cardiologists n(%)	Total n(%)*
Total N	**203**	**75**	**188**	**26**	**492**
SEX					
Female	200 (98)	63 (84)	119 (63)	22 (85)	404 (82)
Male	2 (1)	12 (16)	66 (35)	4 (15)	84 (17)
Prefer not to answer	1 (1)	0 (0)	3 (2)	0 (0)	4 (1)
YEARS OF EXPERIENCE					
< 5 years	38 (19)	12 (16)	23 (12)	10 (39)	83 (17)
5-10 years	28 (14)	17 (23)	47 (25)	8 (31)	100 (24)
11-15 years	29 (14)	9 (12)	26 (14)	3 (12)	67 (14)
> 15 years	107 (53)	36 (48)	92 (49)	5 (19)	240 (49)
Prefer not to answer	1 (0.5)	1 (1)	0 (0)	0 (0)	1 (0)
STATE OF PRACTICE					
New South Wales	103 (51)	17 (23)	55 (29)	8 (31)	183 (37)
Victoria	29 (14)	23 (31)	39 (21)	17 (65)	108 (22)
Australian Capital Territory	7 (4)	0 (0)	8 (4)	0 (0)	15 (3)
Queensland	26 (13)	13 (17)	35 (19)	0 (0)	74 (15)
Northern Territory	5 (3)	2 (3)	4 (2)	0 (0)	11 (2)
South Australia	17 (8)	5 (7)	16 (9)	1 (4)	39 (8)
Tasmania	5 (3)	0 (0)	11 (6)	0 (0)	16 (3)
Western Australia	9 (5)	15 (20)	20 (11)	0 (0)	44 (9)
SEE/TREAT WOMEN WITH HISTORY OF PE OR GH					
Yes	139 (95)	73 (97)	177 (94)	18 (69)	461 (94)
No	10 (5)	2 (3)	11 (6)	8 (31)	31 (6)
ROUTINELY ASK ABOUT PREGNANCY HISTORY INCLUDING GH OR PE					
Always	174 (86)	40 (53)	161 (86)	8 (31)	383 (78)
Often	18 (9)	21 (28)	16 (8)	8 (31)	63 (13)
Sometimes	8 (4)	14 (19)	11 (6)	9 (35)	42 (9)
Never	3 (2)	0 (0)	0 (0)	1 (4)	4 (1)

* Percentages may not add to 100% as figures are rounded to whole numbers only

PE = preeclampsia GH = gestational hypertension

Table 2: Respondent answers on existence of cardiovascular risk after preeclampsia and/or gestational hypertension

	Midwives n= 203	GPs n=75	Obstetricians n=188	Cardiologists n=26	Total n= 492
	n= yes (%)	**n=yes (%)**	**n= yes (%)**	**n= yes (%)**	**n= yes (%)**
PE only	12 (6)	1 (1)	7 (4)	0 (0)	20 (4)
GH only	4 (2)	3 (4)	2 (1)	0 (0)	9 (2)
PE and GH	155 (76)	67 (89)	169 (90)	26 (100)	417 (85)
Neither	1 (1)	0 (0)	3 (2)	0 (0)	4 (1)
I am not sure	31 (15)	4 (5)	7 (4)	0 (0)	42 (9)
Proceed to rest of survey	171 (84)	71 (95)	178 (95)	26 (100)	446 (91)
Discontinued from data collection	32 (16)	4 (5)	10 (5)	0 (0)	46 (9)

Overall, most professions had ‘high’ knowledge with regards to women developing CH after PE and GH (Table 3). Although ‘high’ knowledge was displayed for HDP recurrence after PE (‘moderate’ for midwives at 0.72, GP 0.84, obstetricians 0.90, cardiologists 0.96), more varied results were noted for recurrence of HDP after GH, ranging from ‘low’ for midwives, ‘moderate’ for GPs and obstetricians to ‘high’ for cardiologists. Lowest knowledge across all four professions regarded future diabetes risk for both PE (range midwives 0.30 to cardiologists 0.81) and GH (from midwives 0.25 to cardiologists 0.65). Another low scoring condition was peripheral vascular disease (PVD), where knowledge was ‘low’ to ‘moderate’ for both PE and GH. Appendix 19 shows the detailed breakdown of respondent answers, including proportion answering ‘I don’t know’ or skipping questions versus giving a firm but incorrect answer. Conditions with the highest proportion of “I don’t know” answers were diabetes, PVD, and the three distractors (breast cancer, leukaemia and seizures).

Table 3: Means of risk factor knowledge score by profession and by pregnancy HDP (PE or GH)

	Midwives n=171		**GPs n=71**		**Obstetricians n=178**		**Cardiologists n=26**		***P***	
	PE	**GH**	**PE**	**GH**	**PE**	**GH**	**PE**	**GH**	**PE**	**GH**
CH	0.70 (mod)	0.65 (mod)	0.83 (high)	0.85 (high)	0.88 (high)	0.86 (high)	1.00 (high)	1.00 (high)	≤0.001	≤0.001
Diabetes	0.30 (low)	0.25 (low)	0.39 (low)	0.41 (low)	0.40 (low)	0.39 (low)	0.81 (high)	0.65 (mod)	≤0.001	≤0.001
Renal Disease	0.63 (mod)	0.50 (low)	0.81 (high)	0.71 (mod)	0.81 (high)	0.71 (mod)	1.00 (high)	0.88 (high)	≤0.001	≤0.001
Cardiac Death	0.54 (mod)	0.46 (low)	0.76 (mod)	0.67 (mod)	0.79 (mod)	0.69 (mod)	0.88 (high)	0.81 (high)	≤0.001	≤0.001
IHD/MI	0.56 (mod)	0.48 (low)	0.76 (mod)	0.77 (mod)	0.82 (high)	0.74 (mod)	0.96 (high)	0.92 (high)	≤0.001	≤0.001
HDP repeat	0.72 (mod)	0.49 (low)	0.84 (high)	0.77 (mod)	0.90 (high)	0.74 (mod)	0.96 (high)	0.92 (high)	≤0.001	≤0.001
Stroke	0.60 (mod)	0.52 (mod)	0.76 (mod)	0.72 (mod)	0.80 (mod)	0.68 (mod)	0.92 (high)	0.88 (high)	≤0.001	≤0.001
PVD	0.47 (low)	0.41 (low)	0.59 (mod)	0.51 (mod)	0.58 (mod)	0.54 (mod)	0.73 (mod)	0.65 (mod)	0.250	0.022
Overall Mortality	0.61 (mod)	0.51 (mod)	0.77 (mod)	0.67 (mod)	0.78 (mod)	0.71 (mod)	0.92 (high)	0.88 (high)	≤0.001	≤0.001
*Breast Cancer**	0.28 (low)	0.28 (low)	0.43 (low)	0.41 (low)	0.48 (low)	0.46 (low)	0.42 (low)	0.50 (low)	≤0.001	≤0.001
*Leukaemia**	0.29 (low)	0.28 (low)	0.32 (low)	0.37 (low)	0.46 (low)	0.46 (low)	0.46 (low)	0.50 (low)	0.003	≤0.001
*Seizures**	0.16 (low)	0.25 (low)	0.33 (low)	0.49 (low)	0.44 (low)	0.46 (low)	0.27 (low)	0.35 (low)	≤0.001	≤0.001
Overall mean Knowledge score (out of 12)	**5.85** (low)	**5.08** (low)	**7.59** (mod)	**7.36** (mod)	**8.15** (mod)	**7.45** (mod)	**9.35** (high)	**8.96** (high)	**≤0.001**	**≤0.001**

CH= Chronic Hypertension, IHD=Ischaemic Heart Disease, MI= Myocardial Infarction, HDP= hypertensive disorder of pregnancy, PVD= Peripheral Vascular Disease, mod= moderate.

* Breast cancer, leukaemia and seizures are distractors within the survey. These were included despite being conditions that women after HDP are not at greater risk of.

Overall average knowledge scores were ‘low’ for midwives (5.9 for PE and 5.1 for GH), ‘moderate’ for GPs (7.6 PE, 7.4 GH) and obstetricians (8.2 PE, 7.5 GH) and ‘high’ for cardiologists (9.3 PE and 9.0 GH). Only 34% were aware that the risks start to manifest less than 10 years after an affected pregnancy (Table 4). Regarding usual practice around risk discussion with women after HDP, the most frequent practices by all professions were assessing CVD risk (61%) and recommending lifestyle changes (66%) (Table 5).

Table 4: Respondent answers concerning timing of risk signs and symptoms rise after HDP in numbers and percentages

	Midwives n= 171	**GPs n=71**	**Obstetricians n=178**	**Cardiologists n=26**	**Total n= 446**
	n (%)*	**n (%)***	**n (%)***	**n (%)***	**n (%)***
< 10 years after pregnancy	44 (28)	25 (38)	67 (39)	14 (54)	150 (34)
11-15 years after pregnancy	46 (29)	29 (44)	71 (42)	10 (39)	156 (32)
16-20 years after pregnancy	17 (11)	5 (8)	9 (5)	1 (4)	32 (7)
>20 years after pregnancy	11 (7)	1 (2)	6 (4)	0 (0)	12 (3)
Not sure/I don't know	42 (26)	6 (9)	17 (10)	1 (4)	49 (11)
Did not answer	11 (6)	5 (7)	8 (4)	0 (0)	24 (5)
Total answers	160 (93)	66 (93)	170 (96)	26 (100)	422 (95)

* Percentages may not add to 100% as figures are rounded to whole numbers only

Table 5. Healthcare provider's practice regarding risk discussions in numbers and percentages

	Midwives n=171	**GPs n=71**	**Obstetricians n= 178**	**Cardiologists n=26**	**Total n=446**
	n (%)**	**n (%)****	**n (%)****	**n (%)****	**n (%)****
Assess CV risk	69 (40)	59 (83)	120 (67)	23 (88)	71 (61)
Medication	21 (12)	16 (23)	28 (16)	10 (38)	75 (17)
Lifestyle adjustments	84 (49)	56 (79)	134 (75)	20 (77)	294 (66)
Not discussed risk	68 (40)	4 (6)	15 (8)	2 (8)	89 (20)
*Other**	4 (2)	0 (0)	3 (2)	0 (0)	7 (2)

* Other includes (n=7): Further specialist follow-up (n=3), referral letter to GP informing of risks and organise long-term care post-HDP (n=1), mental health assessment/solutions (n=2), advise women to disclose HDP as part of their medical history (n=1).

**Percentages may not always add up to 100% as HCPs were asked to select any/all that apply

Discussion

In this novel Australian HCP survey, most respondents (85%) were aware that both GH and PE increase the long-term risk of CVD and 'always' (78%) ask about HDP history. Despite this reasonably high awareness of HDP being linked to future CVD risks, we identified significant knowledge gaps regarding individual conditions. All professions had consistently lower knowledge scores regarding conditions after GH. This may be because GH is seen as a more benign form of HDP, although studies show GH has similar CVD risk to PE (Riise et al. 2018; Theilen et al. 2016).

Within the context of the selected sample of HCPs, findings were expected to reflect a 'best-case' scenario of knowledge as their specialised training theoretically indicates high overall knowledge. Of the total respondent number (n = 573), 48 (8%) were excluded for not answering the key risk question asked ('Do you think that there is an increased risk of developing future cardiovascular disease after GH or PE?') and 46 of the n = 492 respondents (9%) for being unsure or not believing there are health risks after HDP. Therefore, even in this sample, with sufficient interest in the topic to undertake the survey, a minority had very low or incorrect overall knowledge. Education developed will need to cater to HCPs with no pre-existing knowledge as well as focus on the specific gaps identified by the survey.

International studies exploring HCPs knowledge have reported overall low knowledge (Roth et al. 2019). These studies feature results from highly specialised HCPs with substantial involvement in maternity and women's health care. Only one study has examined knowledge of HCPs on long-term health risks after both PE and GH, whilst all others focus on risks after PE only (MacDonald et al. 2007). In line with another study that found that higher knowledge was associated with belonging to a particular profession (Adekanle et al. 2015), we found higher knowledge among medical professionals compared with midwives. However, in contrast to an American study that found obstetricians generally had more awareness of CVD after PE than internal medicine physicians (Young, Hacker & Rana 2012), cardiologists were the highest scoring profession in this survey, DRANZCOG GPs and obstetricians were quite similar.

This study identified some significant knowledge gaps amongst specialist HCPs. Our study findings resonate with those from similarly targeted HCPs in Canada, Germany, Nigeria and the USA conducted between 2007 and 2017 (Roth et al. 2019). Therefore, from a global perspective, this reinforces the research to practice gap in yet another country a few years on. With international guidelines, including ISSHP 2018 (Brown, Magee, et al. 2018), specifically targeted to assist HCPs on an international scale to better manage and address health after HDP, this practice gap would be expected to narrow.

Given the different scope of practice of various professions, different knowledge and knowledge gaps were expected, and our results can help tailor future education of different HCPs on this topic. For example, options might include improving knowledge about the risks associated with GH amongst specialist GPs and obstetricians. Once this educational material has been piloted with the specialised HCPs, it may be adapted to suit a broader distribution which would include, for example, GPs without specialist qualification in women's health.

In this study, the condition following PE or GH associated with the highest knowledge was CH, consistent with previous HCP studies (Adekanle et al. 2015; Heidrich et al. 2013; MacDonald et al. 2007; Young, Hacker & Rana 2012). Knowledge was lowest with regards to PVD and diabetes across all groups. The wide range of knowledge levels displayed within this study concerning risk of recurring HDP was an unexpected finding and suggests further need for maternity care provider education on this topic.

Only one-third of respondents were aware that risks start to manifest under 10 years after an HDP pregnancy, which may negatively impact on timely follow-up and counselling of affected women. In combination with predominantly low to moderate knowledge of most individual CVD conditions explored within this study, this suggests opportunities are currently being lost to discuss preventive strategies that could improve women's health trajectories. The majority of participants were female. Given that midwifery is a predominantly female occupation in Australia, and GPs and obstetricians closer to 50:50, the response rate of male versus female within these three professions is not unexpected. However, given that a minority of Australian cardiologists are female, the high fraction of cardiology respondents being women suggests bias in this sample.

As with all surveys, it is uncertain how representative it is of the population under study i.e. it is unknown whether knowledge of non-respondents is comparable to that of respondents. Furthermore, the number of respondents in all included subgroups are a small proportion of the national registers (particularly cardiologists) which suggests volunteer bias and also affects generalisability. However, non-representative national HCP numbers along with a highly specialised sample of HCPs can be noted within all research addressing HCP knowledge (Roth et al. 2019). This study was also subject to sample limitations as specialised maternity and women's health HCPs with prior knowledge of the link between HDP and CVD were included in the analysis e.g. the targeting of GP distribution to DRANZCOG holders. This was, however, a deliberate decision, since it can reasonably be expected that these specialised GPs have highest, relative knowledge. Therefore, the knowledge gaps that were found can be expected to extend to the wider Australian GP population. In addition, we targeted these specialised GPs with awareness that response rates to GP surveys are generally very low. For example, recruited numbers were < 15% in this study despite various, targeted recruitment strategies in place (Parkinson et al. 2015). A more general/inclusive spread of midwives, GPs, obstetricians would likely have lesser knowledge than our sample as fewer maternal health qualifications (GPs) and/or not be interested enough in the topic to take the survey. Therefore, when designing education it would be wise to cater for no higher than the levels of knowledge exhibited in our sample, and also cater for lower levels of knowledge.

Our custom-created knowledge score is both a strength, as it allows for a summary of findings across all the conditions and risks, and a limitation, as assigning cut-points is an arbitrary designation. Having included the distractor conditions (breast cancer, leukaemia and seizures) may also have altered the overall score. However, we believe it is important that knowledge is both of conditions that actually do occur more often after GH/PE, plus not incorrectly believing these women are at increased risk of more conditions than they are.

What are the implications?

Research on increased CVD risk after HDP emerged in the early 2000s with the first systematic review published in 2007 (Bellamy et al. 2007). Since then, further research has supported these findings (Brown, Best, et al. 2013), providing close to two decades worth of data signalling the link between HDP and increased CVD risk. Given the length of time that this topic has been addressed in research, it can be an expectation that this knowledge would by now have been translated into practice, particularly amongst our sample that was most likely to include ‘best-case knowledge’ HCPs. That our results did not find this suggests both an even greater knowledge gap in those unaware of the link as well as amongst the non-specialised groups, and ongoing failure to close the knowledge to practice gap on health after HDP. Therefore, this study is valuable from the public health perspective, given the wider context of prevalence and importance of CVD in women.

ISSHP (Brown, Magee, et al. 2018) and SOMANZ (Lowe et al. 2015) recommendations suggest regular follow-up after HDP as well as counselling about women’s individual long-term CVD risk. Designing suitable education for HCPs, appropriate for general use in the Australian healthcare setting and trialling their implementation, would be an important step towards closing the knowledge gap. It is important to establish preferred content and presentation of education for post-HDP health for clinicians, as well as gain insight on enablers and barriers to referral, access and uptake of follow-up consultations.

Conclusion

In our Australian survey of HCP knowledge of risks after HDP, we have found varying knowledge from the targeted professions. Despite ‘high’ knowledge being demonstrated in some areas, significant knowledge gaps were identified. These gaps with regards to general and specific disease risks for women post-HDP are important in planning tailored education for HCPs. This may in turn assist in early identification of CVD risk factors in women with a history of HDP and improved subsequent counselling and management.

Chapter 6: Preferences of Australian healthcare providers regarding education on long-term health after hypertensive disorders of pregnancy: a qualitative study

Context

Chapter Five provided insight into the findings from the national survey, exploring HCP knowledge and consultation practices regarding post-HDP health. This chapter will illustrate the findings from the post-survey interviews. These were conducted with focus on HCP preferences regarding education content, format and access in response to the knowledge gaps identified in the previously conducted survey. This chapter, Chapter Six, is the last of five manuscripts that have been published or prepared for publication as part of this thesis. This chapter relates to overall objective 4(ii) To elicit preferred educational content, format and access regarding health after HDP, as a basis for creating tailored information and health advice for targeted healthcare providers practicing in Australia, including general practitioners, midwives, obstetricians and cardiologists.

Publication details

This paper has been submitted to Health Professions Education for review on 24 June 2021. The journal is peer-reviewed and shares new empirical findings and new ideas in the emerging field of health professions education. This paper has only recently been submitted for review, therefore no peer review comments have been received at the time of the submission of the thesis.

Roth H, Morcos V, Roberts L, Homer CSE, Henry A. Exploring education preferences of Australian healthcare providers regarding long-term health after hypertensive disorders of pregnancy: a qualitative study (submitted to Health Professions Education on 24 June 2021).

Abstract

Purpose: To explore Australian healthcare providers' (HCP) preferred content, format and access to education regarding long-term health after hypertensive disorder of pregnancy (HDP), in order to guide the development of education programs.

Methods A qualitative study was undertaken using a framework analysis. HCP who previously completed a survey about long-term health after HDP were invited to participate. Telephone interviews were undertaken. Participants were asked about preferences and priorities concerning knowledge acquisition around long-term health after HDP.

Results: Twenty HCP (midwives, general practitioners, obstetricians and cardiologists) were interviewed April-May 2020. Four main categories were identified. 'Obtaining evidence-based information for own learning' addressed their own learning with a preference for multi-disciplinary education, preferably endorsed or facilitated by professional organisations. 'Optimising the referral process from hospital to community health services' was about the need for structured long-term follow-up to transition from hospital to community health and align with HDP guidelines. 'Facilitating women's health literacy' addressed the need for evidence-based, print or web-based material to assist risk discussions with women. 'Seizing educational opportunities' addressed the responsibility of all HCP to identify education opportunities in order to initiate key health discussions with women.

Discussion: HCP wanted targeted education about the link between HDP and increased risk of future disease for women and their children, the timing of risk onset and how to mitigate the risk. They provided ideas on how to format and access education for HCP, within the parameters of the Australian healthcare context. This evidence will guide educational developments for HCP on post-HDP health to ensure they can better care for women and families.

Highlights

- Healthcare providers (HCP) have limited post-hypertensive pregnancy (HDP) health knowledge
- The education preferences of HCPs were identified including content, format and access.

- Multidisciplinary education and evidence-based materials is valued by HCPs as well as improved, structured post-HDP care pathways
- These findings will inform development of future education for HCP

Introduction

Hypertensive disorders of pregnancy (HDP), including pre-existing or chronic hypertension (CH), gestational hypertension (GH) and preeclampsia (PE), affect 5-10% of pregnant women globally (Payne et al. 2016). HDP are among the leading causes of maternal and perinatal death, with preeclampsia leading to over 50,000 maternal and 400,000 perinatal deaths globally each year (Duley 2009; Ghulmiyyah & Sibai 2012). HDP are also associated with significant, ongoing risks of maternal disease. Ischaemic heart disease and stroke, two leading causes of death in women globally (Naghavi et al. 2017), are 2-2.5 times higher after PE versus normotensive pregnancies (Brown, Best, et al. 2013; McDonald et al. 2008; Theilen et al. 2016), and risks of Type 2 diabetes and renal disease are also increased (Giorgione et al. 2021). Risks are present within 5-10 years of an affected pregnancy (Arnott et al. 2020; McDonald et al. 2008; Wu et al. 2017) and continue lifelong (Theilen et al. 2016). GH is associated with similar long-term cardiovascular sequelae (Oliver-Williams et al. 2019; Riise et al. 2018; Theilen et al. 2016), while CH is an established CVD risk factor.

Prior studies have mostly found that healthcare providers (HCP) have poor knowledge of women’s increased cardiovascular disease (CVD) risks after HDP (Roth et al. 2019). In general, obstetricians are aware, however they do not always communicate this knowledge to women or other HCP. A recent Australian survey found moderate HCP knowledge, but gaps in knowledge regarding post-GH risk versus PE, how soon health risks increase, and poor knowledge of some specific risks e.g. diabetes (Roth, Homer, Arnott, et al. 2020). Women’s postnatal follow-up engagement is also often limited for reasons including family and caregiving responsibilities, lack of knowledge, and lack of appropriate, and accessible follow-up (Brown, Bell, et al. 2013; Hoedjes et al. 2012; Robbins et al. 2011; Seely et al. 2013). Fragmented models of care and information systems make the transition from hospital-based to community-based care an additional system-level barrier (Seely, Tsigas & Rich-Edwards 2015). HCP awareness of post-HDP risks, along with facilitation of knowledge transmission and the referral process, potentially provides a unique opportunity to plan future screening and preventative health recommendations.

It is now necessary to expand awareness and knowledge amongst HCP of post-HDP health recommendations, but it is not clear how HCP would prefer to learn about this topic. The aim of the study was therefore to explore HCP preferred content, format and access to education regarding long-term health after HDP.

Materials and Methods

Design

A qualitative study using a framework analysis was undertaken. Framework analysis is an approach to facilitate interpretation of qualitative data (Furber 2010; Gale et al. 2013) and is increasingly used across multiple disciplines, including health (Gale et al. 2013; Srivastava & Thomson 2009). The framework offers a flexible, pragmatic and thorough approach to data analysis (Parkinson et al. 2016).

Ethical approval was provided by the local health district's Human Research Ethics Committee (Ref: 18/POWH/326) and the relevant university (ETH18-3061).

Participant recruitment

Participation was open to HCP who had taken part in a recent survey assessing HCP knowledge after HDP (Roth, Homer, Arnott, et al. 2020). These included midwives, specialist obstetrician/gynaecologists, general practitioners (GP) with a diploma in obstetrics and gynaecology, and cardiologists. Participants left contact details at the end of the survey if interested in follow-up interviews. Of the 492 survey participants, 67 left their details and were contacted in March 2020 via email. Twenty (30%) consented to interview, 14 after the initial email, with a further six HCP recruited after a reminder email was sent to call for further participants, in particular GPs and female obstetricians, to establish a more representative sample. All participants were English-speaking HCP, registered to practice in Australia.

Data collection

Data were collected through semi-structured interviews, all conducted by HR in April and May 2020. Nineteen interviews were audio recorded with consent and later transcribed. One interview was conducted via email due to remote participant location, with questions, responses, and follow-up clarifying questions communicated via email, and transcript creation based on the emailed responses. All interviews commenced with the researcher introducing herself and providing a brief summary of the findings of the preceding survey study (Roth, Homer, Arnott, et al. 2020). This assisted in the contextualisation of the questions that followed and provided a transition from the survey to the interview. HCP were asked about preferences and priorities concerning knowledge acquisition and transmission around long-term health after HDP (Appendix A).

Telephone interviews were chosen as they offered greater flexibility in interview scheduling, given the participants were geographically diverse, and also reduced costs and increased convenience (Shuy 2002). As COVID-19 pandemic related travel and contact restrictions were in place, this form of method was practical and appropriate. Phone interviews are increasingly accepted as providing a rich data source for qualitative analysis (Cachia & Millward 2011).

Data analysis

Interviews (n=19) were transcribed verbatim, then all 20 were analysed qualitatively using framework analysis (Furber 2010; Gale et al. 2013). Data analysis was performed independently by two authors (HR, VM). The authors familiarised themselves with the data by reading and re-reading interview transcripts, taking note of preliminary themes. Participants were allocated codes based on the participant's discipline. To increase confidentiality, identifiable features including locations were removed. Both authors coded the data and established the initial themes. The first author abstracted the content further, prior to sharing these for discussion and debate between other authors.

A matrix (Excel Version 16.16.25 for Macintosh) (Microsoft 2018) was used to allocate themes to HCP quotes. A thematic framework was devised from the data and synthesis enabled early data abstraction in the analytic process. Data were then re-assembled from different areas of the interviews and organised into categories. Descriptive and explanatory accounts were developed during the interpretative process and relationships between categories were constructed (Furber 2010; Gale et al. 2013; Pope, Ziebland & Mays 2000) (Appendix B).

Saturation was achieved after 14 interviews, however a reminder email was sent to call for further participants as potential sampling bias was noted. The sample mainly included midwives, obstetricians and a cardiologist but we also wanted to hear from GPs to establish a proportionally similar sample to the preceding survey. Further interviews confirmed that saturation was achieved at 14 interviews and that the suggestions expressed by all four professions were similar.

Results

The 20 participants consisted of 11 midwives (55%), five specialist obstetricians/gynaecologists (25%), three GPs with obstetrics/gynaecology diploma (15%) and one cardiologist (5%). Similar proportions of participants belonging to a given profession took part in the survey and interviews. Fourteen participants were female (70%) and six were male (30%). The HCP worked across six Australian States and Territories, in a mixture of regional and metropolitan practice, public and/or private sectors, and clinical focus versus a more academic focus (Appendix C).

Participants were asked about their preferred content, format of and access to educational materials to assist their knowledge of long-term health after HDP. The four main categories identified were ‘Obtaining evidence-based information for own learning’, ‘Optimising the referral process from hospital to community health services’, ‘Facilitating women’s health literacy’, and ‘Seizing educational opportunities’.

Obtaining evidence-based information for own learning

HCP wanted evidence-based information to expand their own knowledge base. Defining HDP, and clarifying signs and symptoms of various HDP conditions, was important as was explaining the link between HDP and increased CVD and metabolic disorders in women and their children. Evidence-based information regarding follow-up and healthcare planning for women and their children post-HDP was a popular request.

HCP wanted educational materials to be supported by relevant and recent evidence and simple statistics. Access to these resources would provide the HCP with the option to review the evidence themselves and further expand their knowledge on the topic. Including best-practice guidelines for women post-HDP, and more visible promotion of guidelines that already contain post-HDP advice (e.g. ISSHP and SOMANZ) (Brown, Magee, et al. 2018; Lowe et al. 2015), in a more summative manner, was suggested by most participants as they were uncertain of current medium to long-term follow-up recommendations and health planning.

> *I wouldn't know really what to do other than take the blood pressure, maybe ask for a renal function and that's it (Specialist obstetrician)*
>
> *I wouldn't know what the follow-up would actually look like for them. What is the recommendation? (Midwife)*
>
> *If it was presented as advances or changes in protocols, that would be useful (GP)*

Participants expressed a number of preferences regarding the format of educational resources. Face-to-face, interdisciplinary education was preferred by most to promote mutual, professional respect and a team approach. Education delivered to a multi-disciplinary group such as formal or informal clinical meetings, grand-rounds or workshops, using the case-study approach was suggested.

> *It would be good if it was presented by a multi-disciplinary team of GPs, obstetricians, cardiologists and midwives. Because presenting it from a group perspective like that would make it more useful to all of us I think (GP)*
>
> *If members of the team get along together and respect each other’s area of expertise, hence trust each other to impart the correct knowledge to patients. It is important to listen to other professions, respecting other professions, having trust in other professions (Specialist obstetrician)*

Web-based learning was expressed as a popular alternative when face-to-face learning was unavailable e.g. dedicated, topic specific website access to evidence-based information and links. Conferences with interprofessional participation, professional education evenings and journal articles were deemed further opportunities for knowledge expansion. Interprofessional podcasts were also suggested, where a topical series with representation of the various specialty perspectives could be broadcast. Smartphone applications could be another convenient way to access information. These suggestions were practical and geographically inclusive of HCP working in rural or remote areas, where access to face-to-face education may be more challenging.

Most participants stated education should be produced for, and directed at all HCP as a collective, rather than profession or scope specific. This would enable uniform learning amongst multi-disciplinary teams which in turn was conducive to uniform transmission of knowledge to women.

> *In essence if working with a multi-disciplinary team, say midwives and doctors it is important that you are all 'singing from the same hymn sheet' (Specialist obstetrician)*

Professional colleges as well as recognised health bodies and societies were deemed trustworthy distributors of information. Endorsement of these was also seen as acceptable if an independent website was established. HCP mentioned that obtaining 'Continuing Professional Development' (CPD) points for any organised education would be an attractive bonus.

A further suggestion was a yearly awareness day where various stakeholders could provide a platform for educational campaigns, re-enforcing the existing evidence and potentially enhanced by perspectives from women with a lived experience of HDP.

> *It is important to try to push the information out. I think it is important to have enough people saying 'Hey, this is a big deal' or if you have multiple Societies coming out and saying, 'It's a big deal' (Cardiologist)*

Optimising the referral process from hospital to community health services

HCP felt postpartum referral/transition from hospital to community health could be optimised to improve communication about risk factors and recommended follow-up. Referral letters from the specialist or maternity service to the community HCP were felt to be particularly important in establishing an appropriate post-HDP care pattern; including informing the community-based GP about the woman's HDP history, her risk profile and recommended follow-up. To maintain transparency, it was suggested that referrals should also include the information the woman has received thus far, for example:

> *...ensuring decent clinical handover to her GP, so that when she went back to the primary care setting the GP understood that the patient had preeclampsia. What we had warned her about and that she would need to keep her blood pressure under regular surveillance. GPs normally look after things in the first three months of pregnancy. So, you just want to make sure that there was good clinical handover back into primary care, so that the woman and the GP had a shared understanding of what my concerns were and how her care should be programmed for next time (Specialist obstetrician)*

HCP suggested that they often sourced learning from other HCP clinical documentation regarding recommended treatment or follow-up for women. Case discussions or reviews were also deemed conductive to learning. A letter with instructions regarding the medium to long-term care of the woman post-HDP was suggested useful as keeping up to date with evolving specialty practices, especially as a GP, was considered a challenge.

> *If we got more clear instructions as to what to do next, we can't know everything. I don't think there's any harm having a referral template. It's a standard thing that comes with every woman who's a diabetic, who's being seen by the specialist (GP)*

Reminder systems sent to the women would help her to establish good health habits. Existing systems such as for Cervical Screening in Australia were mentioned as examples of efficient health reminder systems which may also work for women with HDP. Other reminders, set through internal GP practices, were also potentially useful post-HDP, including for early intervention in subsequent pregnancies.

Facilitating women's health literacy

All participants wanted to transmit information to women post-HDP and facilitate women's health literacy. To assist this process, all requested information they could provide women in conjunction with their risk discussion, to help with knowledge transmission. This included suitable, supportive materials that could be given to women or that women could be referred to online. Availability of targeted, evidence-based materials such as these could be time-saving and useful for HCP.

Other identified facilitators of knowledge transmission included continuity of care, reminder systems for timely follow-up of women, identifying opportunities where aspects of health could be addressed, and building women's self-advocacy for health. For some, continuity of care contributed to more effective information transmission as there was an established relationship and trust between the woman and the HCP.

> *In the long-term the women have formed that association, they're more comfortable with discussing certain issues. So that gives us an opportunity to look at their overall health. So, in that way, I think we are better placed (GP)*

HCP stated that where women experienced psychological sequelae post-HDP, it was more challenging to constructively address long-term health concerns and focus needed to first be directed to addressing women's mental health. Further challenges expressed by HCP regarding knowledge transmission were the health beliefs held by women and their commitment to engage with and maintain suggested lifestyle changes.

Practices regarding the transmission of health information differed, including relaying information to women based on their assumed health literacy, using research, and tailoring language and discussion so that the women were able to understand it. Most acknowledged it was the HCP’s responsibility to adjust and adapt in order to relay the information in a language and context that the women can relate to and understand.

> *It depends on the woman and about her health literacy. If a woman was really interested in it and I thought that she'd be able to understand it, well then I'd usually give her some quite detailed information (Specialist obstetrician)*
>
> *I usually give them a copy of the paper, and just say to them: ‘Look, this is the actual literature, if you want to read it and this is what I've found and this is why it's really important, this is what underpins the basis of me seeing you today and the reason why I should be seeing you for a long time’. That’s what I do for all my patients (Cardiologist)*

In order for women to become stronger advocates for their own health, HCP deemed it especially important to promote risk mitigation strategies and facilitate women’s health literacy.

HCP addressed the timing of risk discussions and the potential psychological effect of HDP on women’s capacity to process information regarding their future health. Transitioning to parenthood in addition to HDP related, unexpected outcomes regarding pregnancy, birth or postpartum was seen as potentially overwhelming for women, so planning a discussion about their long-term health risks needed to be appropriately timed. Many women post-HDP needed to process the recent pregnancy related events prior to being able to absorb new information.

Seizing educational opportunities

HCP felt they needed to raise targeted health discussions post HDP; that is, they needed to be accountable to women. Some highlighted the importance of not ‘passing the buck’ regarding information transmission to women. It was deemed equally relevant for midwives as it was for obstetricians, cardiologists and GPs to have these discussions. One midwife explained that all HCP should find educational opportunities to address the relevant health topic, implications and ways of mitigating risk. Participants admitted that at times, assumptions may be made about what another

HCP would or should discuss with women post-HDP, meaning women may miss out on important health information and opportunity to address modifiable risks in a timely manner.

> *It's everyone's business. So not saying, 'Oh, that's for the GP to talk about,' because they might not. Or, 'that's the obstetrician's job,' or 'the midwife should've done that. The child and family health nurses will do that.' And so if you have an opportunity to have that conversation and convey that information, then we're all working for the same purpose. So, if you have that opportunity, you find out that someone's got that history, you say, 'Oh, did you know? Has anyone spoken to you about this?' You know? (Midwife)*

HCP also mentioned some aspects of care or information transmission were out of their control. These included women's attitude towards their own health, their general world view as well as their health literacy. Some perceived those with a family history of CVD to be more receptive to information.

> *Women's health literacy is certainly another important factor. The woman being open to such a discussion and able to absorb and reflect on the risks and discussions. The woman's view of medicine in general and how it affects her as a person can interfere with how she takes on information. Are there any other, outside, medical or non-medical influences that may alter her behaviour to be different to what you advise (Specialist obstetrician)*

Discussion

In this study, HCP expressed their preferred content, format of and access to, educational material relating to health after HDP. These preferences were illustrated via the four main categories identified: 'Obtaining evidence-based information for own learning', 'Optimising the referral process from hospital to community health services', 'Facilitating women's health literacy' and 'Seizing educational opportunities'.

HCP supported the need for content to include targeted education about the link between HDP and increased risk of future disease for women and their children, the timing of risk onset and how to mitigate risks. They provided ideas on how to format and access education for HCP, within feasible parameters of the healthcare context.

Suggestions to explore more structured referral and follow-up processes in the transition from hospital to community healthcare were also made. Most HCP were in favour of women-targeted, educational pamphlets or a centralised, reliable, web-based information source with printable documents they could share with women to support their risk discussion. The importance of seizing accountability and opportunity to share important post-HDP health information with women was highlighted by participants, rather than making assumptions that this will be attended by another HCP.

Since the first (2008) systematic review reporting on the link between HDP and CVD (Bellamy et al. 2007), actioning education and awareness amongst HCP and women about post-HDP health has been suggested by both local (Lowe et al. 2015) and international guidelines (Bick et al. 2020; Roth et al. 2019; Savage et al. 2020; Seely et al. 2021). Participants in this study suggested increased visibility of existing guidelines, with some not aware they covered post-HDP health risks and screening. Availability and awareness of guidelines are associated with higher HCP knowledge regarding risk and recommended long-term follow-up (Heidrich et al. 2013).

Access to and awareness of guidelines impacts not only HCP awareness and risk discussion with women, it may also affect handover when women transition postpartum from hospital back to community healthcare. Specialists, who are more likely to have post-HDP risk and recommended follow-up knowledge (Roth et al. 2019), may make assumptions regarding the knowledge of their community healthcare peers, and not clearly document recommended follow-up. Our study found HCP felt that detailed postpartum referrals were an important opportunity to educate peers. A template to assist with this process was supported, as was optimising referral processes via electronic health records and automated reminders.

Integrated primary healthcare involves the coordination of healthcare, connecting care internally and with other, health and related services to assist people achieve best health outcomes (Davies et al. 2009; Starfield, Shi & Macinko 2005; Trankle et al. 2019). In Australia, primary healthcare services are administered at different government levels (state and federal) and funding arrangements (public and private), with little overarching policy or organisation, potentially impeding appropriate post-HDP primary care. Participants in our study, midwifery and medical, recognised the importance of collaborative relationships with primary care networks to adequately address follow-up and continuation of care for women post-HDP.

The concept of shared responsibility of health and hence shared decision making was seen as important by HCP, consistent with other studies addressing disease prevention, screening and treatment (Hird et al. 2017; Keely 2012). For this to occur, both parties need to have knowledge and work in partnership. Clinicians also felt that women needed to take responsibility to make follow-up appointments, attend them and action the advice provided by HCP (Bick et al. 2020).

The HCP in our study mentioned the importance of relaying information to the women as key to understanding their health risks and engagement in mitigation of risks. They considered print or online information useful facilitators when discussing post-HDP, both during consultation and to refer women to post-discussion. This is in line with prior studies involving women after PE, who wanted information from their HCP and take-home materials for future reference (Skurnik et al. 2016). Similar recommendations were made by Seely et al. (2021) where a tick list was developed for HCP for post-HDP discussion.

The internet can be a knowledge enabler, however in the context of health advice, this becomes more challenging. Study participants expressed frustration with women sourcing information via search engines. Generally however, women's preferred information source regarding their long-term health post-HDP is their HCP, and women want HCP guidance towards reliable online/external information sources rather than encountering irrelevant or potentially inaccurate information at self-initiated search (Hird et al. 2017; Roth, Homer, LeMarquand, et al. 2020; Skurnik et al. 2016).

As part of the research team's broader work, we explored knowledge and knowledge gaps as well as education material preferences with women who had experienced HDP (LeMarquand et al. 2020). Knowledge about health post HDP was overall quite similar between women and HCP (Roth, Homer, Arnott, et al. 2020; Roth, Homer, LeMarquand, et al. 2020). Overlap between women and HCP regarding preferred learning content and format was also evident, with both wanting more detailed information about long-term health and modifiable risk factors. In addition, similar to

HCP, women suggested counselling from their HCP should be complemented by detailed and evidence-based, print or web-based information to take home for future reference. Both groups also expressed that all HCP who may provide care to women with a history of HDP, should discuss post-HDP risk with women at any and all given occasions, and agreed on the need for more structured postnatal follow-up to close the knowledge gap and to more actively facilitate the transition from hospital to the community health service.

Strengths and weaknesses of the study

Selection bias is likely, as only HCP who participated in the preceding survey (Roth, Homer, Arnott, et al. 2020) were invited to participate in the interviews, and therefore there is participant bias from an overall highly engaged group of HCP. Additionally, survey participants likely had higher overall knowledge on this topic than the broader HCP community, particularly the GP participants as those with an obstetrics qualification were the GPs targeted. The interviewed HCP also had a clear understanding of the link between HDP and CVD by the time of the interview and had at least some knowledge of post-HDP women's risk factors. If recruitment had been open to a wider group of HCP, the findings may have been different. However, knowledge gaps and many suggestions for education/improvement were still found in the survey and interviews, and there is no reason to believe that suggestions made by our study participants will not be relevant to the broader HCP community. Finally, the concurrent onset of the COVID-19 pandemic and related healthcare setting adjustments may also have led to selection bias, by limiting participation in the interviews for potential participants more affected by the pandemic than others.

Implications and future directions

Studies published over recent years, reporting on various aspects of long-term health post-HDP, suggest that HCP need to access education regarding women's risks post-HDP, CVD screening and prevention options. However, few studies provide recommendations on what the education should look like. These findings will inform educational material which will be piloted by HCP in planned future projects at a local level. Once this educational material has been piloted with the specialised HCP, it may be adapted to suit a broader distribution which would include, for example, GPs without specialist qualification in women's health. A more knowledgeable HCP, as a result of having access to tailored education, may in turn positively contribute to improved communication to women about risk factors, associated recommendations regarding their lifestyle. A structured follow-up medium to long-term may ensue to positively alter a women's health trajectory.

Conclusion

HCP preferred to learn about post-HDP health risk and how to mitigate the risks where possible via multi-disciplinary learning opportunities, and to access further learning via a central, web-based information portal. Information for women as well as referral templates were recommended to facilitate women's transition from hospital to community healthcare and support HCP risk discussions. Endorsement or distribution of education materials was suggested to be via the various professional colleges or via reputable healthcare organisations. The gathered evidence will guide the development of education programs for HCP on health after HDP.

Chapter 7: Discussion and Conclusion

Introduction

This study identified knowledge and knowledge gaps of women and healthcare providers in Australia with regards to health risks after hypertensive disorders of pregnancy and explored their education preferences, informing the development of recommendations to best address the findings within the Australian healthcare setting.

This study included the conduct of a scoping review of the literature addressing knowledge gaps of women and healthcare provider with regards to CVD risk after HDP. The scoping review informed survey design for 1) women's and 2) healthcare provider knowledge about long-term health. The surveys were co-designed and face validated with the end-users i.e. women who have had a lived experience of HDP, and Australian healthcare providers. Current knowledge and knowledge gaps on the topic of long-term health after HDP were identified amongst women in Australia and targeted healthcare providers practicing in Australia, including general practitioners, midwives, obstetricians and cardiologists. Interviews then further explored the views of women and healthcare providers on preferred educational content, format and access regarding health after HDP. These findings can now be used as a basis for creating tailored information and health advice for women who have had a lived experience of HDP and the targeted healthcare providers practicing in Australia.

This chapter provides a synthesis of the findings (Table 1), whilst addressing the aims and objectives and discusses the findings in relation to the evidence from the field. Recommendations are drawn from the combination of the study's findings and they provide a foundation of suggested, essential components when developing education initiatives to address long-term health post-HDP within the Australian healthcare sector.

Table 1: Summary illustrating thesis findings by chapter addressing the research aims and objectives

Aims	**Objectives**	**Summary of findings**
Identify knowledge and knowledge gaps of women and HCP in Australia with regards to health risks after HDP	To conduct a scoping review of the literature addressing knowledge gaps of women and HCP with regards to CVD risk after HDP.	A scoping review was conducted (Roth et al. 2019). Overall, it was found that: • there was a low level of knowledge amongst women and HCP about increased CVD risk after HDP • where women expressed awareness of the link, the majority had sourced their own information, rather than obtaining it through their HCP • most HCP had limited knowledge about the link between HDP and later CVD risk. There were variations in knowledge of HCP, with obstetricians generally more aware than other professions.
	Co-design and face validate a survey with: (i) women who have had a lived experience of HDP (ii) HCP	Two custom-created, face-validated online surveys were designed. They explored: • women's (with a history and without a history of HDP) general and specific knowledge about long-term risks after HDP • women's (with a history of HDP) preferred content, format and access to education about long-term health post-HDP • the survey for women was translated into Arabic and Mandarin. • HCP general and specific knowledge about long-term risks after HDP.

	To explore current knowledge and identify knowledge gaps on the topic of long-term health after HDP amongst: (i) women in Australia (comparing knowledge of women with a lived experience of HDP and women without HDP or other major health concerns) (ii) targeted HCP practicing in Australia, including general practitioners, midwives, obstetricians and cardiologists.	The survey for women revealed that: • knowledge about health post-HDP was moderate in both groups (history of HDP and no HDP) • knowledge was highest regarding risk of repeat HDP & future hypertension • knowledge was lowest for diabetes and renal disease • 36% were aware that risks start <10 years post-HDP • women wanted to receive risk counselling from their HCP early post-HDP birth The survey for HCP revealed that: • most were aware of increased CVD risk post-HDP • knowledge was highest regarding risk of repeat HDP & future hypertension • knowledge was lowest regarding all risks after GH and some specific risks e.g. diabetes. • 34% were aware that risks start <10 years post-HDP • HCPs wanted to receive education about the link between HDP and long-term health risk & modifiable risks for women and their children.

Explore Australian women and HCP education preferences in order to develop recommendations to best address these findings within the Australian healthcare setting	To elicit preferred educational content, format and access regarding health after HDP, as a basis for creating tailored information and health advice for: (i) women who have had a lived experience of HDP (ii) targeted HCP practicing in Australia, including general practitioners, midwives, obstetricians and cardiologists.	Women's interviews found that: • women wanted to receive risk counselling from their HCP early post-HDP birth • evidence-based, print or web-based information to take home • structured PN follow-up with automated reminders for key appointments • automated reminders should detail rationale for follow-up, recommended tests and discussion topics to be addressed at the appointment. HCP interviews found that: • face-to-face, multi-disciplinary, case-based learning (same education across professions) • a web-based information hub would be useful • endorsement or distribution of education by the professional colleges/health organisations • structured referrals from maternity to community health with follow-up plan • HCPs wanted access to educational materials designed for post-HDP women to facilitate risk discussion.

CVD = cardiovascular disease GH = gestational hypertension HCP = healthcare providers HDP = hypertensive disorder of pregnancy

Overview of findings

The scoping review

A scoping review exploring published studies addressing women's and healthcare provider knowledge regarding long-term health after HDP was conducted (Roth et al. 2019) at the commencement of the study, in order to identify existing evidence on the topic and to confirm the validity of the planned research. Overall, it was found that there was a low level of knowledge amongst women and healthcare providers about increased CVD risk after HDP. Where women expressed awareness of the link, the majority had sourced their own information, rather than obtaining it through their healthcare provider. Studies addressing healthcare provider knowledge found that most had limited knowledge about the link between HDP and later CVD risk. There were variations in knowledge of healthcare providers, with obstetricians generally more aware than other professions.

The gaps identified in the scoping review and the gaps addressed in this thesis

The literature review was conducted at the commencement of the study (in 2018, published in 2019) and identified some important gaps that then guided the development of the PhD. The lack of evidence and of clear guidance on how to provide information to women who have experienced HDP represented one of these gaps. More specific aspects of knowledge on the topic needed to be assessed in women and healthcare providers, including more specific knowledge of individual risk factors. Furthermore, it was thought that higher numbers of women and healthcare providers in a variety of countries and healthcare settings, including Australia, could be assessed. The findings contributed to a more in-depth insight into knowledge levels and targeted, knowledge enhancing strategies in this space. Despite having gained insight into some of the enablers to knowledge acquisition and application, it was clear that there was little evidence addressing what form education should take.

It was evident that Australian context-specific research was required in order to further explore women's and healthcare provider knowledge and to make recommendations regarding educational strategies to address knowledge gaps after HDP. By means of online surveys, I then undertook a study to collect information about general and specific knowledge regarding long-term health after HDP from women (with and without a history of HDP) as well as from targeted healthcare providers (obstetricians, midwives, general practitioners and cardiologists). Once the survey findings were analysed, my next study was to conduct interviews with participants from both surveys. These explored educational content, format and access preferences from both groups.

Overview of the combined findings from the women's and healthcare provider studies

The women's study (Phase 1) and healthcare provider study (Phase 2) identified current knowledge and knowledge gaps with regards to long-term, post-HDP health through the use of nationally distributed surveys.

Identified knowledge and knowledge gaps

The women's and healthcare provider level of knowledge about health post-HDP was overall quite similar. Although awareness about some aspects of risk, such as recurrent HDP in a subsequent pregnancy and risk of CH was evident, most risk knowledge was moderate. The most pronounced knowledge gaps amongst women were regarding future risk of heart disease, diabetes and renal disease. Although knowledge levels of the healthcare provider cohort varied greatly amongst the four included professions, the combined healthcare provider knowledge was lowest with regards to peripheral vascular disease and diabetes. Amongst healthcare providers, risk knowledge for health post GH was overall lower. The number of women with a history of GH was too small to draw more conclusive statements, however this group displayed the lowest overall average knowledge regarding their future health risks. Whilst it remains important all aspects of post-HDP health are addressed, overall post GH and diabetes risk knowledge in particular seem to be significant aspects to address in educational material. Our findings furthermore strongly indicate that educational focus should be directed to the evidence suggesting the risks may start to manifest within 10 years after the affected pregnancy. Acknowledging the compounding impact of the post-HDP risk on a woman's age-related, rising absolute risk, is key when assessing and addressing preventive options. These important disease-specific gaps with regards to risks for women post-HDP are important in planning tailored education for women and healthcare providers. Better knowledge amongst women and healthcare providers may in turn assist in early identification of CVD risk factors in women with a history of HDP and improved subsequent counselling and management.

Education preferences

Education preferences were collected from women via the survey and interviews whilst healthcare provider preferences were addressed in the post-survey interviews only (to allow for a shorter survey length and higher survey completion rate). An overlap between the two cohorts regarding suggested learning content and format was evident.

Overall, both, women and healthcare providers wanted more detailed information about long-term and modifiable risk factors. This included information about the risk factors, the signs, symptoms and timing of onset of these post-HDP. They wanted information on the impact of HDP on the health of the children that were exposed to the HDP. Women preferred to receive risk counselling from their healthcare providers early after the HDP-birth. In addition, they suggested that verbal counselling from their healthcare providers should be complemented by detailed and evidence-based, print or web-based information to take home for future reference.

Healthcare providers described wanting access to similar information material that was tailored for women post-HDP and suggested that this would assist them in their risk counselling. They also communicated that all healthcare providers who may provide care to women with a history of HDP should be accountable to discuss post-HDP risk with women and not silently delegate the risk discussion and assume it will be had by another healthcare provider. All professions that participated agreed that all were responsible for raising the topic with the women and to identify moments for educational opportunities. The women's interview findings supported frequent repetition of the health risk information over time as participants felt that as a result, the information would become more embedded in their health knowledge.

Healthcare providers expressed preference of face-to-face, multi-disciplinary, case-based learning and suggested that by a unified approach the same education was offered across professions. Healthcare providers also suggested a web-based information hub to be a useful educational resource, and they preferred educational material to be endorsed or distributed by the various professional colleges and health organisations.

All women proposed a more structured postnatal follow-up to close the knowledge gap and to hence more actively assist the women in the transition from hospital to the community health service. Most women suggested automated reminders for key follow-up appointments to aid this transition. By detailing the rationale for follow-up, recommended tests to be performed, and discussion topics to be addressed at the appointment, these automated reminders serve as educational opportunities which may contribute to the cultivation of women's self-advocacy. Healthcare providers also highlighted the benefits of an optimised and more structured referral process from hospital to community health services, paving the way for evidence-based post-HDP follow-up.

Psychological impact of HDP

Our study found that women felt psychologically affected by the unexpected outcomes of their HDP related pregnancy and birth, suggesting the psychologic sequalae post-HDP need to be acknowledged by healthcare providers and in education materials, in order for women process and act on new longer-term health information. This is echoed by other research studies where psychological aspects acted as a barrier to effective risk discussions post-HDP (Brown, Bell, et al. 2013; Dijkhuis et al. 2020; Hird et al. 2017; Hoedjes et al. 2012; Seely et al. 2021) and women's ability to address recommended lifestyle changes due to the need to prioritise the processing of these unexpected outcomes (Sandsæter et al. 2019).

Linking the findings of this study to existing body of evidence

Chapter Two presents the published literature regarding women's and healthcare provider knowledge about long-term health after HDP, available prior to the commencement of this study. Chapter Three to Chapter Six illustrate all study findings that now contribute to the existing body of knowledge on this topic. The findings for each study segment have been discussed and linked to existing literature, within the individual papers. To avoid further duplication, overarching discussion topics, relevant to the combined results will be addressed in this section.

Creating pathways between professional silos to enhance health knowledge and care for women post-HDP

Studies exploring women's and healthcare provider knowledge on the link between HDP and CVD overall found significant knowledge gaps (Roth et al. 2019). Understanding knowledge gaps in healthcare providers and women regarding CVD health risks after HDP is an important component in addressing these risks. Primary healthcare providers, such as midwives and general practitioners along with women's health specialists such as obstetricians have an opportunity to liaise with women and their families at a transformative time in their lives. Sharing important, evidence-based information on women's health throughout this time enables women to act on their own future health and contribute to healthier futures for themselves, their families and in a larger context to healthier communities.

Healthcare providers often share common core values, skills and knowledge, but are typically taught separately and hence also build their particular professional identities. The functioning of complex healthcare systems such as maternity care, require specialisation within a field (midwifery, obstetrics) and cooperation between professional groups with different professional pathways and expectations which can create professional silos. These occur where areas of the healthcare system are divided functionally and professionally, and often foster relationships based on hierarchies and possibly competition which can create barriers to communication and the development of disjointed work processes. Professional silos commonly affect the ability for maternity services providers to offer multi-disciplinary care that promotes women's choice and continuity of care (Council of Australian Governments: Health Council 2019).

Communication across professions and specialty services is a critical part of good health care (Watson et al. 2016). Research in the domain of health communication has reported on the efficacy of collaboration between different health professionals from different disciplines to ensure quality care (Gotlib Conn et al. 2012; Lewin & Reeves 2011). There is evidence to show that different disciplines, such as midwifery, medicine, and allied health have their own working cultures which can extend to how education is delivered. A further consideration that needs to be made in the context of healthcare provider suggestions regarding distribution of education in Australia is that subscription to the professional colleges is mandatory for medical specialists (general practitioners, cardiologists and obstetricians/gynaecologists), though it remains optional for midwives and not all midwives would be reached through their professional college alone. In view of creating pathways between professionals, educational silos need to be prevented. In our study, healthcare providers predominantly requested that education to be presented to a multi-disciplinary group, rather than specific education created for each group. Studies promote collaborative practice and implementation of strategies that ensure a removal of educational silos (Watson et al. 2016). When different models of interprofessional education are developed for different groups, there is an increased risk of stereotyping behaviours and a reduction of opportunities for creating a level playing field where all participants are valued equally (Bainbridge 2014).

The acute phase of PE is managed within the maternity system where emphasis is on the diagnostic and the immediate treatment rather than on the management of the ongoing, future health risks. In the acute care system, women tend to be guided by healthcare provider expertise and care and may not always be included as part of the care team. Medical practitioners constitute a primary source of information, but women report they do not necessarily get all the information they want from their healthcare providers (Hird et al. 2017). Women are influenced by multiple sources and their motivations and behaviours are complex (Hird et al. 2017). Where women have initiated research or where healthcare providers have guided women to seek specific information, the conversational exchange during appointments tends to be more dynamic (Hird et al. 2017). Women may feel empowered when they engage in web-searches or information searches on social media. Studies have shown that self-initiated searches on social media makes the person, seeking health information or medical treatment, more astute in the decision-making process. Their self-conducted searches have shown to lead to more confidence and engagement during consultations with their healthcare provider (Benetoli, Chen & Aslani 2018; Scull 2020; Smith et al. 2015).

Follow-up post risk discussion: key ingredients

Cardiovascular disease is a significant health problem and one of the leading causes of morbidity and mortality worldwide. In relation to the study topic presented in this thesis, it is evident that in the women's and healthcare provider views, timely risk discussion, promotion and implementation of CVD prevention play essential roles (Roth, Homer, LeMarquand, et al. 2020). Addressing a more generalised approach to CVD prevention, the European Society of Cardiology (D'Ascenzi et al. 2019), discuss the timing of when such CVD prevention should begin. They base their arguments on growing evidence that prevention should start even before the woman gives birth, during pregnancy, aiming to avoid the onset of CVD risk factors. The key, early preventive strategies include adequate nutrition and physical exercise, together with prevention of cardio-metabolic diseases during pregnancy. These initiatives may possibility reverse or mitigate the CVD profile developed in the initial stages of life (Glisic, Muka & Franco 2020).

A number of studies reporting on healthcare provider knowledge regarding this topic have suggested that guidelines may be key in contributing to improved knowledge and care (Roth et al. 2019). Although evidence regarding best practice post-HDP is currently limited, studies exploring normal post-pregnancy parameters and effective strategies to mitigate risk are currently being undertaken by our group (Henry et al. 2020). A further study addressed healthcare knowledge, beliefs and attitudes regarding follow-up care for women with a history of gestational diabetes mellitus (GDM). This study has indicated that increased knowledge about the link between GDM and future diabetes positively influence testing practices and hence opportunity to mitigate risk or engage with early intervention practices (Ehrenthal & Catov 2013).

Studies have shown that common understanding and shared decision-making are important where people attend preventive health consultations with healthcare providers (Kehler et al. 2008). One study found that the person having a consult with their healthcare provider, experienced benefits such as changed thoughts and emotions as well as readiness for lifestyle changes and more accurate perceived knowledge related to health and risk (Kehler et al. 2008). Participants reported that their experienced benefits were related to the general practitioner's communication during the consultation which placed value on the doctor-patient relationship as well as their professional competence. However, participants also expressed some expectations that were not met. These expectations included a limited opportunity to contribute their personal perspective on their health, limited time spent with the general practitioner and appropriate timing of the discussion and lack of personalisation of the risk discussion. This discovery resonates with some of our findings, mainly regarding the women's preferences of appropriate timing and the personalisation of information shared. In addition, to have the opportunity to contribute their personal perspective to the risk discussion concerning their emotional health post-HDP.

A well conducted and well-timed risk discussion with women post-HDP needs to include knowledge of the risks, which ones can be modified and how the rest can be monitored and/or managed. A woman's management of her own health may be hindered if her knowledge and perception of risk are not in line with the actual risk (Lewis, Robinson & Wilkinson 2003). However, primary prevention of CVD also requires accurate assessment of risk status (Davis & Duvernoy 2011). In order to effectively communicate future health risks, important factors that affect the woman's understanding such as her characteristics and health beliefs, the manner, language and the format in which the information is presented (Ghosh & Ghosh 2005; Neuner-Jehle et al. 2011) as well as the communication skills of the healthcare provider need to be considered (Haskard Zolnierek & Dimatteo 2009). In addition, presenting individual risk rather than general population risk has shown to yield better results in proposed interventions (Edwards et al. 2003; Haskard Zolnierek & Dimatteo 2009). This in turn requires the healthcare provider to have adequate knowledge as well as ability to calculate risk.

Sex-specific research in cardiovascular risk prediction

As already explained, cardiovascular disease is the leading global cause of morbidity and mortality amongst women and accounts for about 32% of deaths in females (Institute for Health Metrics and Evaluation 2016). There are a number of female-specific risk factors for CVD, including HDP and metabolic disorders which have been demonstrated to be independent risk factors for the development of premature CVD (Arnott et al. 2020; Bellamy et al. 2007; Brown, Best, et al. 2013; Drost et al. 2012; McDonald et al. 2008). Greater focus needs to be directed towards sex-specific clinical care and research to contribute towards CVD risk prediction. A sex-specific approach to CVD diagnosis may provide opportunity to identify women at risk, implement preventive strategies, provide targeted education and potentially positively influence a women's health trajectory (Arnott et al. 2019). This finding is further supported by a recent collaborative statement which addressed gender based inequalities regarding CVD screening and therapies by the American Heart Association and the American College of Obstetricians and Gynecologists (Brown, Warner, et al. 2018). The statement declares joint responsibility in the improvement of risk identification, creating education opportunities and raising awareness to work together towards a reduction of CVD in women.

The risks of risk disclosure

As illustrated in Chapter 1, women's risk awareness post-HDP, combined with tailored support structures that assist with risk mitigation, may have beneficial consequences on health behaviours. Women with access to knowledge about their increased risk post-HDP and support services that facilitate risk mitigation, may benefit from improved long-term health trajectories. However, for some women, learning about increased risk post-HDP may have a negative impact on their wellbeing. Research on risk disclosure in the more general context of cardiovascular health, has found that emotional and cognitive responses to receiving risk information such as downplaying or fatalism may inform their approach to health behaviours (Honey et al. 2015). Reasons why women may be negatively impacted may be attributed to personal, social or structural reasons.

Women may experience an unrealistic perception of their risk or misunderstand their risk. They may become fearful of their risk with possible disproportionate fear versus actual risk (van Steenkiste et al. 2004). This feeling may be amplified postnatally due to a possibly more limited processing capacity of information received due to fatigue caused by disrupted sleep patterns whilst attending to a newborn baby (Hird et al. 2017). For some women this discovery of ongoing health risks post-HDP, combined

with their recently lived experience of HDP, may drive their decision not to have more children (Brown Bell 2013).
Understanding risk factors and making plans to address these may also result in not finding the suitable service or support to implement their health plan. When services are available, women who may be considered as disadvantaged may not be able to access a service proposed, despite their motivation to address their modifiable risk factors. This access limitation may be due to geographical reasons where travel to the service on a regular basis is too onerous. The lack of childcare options, work exemptions or language may be further service access barriers for women.

Harm may be amplified depending on the way in which the woman learns about her risk. The women's survey conducted as part of this study showed that a significant proportion of women with a history of HDP did not receive a risk discussion with a healthcare provider (Roth, Homer, LeMarquand, et al. 2020). This finding supports Hutchesson et al.'s findings (Hutchesson et al. 2018) that a majority of women with risk knowledge have discovered this by conducting their own research.

Consulting the internet is a valid option to expand on knowledge and seek further details if needed. However, assuming the woman's topic knowledge is suitable, consulting a healthcare provider as primary source is advisable. As this thesis has demonstrated, women prefer to have a risk discussion with their healthcare provider rather than any other delivery format (LeMarquand et al. 2020; Roth, Homer, LeMarquand, et al. 2020), supported by take home information or relevant web-based information to review in their own time. Whilst expert and trustworthy web-based information is available, it may be difficult to locate amongst the many misleading health solutions, the so called 'snake oil', unless it has been specifically recommended by a trusted health source.

Recent research has demonstrated the negative side effects associated with searching for health information via on the internet. Using search engines can make the self-directed information seeker feel worse and increase their health anxiety (Jungmann et al. 2020). Women may also encounter misinformation, whether it is due to the wrong information shortlisted by the search engine (due to the search terms entered) or they shortlist websites that lack relevance, are blogs or opinion pieces rather than evidence based research (Kwan et al. 2012).

Although there is therefore risk of harm with post-HDP health disclosure, failure to do is ethically problematic. When health information is not shared or is withheld from women post HDP, specifically in the context where the healthcare provider is aware of the risks (Wilkins-Haug et al. 2015; Young, Hacker & Rana 2012), it takes away women's autonomy and opportunity to address these risks. In practice, our research (Roth, Homer, LeMarquand, et al. 2020) and that of others (Hutchesson et al. 2018) also demonstrates, as discussed, that many women will self-source information. This can possibly be more harmful than a supported discussion with a healthcare provider. Knowledge of the HDP link to future CVD in both the healthcare providers and women would optimally contribute to progressive adjustments to potentially mitigate the risk of future disease. The benefits of guided, structured follow-up are therefore likely to outweigh risks.

Recommendations for the development of educational material addressing long-term health after HDP

These recommendations were derived from the combined survey and interview findings, from both, the women's and healthcare provider studies and are advised to be considered when developing an educational resource, addressing long-term health after HDP. There are five recommendations:

1. 'Ensure topics considered as essential are included in any educational materials',
2. 'Ensure that the format of educational materials is varied and accessible via a variety of sources',
3. 'Ensure that systems are in place to facilitate the transition from hospital to community healthcare',
4. 'Ensure that women's mental health post-HDP is addressed in educational material',
5. 'Ensure that educational materials support life-long learning and enhance health literacy and self-advocacy in health-related matters'.

A summary of these recommendations, with subtopics and reference to the relevant thesis chapter, is illustrated below.

Recommendation 1: Ensure topics considered as essential are included in any educational materials

This study has identified a number of information items to be included in educational material, addressing long-term health after HDP. These items are based on the findings from this study:

i. Define HDP and its sub-groups clearly.

Thesis chapter reference: Chapters 4 & 6

ii. Explain the link between HDP and future health risks. Explain the pathophysiology (as currently known) where possible. A simplified explanation of the pathophysiology may be of benefit to many women. These should be supported with evidence available online (preferably open publications and linked to local, context-based organisations to provide women with the option to explore further content.

Thesis chapter reference: Chapters 2-6

iii. Define the risks that women and their children are at risk of after HDP. Include risk ratio where available in relative risk and absolute risk with reference to the most recent evidence and linked to local, context-based organisations for further content. Statistics should also be illustrated in simple infographics. The conditions that should be included at minimum are: chronic hypertension, diabetes, renal disease, cardiac death, ischaemic heart disease/myocardial infarction, repeat HDP in subsequent pregnancies, stroke and overall mortality.

Thesis chapter reference: Chapters 2-4 & 6

iv. Explain the signs and symptoms of the health conditions women and their children are at increased risk of. This includes which signs to monitor and when to seek medical advice.

Thesis chapter reference: Chapters 2-4 & 6

v. Address modifiable risk factors. Women want to know how they can reduce their own and their children's risk of developing future complications. This may relate to a subsequent pregnancy or relate to general health long-term. Women wanted to be able to be proactive about their own health. They preferred comprehensive information about modifiable risk factors and (optimal weight, where to go for healthy eating tips and guidance, what exercise to do and how much). Women also wanted to know those risk factors that are not modifiable.

Thesis chapter reference: Chapters 2-4 & 6

i. Explain the timing of when signs and symptoms of the conditions may start to manifest.

Thesis chapter reference: Chapters 3-6

Recommendation 2: Ensure that the format of and access to educational materials is varied

This study identified a number of preferred formats of educational material addressing long-term health after HDP and preferred access to these. These format and access suggestions are derived from findings from this study and are as follows:

i. Prioritise verbal risk discussion to be led by healthcare providers (where possible).

Thesis chapter reference: Chapters 2-4

ii. Provide education via online materials. This may include links to existing research or trusted information by key health organisations.

Thesis chapter reference: Chapters 3, 4 & 6

iii. Provide education via print materials.

Thesis chapter reference: Chapters 2-4 & 6

iv. Provide education via smartphone applications. This is a convenient means to access information.

Thesis chapter reference: Chapters 3, 4 & 6

v. Ensure access to education via social media. Women suggested that specific interest groups may benefit from being targeted with health information.

Thesis chapter reference: Chapters 2-4 & 6

vi. Ensure endorsement of or access to education via professional colleges and health organisations.

Thesis chapter reference: Chapters 2-4 & 6

vii. Language and accessibility need to be considered. Health information should be available in various languages and be suitable for women living with cognitive, hearing and visual impairments.

Thesis chapter reference: Chapters 4 & 6

Recommendation 3: Ensure that systems are in place to facilitate the transition from hospital to community healthcare

This study identified a number of preferences to better support and facilitate the transition from hospital to community healthcare. These suggestions are derived from findings from this study and are as follows:

i. Develop a post-HDP follow-up plan with women, incorporating the advice from current guidelines such as ISSHP and SOMANZ. It would be useful to illustrate a step-by step-follow-up plan for post-HDP women that describes the regularity of health checks with a general practitioner as well as the tests (serology/BP measurement) that are recommended to be done. These should be supported by evidence and include the most recent international and local guidelines such as the ISSHP and SOMANZ guidelines.

Thesis chapter reference: Chapters 2-4 & 6

ii. Ensure the timing of the risk discussion suits the woman. Women want to receive information within 0-6 months of birth and want to hear it on multiple health encounters. Generally, women will receive some form of discharge summary from their maternity services. Certain health conditions experienced by women during pregnancy, like HDP, warrant a more detailed discharge letter from the maternity specialist to the general practitioner. Assumptions of knowledge of the receiving healthcare provider should not be made and the content of the referral should be shared with the woman. A detailed referral addressed to the community healthcare provider should include the long-term health risks relevant to the woman and timing of onset of risk. It should furthermore include, with reference to the relevant guideline, any tests that need to be conducted and further specialist referrals to be considered.

Thesis chapter reference: Chapters 2-4 & 6

iii. Offer automated reminders. Women suggested that it may be preferable to be 'flagged' by a state/national register or the equivalent to the cervical screening program or the Diabetes Register. Without the appropriate resources and infrastructure to set up a register, a form of automated recall system could be considered by the woman's general practitioner. A prompt via email, text or conventional mail can be useful. These reminders should contain a recommended follow-up appointment and mention the rationale. This may include the topics to be addressed and suggested tests to be done at the follow-up appointment.

Thesis chapter reference: Chapters 2-4 & 6

iv. Provide and promote access to continuity of care where possible.

Thesis chapter reference: Chapters 4 & 6

Recommendation 4: Ensure that women's mental health post-HDP is addressed

This study has identified that women with a history of HDP may experience psychological sequelae. These recommendations are derived from findings from this study and are as follows:

i. Address the psychological impact of HDP. Acknowledgement of the psychological impact may assist the woman to process unexpected events during pregnancy, labour and birth and postpartum. Appointments with the healthcare provider may present an opportunity to address this and support women in the referral, if indicated, to counselling or additional support, in addition to general practitioner appointments. As a result of unprocessed events and emotions the woman may not be ready to address her future health until these are addressed.

Thesis chapter reference: Chapters 2, 4 & 6

Recommendation 5: Ensure that educational materials support life-long learning and enhance health literacy and self-advocacy in health

This study has found that both cohorts, healthcare providers and post-HDP women want learning materials that are supported by current and relevant evidence. Access to this information will enhance learning and improve health knowledge. In healthcare providers improved health knowledge may lead to more proactive risk assessments of post-HDP women and enhance risk discussions. An improved knowledge foundation may result in post-HDP women engaging in healthier lifestyle choices and self-initiated health discussions with healthcare providers:

i. Advocate for health and health knowledge.

Thesis chapter reference: Chapters 2, 4 & 6

ii. Promote primary health principles.

Thesis chapter reference: Chapters 2-6

iii. Facilitate women’s and healthcare provider learning; individually and from each other.

Thesis chapter reference: Chapters 2, 4 & 6

iv. Lend assistance with lifestyle changes.

Thesis chapter reference: Chapters 2-4 & 6

v. Conduct further research and promote participation in research.

Thesis chapter reference: Chapters 2-6

Current management versus proposed management for women after an HDP pregnancy

Chapter 1 and 2 illustrated the overall lack of awareness in women and HCP of the extent of health risk post-HDP. It also highlighted a gap in evidence-based guidance addressing optimal post-HDP follow-up as well as a gap regarding advice on what post-HDP education should look like for women and HCP (Adekanle et al. 2015; Brown, Best, et al. 2013; Heidrich et al. 2013; Hird et al. 2017; Hutchesson et al. 2018; MacDonald et al. 2007; Roth et al. 2019; Seely et al. 2013; Skurnik et al. 2016; Traylor et al. 2016; Viana Pinto et al. 2014; Wilkins-Haug et al. 2015; Young, Hacker & Rana 2012).

Postnatal care recommendations for women who have experienced HDP are addressed in a diverse manner in the guidelines available (Brown, Magee, et al. 2018; Gamble et al. 2019; Lowe et al. 2015; Magee et al. 2014). Whilst local guidelines (Lowe et al. 2015) are often adapted and translated into state-based practice guidelines, they do not convey a clear postnatal pathway for healthcare providers and the recommendations for post-HDP care vary (New South Wales Health 2011; Queensland Health 2021; Victorian Agency for Health Information 2021). This study's findings strongly suggest that there is currently no structured follow-up for post-HDP care in Australia, and a minority of women receive advice about ongoing health for themselves and their children post-HDP.

As the summarised recommendations from the study findings suggest, there are therefore additional practices that should be considered in follow up planning for all women who experience HDP. Women would like educational material in conjunction with a risk discussion with their healthcare provider, within 6 months of birth. This education should include information regarding their specific HDP diagnosis, their risks and timing of likely manifestation of risk factors, symptoms or diagnosis of a health condition. The link between HDP and future risk, for themselves and for their children, should be clearly explained and information on strategies that can mitigate this risk, should be discussed.

Women and healthcare providers supported clear and detailed follow-up planning in order to facilitate the transition between hospital and community healthcare. Recommendations from this study illustrate that details such as the regularity of health checks as well as recommended tests should be clarified and that a reminder system initiated by community healthcare or other suitable organisation may be a useful aid to maximise attendance.

The discussion and acknowledgment of the psychosocial impact of HDP is recommended and that appropriate follow up is ensured. The importance of enhancing women’s health literacy is highlighted in the recommendations from this study.

Strengths and limitations

All research has strengths and limitations and this PhD is no exception. In each of the chapters describing the findings, specific section on strengths and limitations are provided and therefore these will not be repeated here. However, this study is the first to examine the Australian context of health awareness amongst women and healthcare providers after HDP and to explore education preferences amongst these two groups in order to adequately address any identified knowledge gaps. The study used data generated from surveys and interviews in order to identify where the knowledge gaps were and to design education recommendations for women post-HDP and for healthcare providers, suitable for general use in Australian healthcare settings. The survey for women was co-created with and face-validated by women who have experienced HDP and by a variety of healthcare providers who provide care within women’s health services, which gives added value to the survey.

Within the context of the selected sample of the two cohorts, findings were expected to reflect a ‘best-case’ scenario of knowledge. The healthcare provider’s specialised training theoretically indicates high overall knowledge and in the women’s study close to half of the participants were recruited via the P4 study or the consumer group AAPEC. Therefore, a more knowledgeable group of women may be represented in the results rather than the overall HDP population. Similarly, if the same survey were to be conducted with less specialised healthcare providers such as general practitioners, the results may have illustrated different results and overall provided a more balanced overview.

Despite making the survey for women also available in Arabic and Mandarin and the reasonable effort to target multicultural groups, the language options were not engaged with to their full potential. Therefore, the surveys nor the interviews conducted with women adequately reflected Australia's cultural diversity.

Recommendations for future research

Suggested future research would involve the development, implementation and assessment of educational material, based on the findings of this thesis and recommendations in this Chapter, including acceptability and utility to women and healthcare providers.

A future study may aim to enhance risk counselling, management of health after HDP and potentially contribute towards improving women's health trajectories. In an initial stage, a web-based educational resource targeted at women post-HDP and at healthcare providers could be developed, implemented and its acceptability and utility assessed.

To further enhance impact of an educational resource and to address the transitional (maternity to community care) health support preferences expressed by both women and HDP, acceptability and utility of reminder systems for post-HDP follow-up visits may be evaluated. Furthermore, improvements in women's and healthcare provider knowledge about health after HDP could be assessed by pre-and post-educational knowledge assessment. Obtaining information and suggestions from women and healthcare providers may be of use in order to improve the educational resource for potential wider scale-up. Measuring women's self-reported health behaviour changes pre- versus post-education and comparing program acceptability and utility between HDP subgroups (preeclampsia, gestational hypertension, chronic hypertension) may provide further useful feedback. Such an educational resource may contribute to enhanced knowledge and result in improved, evidence-based follow-up with a potential for early detection and intervention to modifiable CVD risks post-HDP. Findings may inform adjustments to existing resources in order to prepare for more broad distribution with potential national scale up.

Conclusion

In line with prior literature, reflecting insufficient knowledge amongst healthcare providers and women regarding CVD risks after HDP, this study has identified knowledge and knowledge gaps of women and healthcare providers in Australia with regards to health risks after HDP. In view of closing the knowledge gap and developing future educational materials, this study has identified women's and healthcare provider's preferred education elements in order to learn about post-HDP health risk and how to mitigate the risks. Psychologic sequelae post-HDP need to be acknowledged and addressed as doing so will help women access further support as they negotiate their health journey post-HDP. Recommendations have been developed to guide future, tailored education within the Australian healthcare setting. Improving awareness of risk factors may assist in early identification of CVD risk factors in women with a history of HDP and provide, in conjunction with further research on effective risk reduction methods, a unique opportunity to plan future screening and preventative health recommendations by primary healthcare providers. This combination of actions may positively enhance health behaviours amongst post-HDP women, especially in the context of the relatively early timing of when health risks increase after HDP.

The development of tailored education as well as the exploration of the utility and feasibility of such a resource is now indicated. Multicultural input and education in languages such as Arabic and Mandarin would expand the education support to a wider community. Integration of follow-up strategies that aid women's transition from maternity services to the community and enhance interprofessional communication are recommended, enabling features. Whilst information alone does not equate to action on change, it is an important step in the approach for change. Education may lead to improved knowledge in both, post-HDP women and healthcare providers and may, in turn, lead to timely and improved subsequent counselling, management and overall improved women's health trajectories.

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Appendices

Appendix 1: Prince of Wales Research Governance Ethics approval letter

NSW
GOVERNMENT
Health
South Eastern Sydney
Local Health District

HUMAN RESEARCH ETHICS COMMITTEE
Room G71 East Wing
Edmund Blacket Building
Prince of Wales Hospital
RANDWICK NSW 2031
Tel: 02 9382 3587 Fax: 02 9382 2813
SESLHD-RSO@health.nsw.gov.au
www.seslhd.health.nsw.gov.au/services-clinics/directory/seslhd-research

04 October 2018

Dr Amanda Henry
Attention: Mrs Heike Roth
St George Hospital
Women's and Children's Health
KOGARAH NSW 2217

Dear Dr A Henry

HREC ref no: 18/156 (HREC/18/POWH/326)
Project title: Postnatal cardiovascular risk after hypertensive disorders of pregnancy (preeclampsia, gestational hypertension): Narrowing the knowledge gap for women and healthcare providers by applying tailored education.

Thank you for submitting the above application for ethical and scientific review and for your correspondence dated **04 October 2018** to the Executive Officer responding to questions which arose at the Executive Committee meeting on **19 September 2018.** Authority to grant final approval was delegated to the Executive Officer. I am pleased to advise that that the proposal meets the requirements of the National Statement on Ethical Conduct of Human Research and ethics approval has been given for the following:

- HREA submission code AU/1/FC87310, dated 30 June 2018
- Ethics Project Description Version 1 dated 26 June 2018
- Distress Protocol Version 1 dated 26 June 2018
- Participant Withdrawal Focus Groups Version 1 dated 26 June 2018
- Sample Survey for HealthCareProviders Version 1 dated 29 June 2018
- Sample Survey for Women Version 1 dated 29June 2018
- PISCF Education Package Focus Group Women Version 3 dated 04 October 2018
- PISCF Presurvey Focus Group Women Version 3 dated 04 October 2018
- Letter of Invitation to the survey HealthCareProviders Version 2 dated 20 August 2018
- Letter of Invitation to the survey Women Version 2 dated 20 August 2018
- PISCF Focus Group HealthCareProviders Version 3 dated 04 October 2018
- Verbal script for consent over phone Education Interview Women Version 2 dated 20 August 2018
- Verbal script for consent Post Survey Education Interviews HealthCareProviders Version 2 dated 20 August 2018

- HCP draft survey Version 2 PDG from SurveyMonkey
- Process of translation Version 1 dated 20 August 2018

Ethics approval is valid for the following site(s):

- St George Hospital

Conditions of approval

1. This approval is valid for 5 years from the date of this letter.
2. Annual reports must be provided on the anniversary of approval.
3. A final report must be provided at the completion of the project.
4. Proposed changes to the research protocol, conduct of the research, or length of approval will be provided to the Committee.
5. The Principal Investigator will immediately report matters which might warrant review of ethical approval, including unforeseen events which might affect the ethical acceptability of the project and any complaints made by study participants.

Optional It is the responsibility of the sponsor or the principal (or co-ordinating) investigator of the project to register this study on a publicly available online registry (eg Australian New Zealand Clinical Trials Registry www.anzctr.org.au).

For Public Health Sites: You are reminded that this letter constitutes ethics approval only. You must not commence this research project until you have submitted your Site Specific Assessment (SSA) to the Research Governance Officer of the appropriate institution and have received a letter of authorisation from the General Manager or Chief Executive of that institution.

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website: https://www.seslhd.health.nsw.gov.au/services-clinics/directory/seslhd-research

Please quote **18/156** in all correspondence.

We wish you every success in your research.

Yours sincerely

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Andrew Bohlken
Executive Officer, Human Research Ethics Committee

Appendix 2:

(a) Site Specific Approval for St George Hospital in the SESLHD

NSW GOVERNMENT | Health
South Eastern Sydney
Local Health District

RESEARCH SUPPORT OFFICE

Room G71, East Wing
Edmund Blacket Bldg
Prince of Wales Hospital
Cnr High & Avoca Streets
RANDWICK NSW 2031
Tel: (02) 9382 3587
Fax: (02) 9382 2813

5 December 2018

Dr Amanda Henry
Department of Maternal Fetal Medicine
Royal Hospital For Women
Barker St
Randwick NSW 2031

Attention: Heike Roth

Dear Dr Henry,

SSA Ref: 18/G/213
HREC ref no: 18/156 (HREC/18/POWH/326)
Project title: Postnatal cardiovascular risk after hypertensive disorders of pregnancy (preeclampsia, gestational hypertension): Narrowing the knowledge gap for women and healthcare providers by applying tailored education

I refer to your Site Specific Assessment application for the above titled project. I am pleased to advise that on 4 December 2018, the General Manager granted authorisation for the above project to commence at the St George Hospital.

In addition to the documents approved by the lead Ethics Committee which provided the ethical approval for this study, the following documents have been reviewed and approved for this study at the St George Hospital:

- St George Hospital, Participant Information Sheet/Consent Form – Education Package Focus Group, Local governance version 3, dated 4 December 2018
- St George Hospital, Participant Information Sheet/Consent Form – Healthcare Providers, Local governance version 3 dated 4 December 2018
- St George Hospital, Participant Information Sheet/Consent Form – Presurvey Focus Group, Local governance version 3, dated 4 December 2018

The following conditions apply to this research project. These are additional to any conditions imposed by the Human Research Ethics Committee that granted ethical approval:

2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.

Please find enclosed the following documents which have been executed:

- Honorary Research Associate Approval Letter for Heike Roth.

If you have any queries relating to the above please contact the Research Support Office on (02) 9382 3587.

Yours sincerely

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Asatina Viviani-Tukutama
Research Governance Officer

Enc.

(b) Honorary Research Associate approval letters

NSW GOVERNMENT
Health
South Eastern Sydney
Local Health District

RESEARCH SUPPORT OFFICE

Room G71, East Wing
Edmund Blacket Bldg
Prince of Wales Hospital
Cnr High & Avoca Streets
RANDWICK NSW 2031
Tel: (02) 9382 3587
Fax: (02) 9382 2813

5 December 2018

Dr Amanda Henry
Department of Maternal Fetal Medicine
Royal Hospital For Women
Barker St
Randwick NSW 2031

Attention: Heike Roth

Dear Dr Henry,

SSA Ref:	18/G/213
HREC ref no:	18/156 (HREC/18/POWH/326)
Project title:	Postnatal cardiovascular risk after hypertensive disorders of pregnancy (preeclampsia, gestational hypertension): Narrowing the knowledge gap for women and healthcare providers by applying tailored education

Thank you for the request for addition of an Associate Investigator to the above study.

The addition of Heike Roth as an Associate Investigator at the St George Hospital for the duration of the above study is noted and authorised.

The Associate Investigator's appointment as Honorary Research Associate has been authorised by the General Manager – Ms Leisa Rathborne.

Yours sincerely

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Asatina Viviani-Tukutama
Research Governance Officer

Appendix 3: University of Technology Sydney Ratification approval letter

UNIVERSITY OF TECHNOLOGY SYDNEY

Human Research Ethics Committee
Ethics Secretariat
C/O Research and Innovation Office
15 Broadway, Ultimo NSW 2007

T: +61 2 9514 9681
Research.Ethics@uts.edu.au

PO Box 123
Broadway
NSW 2007 Australia
www.uts.edu.au

UTS CRICOS PROVIDER CODE 00099F

29 March 2019

Professor Caroline Homer
Faculty of Health
UNIVERSITY OF TECHNOLOGY SYDNEY

Dear Carolyn

UTS HREC ETH18-3061 – "Scientific title: Postnatal cardiovascular risk after hypertensive disorders of pregnancy (preeclampsia, gestational hypertension): Narrowing the knowledge gap for women and healthcare providers by applying tailored education. Public use title: Postnatal health risks after blood pressure complications during pregnancy: Increasing awareness amongst women and healthcare providers by applying tailored education" [External Ratification: Prince of Wales Hospital HREC 18/156 – HREC approval (HREC/18/POWH/326) – 04/10/2018 to 04/10/2023]

The UTS Human Research Ethics Expedited Review Committee has reviewed your application and agreed that the application meets the requirements of the NHMRC National Statement on Ethical Conduct In Human Research (2007). I am pleased to inform you that your external ethics approval has been ratified.

This ratification is subject to the standard conditions outlined in your original letter of approval. You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy (http://www.gsu.uts.edu.au/policies/research-management-policy.html).

Your approval number is UTS HREC REF NO. ETH18-3061.

Approval will be for the period specified above and subject to the provision of annual reports and evidence of continued support from the above-named Committee. Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact Research.Ethics@uts.edu.au.

Yours sincerely

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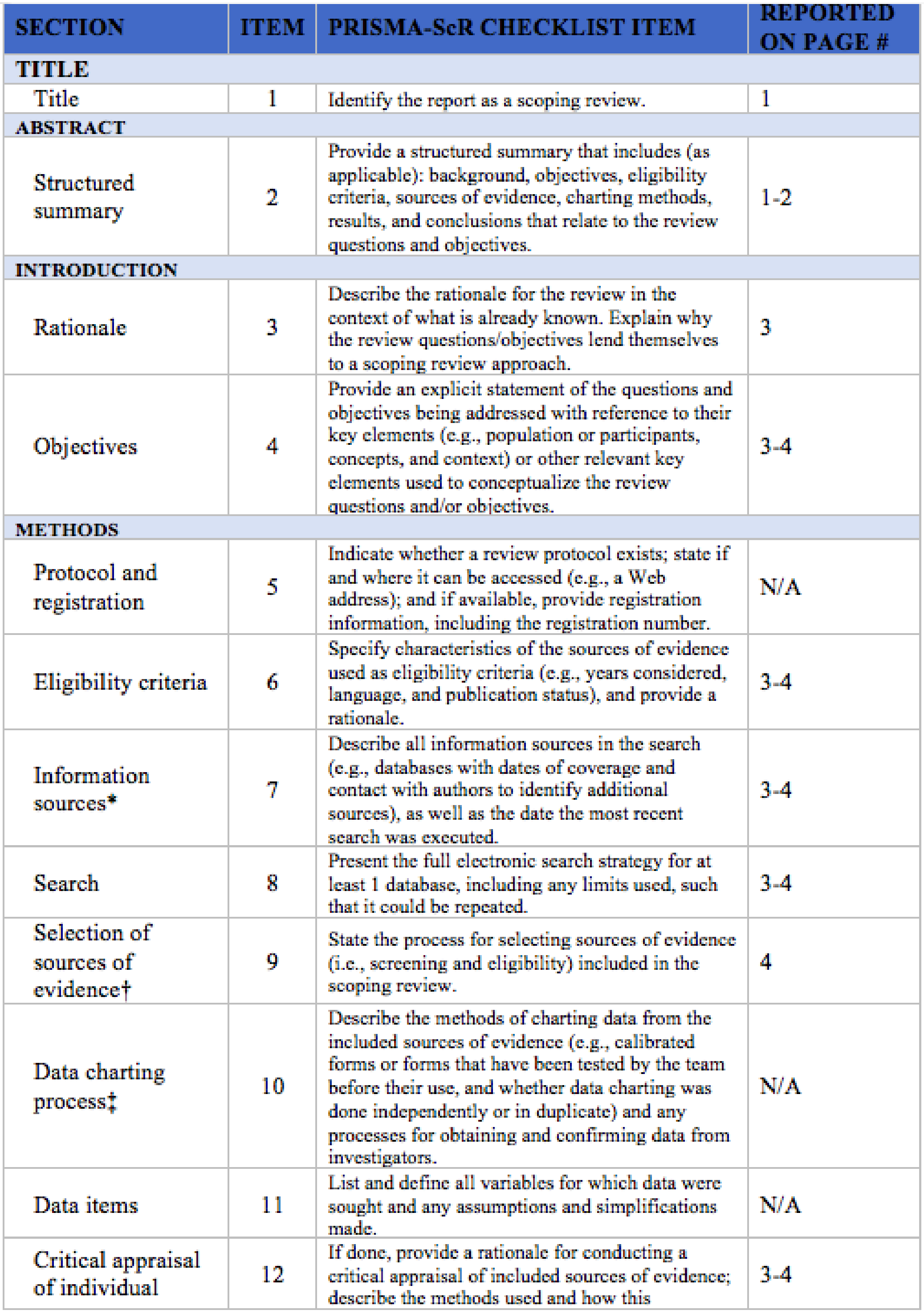
Associate Professor Beata Bajorek
Chairperson
UTS Human Research Ethics Committee

Appendix 4: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	3-4
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	3-4
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	3-4
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	3-4
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	4
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	N/A
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	N/A
Critical appraisal of individual	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this	3-4

Appendix 4 (cont.)

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
sources of evidence§		information was used in any data synthesis (if appropriate).	
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	3-4
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	4
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	4
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	4-9
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	4-9
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	4-9
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	9-13
Limitations	20	Discuss the limitations of the scoping review process.	14
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	14
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	14--15

Appendix 5: CASP Quality Appraisal of Included Studies

Qualitative Research	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	**Comments**	**Number of Criteria Met**
Brown et al.	✓	✓	**X**	✓	✓	✓	✓	✓	✓	✓		9/10
Seely et al.	✓	✓	✓	**CT**	✓	**X**	✓	✓	✓	✓		8/10
Skurnik et al.	✓	✓	✓	✓	✓	✓	**X**	✓	✓	✓		9/10
Hird et al.	✓	✓	✓	✓	✓	**CT**	**X**	✓	✓	✓		8/10

✓= yes, X = no, CT = cannot tell

Appendix 6: Search Terms used in electronic bibliographic databases

Education, knowledge, barriers and Motivators	Hypertensive Disorders of Pregnancy	Risk of Cardiovascular Disease
Education Education, Medical, Graduate Education, Public Health Professional Patient Education as Topic Education, Nursing, Continuing Education, Nursing, Graduate Education, Nursing, Baccalaureate Education, Nonprofessional Nursing Education Research Education, Medical Education, Medical, Undergraduate Education, Nursing Education, Nursing, Associate Education, Professional Education, Continuing Health Education Education, Medical, Continuing Education* Educational intervention Information dissemination Knowledge sharing Health Knowledge, Attitudes, Practice Knowledge Knowledge Management Knowledge Bases Risk Assessment Knowledge gap Awareness Belief Risk perception Perception Risk knowledge Attitude of Health Personnel Perspectives Attitude*	Preeclampsia Pre-Eclampsia Gestational hypertension Hypertension, Pregnancy-Induced	Risk identification Risk Factors Future cardiovascular disease Later cardiovascular disease Long-term cardiovascular risk

Appendix 7: Characteristics of the included literature

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
Women's knowledge							
Brown et al. 2013 (Brown, Bell, et al. 2013) **United Kingdom** **Women's perception of future risk following pregnancies complicated by preeclampsia**	Determine women's understanding of cardiovascular risk following a pregnancy complicated by PE	QUALITATIVE Semi-Structured Interviews	At 5.8 – 19 months post PE	Women with history of PE n=12	Family history of CVD associated with increased understanding of future cardiovascular risk 4 women with first degree relatives with CVD and 3 with HT were more likely to recall their increased risk 5 women did not recall future risk	Planning future pregnancy Family history CVD Healthy home for family	Lack of knowledge Caregiving responsibilities

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
					being discussed in clinic 10 women stated they were not the "typical stereotype of a person at risk of heart problems"		
Seely et al. 2013 (Seely et al. 2013) **United States of America** **Risk of future cardiovascular disease in women with prior preeclampsia: a focus group study**	To assess level of knowledge regarding link between PE and CVD, motivators and barriers to lifestyle change and interest in a lifestyle modification	QUALITATIVE Focus Group	≤ 5 years after pregnancy with PE	Women with history of PE n=20	"Majority" had no prior knowledge of link between PE and CVD "Few" said clinician had discussed long-term CVD risk. "Few" knew about link from online reading	Knowledge of risk Desire to stay healthy for family Access to community of women also affected by PE	Lack of time. Cost of healthy foods Family responsibilities Transition from obstetric care to primary care

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
	program in women with a history of PE				"Majority" said PE not fully explained during pregnancy. "Many" indicated post-partum period was a good time to incorporate lifestyle changes		
Viana Pinto et al. 2014 (Viana Pinto et al. 2014) 2014 **Portugal** **Preeclampsia and future cardiovascular risk: are women and general**	To evaluate the impact of PE on the modification of lifestyle habits and decreasing cardiovascular risk factors in women at least	CQUANTITATIVE Survey	Pregnancy > 6 months ago	Women with PE and with CH with super-imposed PE n=78	31% of the women stated that their basic HCP had addressed the item preeclampsia and future cardiovascular risks.		Lack of follow-up care structure

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
practitioners aware of this relationship? The experience from a Portuguese Centre	6 months following PE				Almost 58% assessed blood pressure at least monthly 28% undertook aerobic exercise at least weekly Significant reduction in weight in women with superimposed PE 23% women had one appointment per year with their HCP		
Skurnik et al. 2016 (Skurnik et al. 2016)	To investigate barriers and facilitators	QUALITATIVE Focus Group	At ≤ 6 months of	Women with a history of PE	71% women were unaware of link	Tracking behaviour change	Lack of knowledge

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
United States of America **Improving the postpartum care of women with a recent history of preeclampsia: a focus group study**	towards learning about link between CVD and PE and engaging in lifestyle modifications to reduce this risk		experiencing PE	n=14	between PE and future CVD 100% had access to primary HCP "Most" said HCP did not explain link between PE and CVD	Support groups with other women Health of family as a motivator	Lack of social support in lifestyle changes Feeling of isolation post PE
Traylor et al. 2016 (Traylor et al. 2016) **United States of America** **Risk perception of future cardiovascular disease in women diagnosed with a hypertensive disorder of pregnancy**	To evaluate a woman's risk perception for future CVD following HDP at hospital discharge and at 2 weeks postpartum	QUANTITATIVE Survey	Survey 1: prior to hospital discharge Survey 2: at 2 weeks post discharge	Women with a history of PE and CH n=146 (PE no severe features n=76, PE with severe	A moderate or high risk perception of hypertension in later life was more likely to be reported by those with severe PE (65%) and chronic hypertension (75%) than those with PE	More severe PE and/or preterm delivery	Lack of knowledge Lack of professional support after delivery Higher rates of depressive symptoms

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
				features n=41, CH n=29)	without severe features (43%) Approximately 70% of women believed that having had HDP, exercising regularly, or controlling weight gain had NO effect on their risk for future CVD More than 75% of women correctly identified that smoking and high cholesterol increased the risk of CVD		

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
					Women delivering before 37 weeks were more likely to correctly identify an increased risk for future HDP, chronic hypertension, myocardial infarction, and stroke in their lifetime. They were also more likely to express a decreased desire for a future pregnancy compared with		

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
					women delivering at term		
Hutchesson et al., **2018** (Hutchesson et al. 2018) **Australia** **Are women with a recent diagnosis of preeclampsia aware of their cardiovascular disease risk? A cross-sectional survey**	To determine in women with prior PE, their awareness of future CVD risk, and the extent of CVD risk factor screening and advice offered since their diagnosis	QUANTITATIVE Survey	Within ≤2 years of experiencing PE	Women with a history of PE n=127	96% knew of higher risk of hypertension, 67% for stroke and 66% for other CVD Of those aware of raised CVD risk, 60% found out from own research, 25% their obstetrician, 13% their GP and 6% their midwife 95% had their blood pressure measured, and		

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
					41% had cholesterol or glucose measured		
Healthcare provider's knowledge							
MacDonald et al., 2007 (MacDonald et al. 2007) **Canada** **Hypertensive Disorders of Pregnancy and Long-Term Risk of Hypertension: What Do Ontario Prenatal Care Providers Know and**	To determine the knowledge base of Ontario maternity care providers regarding future health risks of GH and PE, and the communication of these risks	QUANTITATIVE Survey	N/A	Total HCP n=554 (obstetricians n = 241, midwives n=139, family physicians n=174)	58% of family physicians informed by maternity care providers of patients with hypertensive pregnancy 83% of maternity care providers say they inform family physicians		

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
What Do They Communicate?							
Young et al., 2012 (Young, Hacker & Rana 2012) **United States of America** **Physicians' knowledge of future vascular disease in women with preeclampsia**	To determine if primary care providers were aware of the association between PE and future CVD, and whether they were providing appropriate counselling.	QUANTITATIVE Survey	N/A	Internists n=118 and obstetricians n=53	"Majority" of physicians were unaware of the association between PE and future CVD Internists and Obstetricians were unaware of ischemic heart disease risk (56% & 23% respectively), stroke risk (48% and 38% respectively) and	Implementation of guidelines	Lack of knowledge of HDP link to CVD in HCP Lack of communication between HCP Inconsistencies in clinical education

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
					reduced life expectancy (79% and 77% respectively) 9% internists & 38% obstetricians counselled on CVD risk in women with PE. 5% internists and 42% obstetricians included PE in history		
Heidrich et al., 2013 (Heidrich et al. 2013) **Germany**	To assess whether obstetrician-gynaecologists are aware of	QUANTITATIVE Survey study of Obstetricians (n=212)	PE		86.6% physicians knew of link between PE and future hypertension	Knowledge of guidelines	

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
Preeclampsia and long-term risk of cardiovascular disease: what do obstetrician-gynaecologists know?	the association between PE and maternal long-term adverse outcomes and providing appropriate counselling				79% knew about association with stroke risk 76% aware of lower life expectancy Physicians with knowledge of guidelines regarding PE (45%) had increased understanding of risk and are more likely to offer counselling 94% included recommendations		

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
					for lifestyle changes in counselling strategy. Blood pressure measurement 3 months' post-partum (per guidelines) was undertaken by 76% of gynaecologists in outpatient settings		
Adekanle et al., 2015 (Adekanle et al. 2015) **Nigeria**	To assess the knowledge of health workers about the association	QUANTITATIVE Validated Survey undertaken at family planning clinics.	N/A		69% had knowledge of future risk of CVD following PE.		Lack of knowledge of HCP

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
Health workers' knowledge on future vascular disease risk in women with preeclampsia in South Western Nigeria	between PE with future CVD and offering any risk-reduction counselling to women with PE	Physicians n=88, nurses/midwives n=19, community health workers n=39			Medical doctors had better knowledge than both midwives and community health workers (78%, 58%, 54% respectively). 46% of surveyed HCP offered CVD risk-reduction counselling 64% did not know of reduced life expectancy		Type of healthcare profession Differences in clinical training
Wilkins-Haug et al., 2015 (Wilkins-Haug et al. 2015)	To assess HCPs knowledge	QUANTITATIVE Survey		Total n=124 Gynaecologists	Gynaecologists were more likely to assess history of		

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
United States of America **Recognition by women's health care providers of long-term cardiovascular disease risk after preeclampsia**	regarding pregnancy outcome as a risk factor for CVD and evaluate the factors associated with their responses to questions about routine surveillance for CVD			n=49, Internists n=75	PE when undertaking CVD assessment than internists (73% vs 55%) If history of PE, internists were more likely to order fasting glucose test than gynaecologists (48% vs. 21%)		
Women's knowledge and Healthcare provider's knowledge							
Hird et al., 2017 (Hird et al. 2017) **Canada**	To analyse women and HCPs perceptions of	QUALITATIVE Semi-Structured Interviews	Conducted 2 years after MacDonald	Total HCP n= 8 (Obstetricians n=5, GPs n=2, Midwives n=1)	41% HCP did not inform patients of increased risk more		Urgency of situation prioritised over information.

Author(s), Year, Country, Publication Title	Study Objective	Study design	Timing of study (Assessing women's knowledge only)	Sample	Main Findings	Enablers of knowledge acquisition and action on knowledge	Barriers of knowledge acquisition and action on knowledge
Risk for cardiovascular disease after preeclampsia: differences in Canadian women and healthcare provider perspectives on knowledge sharing	and attitudes towards the relationship between PE and CVD risk and assess how that is acted upon in Canadian healthcare		study (with focus on HCP) The timing after PE/pregnancy of the women is unclear	Sourced from same sample recruited by the included HCP study by MacDonald et al. (2007). Total women with history of PE n=5 Sourced from 'former patients' – unclear sample source	than 50% of the time Lack of guidelines and referrals were cited as concerns by healthcare professionals		Unreliable referrals and discharge management No guidelines for post PE follow-up Appointments too brief Focus on next pregnancy rather than future Lack of knowledge (women)

PE = preeclampsia, CVD = cardiovascular disease, HCP = healthcare provider GH = gestational hypertension, CH =chronic hypertension, HT = hypertension, IUGR = intrauterine growth restriction, GDM = gestational diabetes mellitus, Obstetricians = Obstetrician/Gynaecologists.

Appendix 8: Long-term health after blood pressure problems in pregnancy - Survey for women

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

ABOUT YOU

These first few questions are to find out about you, your background, and occupation. Questions marked with a green asterisk (*) simply mean that they must be answered in order to continue.

* 2. What age group are you in?

○ 18-25
○ 26-35
○ 36-45
○ 46-55
○ 56+
○ Prefer not to answer

* 3. What ethnic group do you identify with? (Please select one answer)

○ Caucasian
○ Asian
○ Polynesian or Maori
○ Other (please specify)
○ Aboriginal or Torres Strait Islander
○ European
○ Prefer not to answer

* 4. What is your highest level of formal education?

○ Secondary school
○ Trade Certificate/Diploma
○ Other (please specify)
○ University degree
○ Prefer not to answer

5. What is your usual occupation/profession?

* 6. Are you currently in a relationship?

○ Yes
○ No
○ Prefer not to answer

* 7. Where did you hear about this survey?

○ P4 Newsletter

○ Australian Action on Preeclampsia (AAPEC)

○ Tresillian

○ Maternity Choices Australia

○ Maternity Consumer Network

○ Maternity Clinics

○ Social media (Facebook, Twitter)

○ Australian College of Midwives

○ Other (please specify)

☐

ABOUT YOUR HEALTH

These next questions are about your general health.
Questions marked with a green asterisk (*) simply mean that they must be answered in order to continue.

* 8. Are you currently pregnant?

○ Yes
○ No
○ Prefer not to answer

ABOUT YOUR HEALTH

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

9. How many weeks pregnant are you? (provide whole numbers only, for example: 24)

10. How many children have you given birth to (20 weeks gestation and over)?

* 11. Have you ever had any of the following, whilst pregnant or before or after pregnancy? (select all that apply)

☐ High blood pressure
☐ High BMI (overweight)
☐ Angina
☐ Diabetes
☐ Kidney problems
☐ Other (please specify)
☐ Stroke
☐ Significant illness
☐ Heart attack
☐ None of the above/ no significant other medical complication

* 12. From the list below, which currently apply to you? (select all that apply)

☐ Smoking
☐ Obesity
☐ Alcohol consumption
☐ Family history of heart disease
☐ High cholesterol
☐ High blood pressure
☐ Diabetes
☐ None of the above

Other (please specify)

13. Please provide the details of any prescribed medications you are taking

○ I do not take any prescribed medication
○ I take prescribed medication (please list the medications 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.

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 hypertension

○ At least one pregnancy is/was affected by preeclampsia

○ I have only been diagnosed with chronic hypertension

○ I had chronic hypertension before pregnancy and had/have pregnancies that were complicated further by higher than usual blood pressure

○ I had chronic hypertension before pregnancy and had/have pregnancies that were complicated further by preeclampsia

○ No pregnancy is/was affected

YOUR HEALTH DURING YOUR PREGNANCY

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

* 15. As someone who has chronic hypertension are you aware of any long term health issues that you are at risk of? (select all that apply)

☐ Diabetes
☐ Kidney disease
☐ Breast cancer
☐ Cardiac death
☐ High blood pressure complications in another pregnancy
☐ Stroke
☐ Peripheral vascular disease
☐ Other (please specify)
☐ Leukaemia
☐ Seizures
☐ Overall mortality risk is higher
☐ Ischaemic heart disease/heart attack
☐ I think there are health risks but unsure which conditions I may be at risk of
☐ I do not think that there are increased risks

* 16. 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

○ > 20 years after pregnancy

○ Not sure/do not know

○ Other (please specify)

Chronic Hypertension only -TYPE OF CARE RECEIVED DURING PREGNANCY

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

17. If a healthcare provider did speak to you about your future health risks, when did this occur?

☐ Before birth
☐ Immediately after birth
☐ Within first 6 weeks
☐ 6 weeks to 6 months
☐ 6 months to 1 year
☐ 1 year and over
☐ I cannot remember

* 18. When would be a good time to receive information about long term health risks in your gestational hypertension or preeclampsia experience?

During pregnancy/at birth 12 months after birth 24 months after birth ☐

* 19. As a result of your pregnancy affected by blood pressure problems, were you referred to any of the below after your baby was born? (tick all that apply)

☐ Cardiologist
☐ Renal (kidney) Physician
☐ General Practitioner
☐ Other (please specify)
☐ Fitness centre for exercise
☐ Nutritionist for dietary adjustment
☐ I cannot remember

20. During your pregnancies over the last 3 years (20 weeks pregnancy and over), which blood pressure problem were you diagnosed with?

	Gestational Hypertension	Preeclampsia	No blood pressure problem diagnosed this pregnancy	I cannot remember	Not applicable
First Pregnancy	○	○	○	○	○
Second Pregnancy	○	○	○	○	○
Third Pregnancy	○	○	○	○	○

Any comments?

☐

* 21. How long ago was your most recent pregnancy that was affected by a blood pressure problem?

○ 0-6 months

○ 6-12 months

○ 1-2 years

○ 2-3 years

○ more than 3 years ago

* 22. At what point in time were you diagnosed? (Choose a most accurate time frame)

	20-28 weeks	28-34 weeks	34-37 weeks	37-40 weeks	40-42 weeks	During or after giving birth	No diagnosis of blood pressure problem this pregnancy	I cannot remember	Not applicable
First Pregnancy	○	○	○	○	○	○	○	○	○
Second Pregnancy	○	○	○	○	○	○	○	○	○
Third Pregnancy	○	○	○	○	○	○	○	○	○

Any comments?

☐

PREGNANCY

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

* 23. Did you have a *planned* induction of labour or *planned* caesarean section due to your blood pressure problems?

	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	○	○	○	○	○	○
Third Pregnancy	○	○	○	○	○	○

Any Comments?

☐

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:

	Less chance than a woman without blood pressure in pregnancy	Same chance as a woman without blood pressure in pregnancy	Higher chance than a woman without blood pressure in pregnancy	Not sure/I do not know
High blood pressure later in life	○	○	○	○
Diabetes	○	○	○	○
Kidney disease	○	○	○	○
Breast cancer	○	○	○	○
Heart attack	○	○	○	○
High blood pressure in another pregnancy	○	○	○	○
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.

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.

* 25. FOR WOMEN WITHOUT HISTORY OF BLOOD PRESSURE PROBLEMS IN PREGNANCY:

Compare yourself to a woman who HAS had blood pressure problems in pregnancy.

Do you think you have 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 know
High blood pressure later in life	○	○	○	○
Diabetes	○	○	○	○
Kidney disease	○	○	○	○
Breast cancer	○	○	○	○
Heart attack	○	○	○	○
High blood pressure in another pregnancy	○	○	○	○
Stroke	○	○	○	○
Heart disease	○	○	○	○
Seizures	○	○	○	○
Vascular Disease	○	○	○	○

* 26. 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)
- ○ > 20 years after pregnancy
- ○ Not sure/do not know

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.

* 27. 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

○ > 20 years after pregnancy

○ Not sure/do not know

○ I don't think I will get any of these as I maintain a healthy lifestyle

○ Other (please specify)

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

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 Dependency Unit’ or ‘Intensive Care Unit’ as a result of your blood pressure problem in pregnancy?

○ Yes

○ No

○ I am not sure

○ I cannot remember

* 29. Have any of your babies been admitted to 'Neonatal Intensive Care', 'High Dependancy Unit' or 'Special Care Nursery' as a result of your blood pressure problem in pregnancy?

○ Yes

○ No

○ I am not sure

30. After your baby was born have you had any of the following? (select all that apply)

☐ Blood pressure measurement in hospital

☐ Blood pressure measurement with my GP

☐ Consultation with an obstetrician

☐ Consultation with a renal (kidney) specialist

☐ Consultation with an obstetric medicine specialist (doctor who specialises in complications of pregnancy like high blood pressure)

☐ I cannot remember

☐ Other (please specify)

* 31. After your baby was born, did someone speak to you about any of the below future health risks? (select all that apply)

☐ Increased risk of high blood pressure

☐ Increased risk of kidney problems

☐ Increased risk of stroke

☐ Increased risk of heart attack

☐ Increased risk of vascular disease

☐ Other (please specify)

☐ Risk of hypertensive disease in your next pregnancy

☐ I was told to eat a healthy diet, do some exercise and live normally

☐ No risks were discussed

☐ I cannot remember

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

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

32. If a healthcare provider did speak to you about your future health risks, when did this occur?

☐ Before birth
☐ Immediately after birth
☐ Within first 6 weeks
☐ 6 weeks to 6 months
☐ 6 months to 1 year
☐ 1 year and over
☐ I cannot remember

* 33. When would be a good time to receive information about long term health risks in your gestational hypertension or preeclampsia experience?

During pregnancy/at birth   12 months after birth   24 months after birth

○ ☐

* 34. As a result of your pregnancy affected by blood pressure problems, were you referred to any of the below after your baby was born? (tick all that apply)

☐ Cardiologist
☐ Renal (kidney) Physician
☐ General Practitioner
☐ Other (please specify)
☐ Fitness centre for exercise
☐ Nutritionist for dietary adjustment
☐ I cannot remember

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 anything 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 email address to **receive results** from this study (in approx. 1 year). Your details will not be used for any other purpose.

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

Appendix 9: Current CVD risk factors of HDP and non-HDP women (Multiple answers collected) in order of frequency

	GH	PE	CH	Total HDP	non-HDP	P HDP vs non HDP
	n=15	n=143	n=16	n=174	n=92	
	n (%)*	n (%)*	n (%)*	n (%)*	n (%)*	
None of the options	6 (40)	52 (36)	2 (13)	60 (34)	57 (62)	<0.001
Obesity	5 (33)	38 (27)	7 (44)	50 (29)	10 (11)	0.001
Family History Heart disease	3 (20)	37 (26)	6 (38)	46 (26)	14 (15)	0.037
Hypertension	3 (20)	30 (21)	12 (75)	35 (20)	0 (0)	<0.001
Renal problems	0 (0)	21 (15)	2 (13)	23 (13)	0 (0)	<0.001
Smoking	0 (0)	10 (7)	3 (19)	13 (7)	2 (2)	0.075
History of cardiovascular event**	0 (0)	1 (1)	0 (0)	1 (1)	0 (0)	0.356
Diabetes	0 (0)	5 (3)	2 (13)	7 (4)	0 (0)	0.014
Alcohol consumption	0 (0)	0 (0)	1 (6)	1 (1)	0 (0)	0.356
High Cholesterol	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	-

*Table represents frequency of each option; percentages add to over 100% as women were asked to select any/all that applied.

**angina, stroke or heart attack

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia,

HDP= hypertensive disorder of pregnancy

Appendix 10: Participant answers for all conditions

Chronic Hypertension

a) Women with HDP likelihood of risk compared to non-HDP ("Do you think you have a lower/same/higher chance of getting the following")

	GH pregnancy n=15	PE pregnancy n=143	CH pregnancy n=16	Total n=174
	n (%)	n (%)	n (%)	n (%)
Less likely	0 (0)	1 (1)	0 (0)	1 (1)
Same likelihood	2 (13)	14 (10)	1 (6)	17 (10)
More likely (correct)	8 (53)	111 (78)	13 (81)	132 (76)
I do not know	5 (33)	17 (12)	2 (13)	24 (14)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

b) Women without HDP likelihood of risk compared to HDP ("Do you think you have a lower/same/higher chance of getting the following")

	non-HDP n=92
	n (%)
Less likely (correct)	57 (62)
Same likelihood	22 (24)
More likely	1 (1)
I do not know	12 (13)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

Diabetes

Supplementary Table 3: Diabetes

a) Women with HDP likelihood of risk compared to non-HDP ("Do you think you have a lower/same/higher chance of getting the following")

	GH pregnancy n=15	PE pregnancy n=143	CH pregnancy n=16	Total n=174
	n (%)	n (%)	n (%)	n (%)
Less likely	0 (0)	1 (1)	0 (0)	1 (1)
Same likelihood	3 (20)	61 (43)	5 (31)	69 (40)
More likely (correct)	4 (27)	35 (25)	5 (31)	44 (25)
I do not know	8 (53)	44 (31)	6 (38)	58 (33)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

b) Women without HDP likelihood of risk compared to HDP ("Do you think you have a lower/same/higher chance of getting the following")

	non-HDP n= 92
	n (%)
Less likely (correct)	32 (35)
Same likelihood	39 (42)
More likely	4 (4)
I do not know	17 (19)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

Renal Disease

a) Women with HDP likelihood of risk compared to non-HDP ("Do you think you have a lower/same/higher chance of getting the following")

	GH pregnancy n=15	PE pregnancy n=143	CH pregnancy n=16	Total n=174
	n (%)	n (%)	n (%)	n (%)
Less likely	0 (0)	2 (1)	0 (0)	2 (1)
Same likelihood	2 (14)	30 (21)	1 (7)	33 (19)
More likely (correct)	4 (29)	77 (55)	11 (73)	92 (54)
I do not know	8 (57)	32 (23)	3 (20)	43 (25)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

b) Women without HDP likelihood of risk compared to HDP ("Do you think you have a lower/same/higher chance of getting the following")

	non-HDP n=92
	n (%)
Less likely (correct)	39 (42)
Same likelihood	31 (34)
More likely	0 (0)
I do not know	22 (24)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

Heart Attack

a) Women with HDP likelihood of risk compared to non-HDP ("Do you think you have a lower/same/higher chance of getting the following")

	GH pregnancy n=15	**PE pregnancy n=143**	**CH pregnancy n=16**	**Total n=174 n (%)**
	n (%)	**n (%)**	**n (%)**	
Less likely	0 (0)	1 (1)	0 (0)	1 (1)
Same likelihood	1 (7)	20 (14)	1 (7)	22 (13)
More likely (correct)	8 (53)	98 (69)	12 (80)	118 (69)
I do not know	6 (40)	23 (16)	2 (13)	31 (18)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

b) Women without HDP likelihood of risk compared to HDP ("Do you think you have a lower/same/higher chance of getting the following")

	non-HDP n=92
	n (%)
Less likely (correct)	48 (53)
Same likelihood	23 (25)
More likely	0 (0)
I do not know	20 (22)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

HDP next pregnancy

a) Women with HDP likelihood of risk compared to non-HDP ("Do you think you have a lower/same/higher chance of getting the following")

	GH pregnancy n=15	PE pregnancy n=143	CH pregnancy n=16	Total n=174
	n (%)	n (%)	n (%)	n (%)
Less likely	0 (0)	2 (1)	0 (0)	2 (1)
Same likelihood	0 (0)	9 (6)	0 (0)	9 (5)
More likely (correct)	13 (87)	128 (89)	15 (100)	156 (90)
I do not know	2 (13)	4 (3)	0 (0)	6 (4)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

b) Women without HDP likelihood of risk compared to HDP ("Do you think you have a lower/same/higher chance of getting the following")

	non-HDP n=92
	n (%)
Less likely (correct)	65 (71)
Same likelihood	19 (21)
More likely	0 (0)
I do not know	8 (9)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

Stroke

a) Women with HDP likelihood of risk compared to non-HDP ("Do you think you have a lower/same/higher chance of getting the following")

	GH pregnancy n=15	PE pregnancy n=143	CH pregnancy n=16	Total n=174
	n (%)	n (%)	n (%)	n (%)
Less likely	0 (0)	1 (1)	0 (0)	1 (1)
Same likelihood	1 (7)	18 (13)	1 (7)	20 (12)
More likely (correct)	7 (47)	89 (63)	13 (87)	109 (64)
I do not know	7 (47)	33 (23)	1 (7)	41 (24)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

b) Women without HDP likelihood of risk compared to HDP ("Do you think you have a lower/same/higher chance of getting the following")

	non-HDP n=92
	n (%)
Less likely (correct)	49 (53)
Same likelihood	24 (26)
More likely	0 (0)
I do not know	19 (21)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

Heart Disease

a) Women with HDP likelihood of risk compared to non-HDP ("Do you think you have a lower/same/higher chance of getting the following")

	GH pregnancy n=15	PE pregnancy n=143	CH pregnancy n=16	Total n=174 n (%)
	n (%)	n (%)	n (%)	
Less likely	0 (0)	1 (1)	0 (0)	1 (1)
Same likelihood	2 (13)	18 (13)	1 (7)	21 (12)
More likely (correct)	7 (47)	99 (70)	12 (80)	118 (67)
I do not know	6 (40)	24 (17)	2 (13)	32 (19)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

b) Women without HDP likelihood of risk compared to HDP ("Do you think you have a lower/same/higher chance of getting the following")

	non-HDP n=92
	n (%)
Less likely (correct)	46 (50)
Same likelihood	27 (29)
More likely	0 (0)
I do not know	19 (21)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

Peripheral Vascular Disease

a) Women with HDP likelihood of risk compared to non-HDP ("Do you think you have a lower/same/higher chance of getting the following")

	GH pregnancy n=15	PE pregnancy n=143	CH pregnancy n=16	Total n=174
	n (%)	n (%)	n (%)	n (%)
Less likely	0 (0)	0 (0)	0 (0)	0 (0)
Same likelihood	2 (13)	20 (14)	1 (7)	23 (13)
More likely (correct)	5 (33)	72 (51)	8 (53)	85 (50)
I do not know	8 (53)	50 (35)	6 (40)	64 (37)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

b) Women without HDP likelihood of risk compared to HDP ("Do you think you have a lower/same/higher chance of getting the following")

	non-HDP n=92
	n (%)
Less likely (correct)	41 (45)
Same likelihood	29 (32)
More likely	0 (0)
I do not know	22 (24)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

Breast Cancer

a) Women with HDP likelihood of risk compared to non-HDP (“Do you think you have a lower/same/higher chance of getting the following”)

	GH pregnancy n=15	PE pregnancy n=143	CH pregnancy n=16	Total n=174
	n (%)	n (%)	n (%)	n (%)
Less likely	0 (0)	0 (0)	0 (0)	0 (0)
Same likelihood (correct)	3 (20)	74 (53)	5 (36)	82 (48)
More likely	1 (7)	1 (1)	1 (7)	3 (2)
I do not know	11 (73)	66 (47)	8 (57)	85 (50)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

b) Women without HDP likelihood of risk compared to HDP (“Do you think you have a lower/same/higher chance of getting the following”)

	non-HDP n=92
	n (%)
Less likely	6 (7)
Same likelihood (correct)	60 (65)
More likely	1 (1)
I do not know	25 (27)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

Seizures

a) Women with HDP likelihood of risk compared to non-HDP ("Do you think you have a lower/same/higher chance of getting the following")

	GH pregnancy n=15	**PE pregnancy n=143**	**CH pregnancy n=16**	**Total n=174**
	n (%)	**n (%)**	**n (%)**	**n (%)**
Less likely	0 (0)	0 (0)	0 (0)	0 (0)
Same likelihood (correct)	4 (27)	41 (29)	2 (13)	47 (27)
More likely	1 (7)	41 (29)	4 (27)	46 (27)
I do not know	10 (67)	60 (42)	9 (60)	79 (46)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

b) Women without HDP likelihood of risk compared to HDP ("Do you think you have a lower/same/higher chance of getting the following")

	non-HDP n=92
	n (%)
Less likely	25 (27)
Same likelihood (correct)	40 (44)
More likely	0 (0)
I do not know	27 (29)

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

Appendix 11: Proportion of participants scoring ‘high’, ‘moderate’ and ‘low’ by type of HDP and non-HDP

	GH n=15 n(%)	**PE n=143 n(%)**	**CH n=16 n(%)**	**P GH vs PE**	**P GH vs CH**	**P PE vs CH**	**HDP n=174 n(%)**	**non-HDP n=92 n(%)**	**P HDP vs non- HDP**
High (score 8-10)	4 (27)	48 (34)	5 (31)	0.59	0.78	0.67	57 (33)	30 (33)	0.98
Moderate (score 5-7)	3 (20)	52 (36)	7 (44)	0.21	0.16	0.56	62 (36)	25 (27)	0.16
Low (score 0-4)	8 (53)	43 (30)	4 (25)	0.67	0.11	0.85	55 (32)	37 (40)	0.16
Total	15 (100)	143 (100)	16 (100)	-	-	-	174 (101)	92 (100)	-

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy.

The colour coding in addition to the mean scores aims to highlight the areas of ‘low’ (red), ‘moderate’ (orange) and ‘high’ (green) knowledge.

🟥	LOW
🟧	MODERATE
🟩	HIGH

Appendix 12: Means of risk factor knowledge of women with a history of preeclampsia listed by time elapsed since HDP

	PE n=143	PE n=143						PE n=143		
	ALL	0 - 6 month	6 - 12 month	1-2 years	2-3 years	>3 years	P	< 3	> 3	P
		n=26	n=19	n=32	n=20	n=46		n= 97	n= 46	< 3 yrs vs >3 yrs
Chronic Hypertension	0.78	0.77	0.89	0.78	0.80	0.72	0.65	0.80	0.72	0.27
Diabetes	0.24	0.23	0.42	0.31	0.10	0.20	0.14	0.27	0.20	0.35
Renal Disease	0.54	0.50	0.74	0.41	0.65	0.52	0.17	0.55	0.52	0.78
Heart Attack	0.69	0.58	0.89	0.66	0.70	0.67	0.25	0.69	0.67	0.84
Repeat HDP	0.90	0.88	0.89	0.94	0.95	0.85	0.68	0.92	0.85	0.25
Stroke	0.62	0.65	0.68	0.50	0.65	0.65	0.62	0.61	0.65	0.62
Heart Disease	0.69	0.62	0.79	0.63	0.65	0.76	0.50	0.66	0.76	0.21
PVD	0.50	0.54	0.53	0.53	0.40	0.50	0.90	0.51	0.50	0.95
Breast Cancer*	0.52	0.46	0.37	0.63	0.40	0.59	0.25	0.48	0.59	0.26
Seizures*	0.29	0.15	0.16	0.41	0.45	0.26	0.07	0.30	0.26	0.64
OVERALL MEAN KNOWLEDGE SCORE OUT OF 10	**5.8**	**5.4**	**6.4**	**5.8**	**5.8**	**5.7**	0.83	**5.8**	**5.7**	0.89

The colour coding in addition to the mean scores aims to highlight the areas of 'low' (red), 'moderate' (orange) and 'high' (green) knowledge.

MEAN SCORE		
🟥	LOW	0-0.40
🟧	MODERATE	0.41-0.70
🟩	HIGH	0.71-1

Appendix 13: HDP and non-HDP women's answers to timing of rise of risk with signs and symptoms starting to show

	GH	**PE**	**CH**	**HDP**	**Non HDP**	**P**
	n=15	**n=143**	**n=16**	**n=174**	**n=92**	**HDP vs non-HDP**
	n (%)*	**n (%)***	**n (%)***	**n (%)***	**n (%)***	
<10 years	4 (27)	42 (29)	9 (56)	55 (32)	41 (45)	0.036
10-15 years	3 (20)	28 (20)	2 (13)	33 (19)	15 (16)	0.591
16-20 years	0 (0)	13 (9)	0 (0)	13 (8)	1 (1)	0.013
>20 years	3 (20)	5 (4)	0 (0)	8 (5)	2 (2)	0.302
Not sure/don't know	1 (7)	48 (34)	1 (6)	52 (30)	33 (36)	0.319
I don't think I will get any of these as I maintain a healthy lifestyle	4 (27)	7 (5)	2 (13)	13 (8)	N/A	-
TOTAL	15 (101)	143 (101)	16 (101)	174 (102)	92 (100)	

* Percentages may not add to 100% as figures are rounded to whole numbers only

PE = preeclampsia GH = gestational hypertension CH= chronic hypertension worsening in pregnancy and/or with superimposed preeclampsia, HDP= hypertensive disorder of pregnancy

Appendix 14: Proportion of conditions discussed by HDP sub-type when addressing future risk (multiple answers collected) within and over 3 years since last HDP

	GH n=15 N (%)		PE n = 143 N (%)		CH n = 16 N (%)		Total n = 174 N (%)		Overall Total n = 174 N (%)	P value < 3 yrs vs >3 yrs
	<3yrs	**>3yrs**	**<3yrs**	**>3yrs**	**<3yrs**	**>3yrs**	**<3yrs**	**>3yrs**		
HDP next pregnancy	3 (23)	1 (50)	47 (48)	21 (46)	5 (38)	2 (67)	55 (45)	24 (47)	79 (45)	0.78
Chronic Hypertension	4 (31)	1 (50)	47 (48)	16 (35)	4 (31)	2 (67)	55 (45)	19 (37)	74 (43)	0.37
No discussion	**7 (54)**	**1 (50)**	**33 (34)**	**17 (37)**	**5 (38)**	**1 (33)**	**45 (37)**	**19 (37)**	**64 (37)**	**0.93**
Lifestyle changes	4 (31)	-	26 (27)	6 (13)	2 (15)	2 (67)	32 (26)	8 (16)	40 (23)	0.14
Heart Attack	1 (8)	-	20 (21)	6 (13)	1 (8)	1 (33)	22 (18)	7 (14)	29 (17)	0.50
Renal Disease	1 (8)	-	20 (21)	3 (7)	2 (15)	1 (33)	23 (19)	4 (8)	27 (16)	0.07
Stroke	1 (8)	1 (50)	18 (19)	4 (9)	1 (8)	1 (33)	20 (16)	6 (12)	26 (15)	0.45
Peripheral vascular disease	-	-	15 15)	5 (11)	1 (8)	-	16 (13)	5 (10)	21 (12)	0.56
Cannot remember	1 (8)	-	4 (4)	2 (4)	1 (8)	-	6 (5)	2 (4)	8 (5)	0.78

Appendix 15: Post-survey interview guide for women with a history of hypertensive disorder of pregnancy

- Having had high blood pressure during one of your pregnancies, what is your understanding of your future risks of health issues?
- If you think back to the time of or soon after giving birth to your baby, there are a couple of questions I'd like you to comment on if possible:
- what information did you find helpful knowing early on?
- In hindsight, is there anything about your future risk or how to lower the risk you have since found out, that would have been helpful to have known earlier - for example when diagnosed or around the time of birth and early follow-up?
- Could you describe to me your ideal sequence of events with regards to your follow-up after a pregnancy and birth complicated by blood pressure? How would you like to have your health followed up?
- What else would you, and maybe other women, who get high blood pressure in pregnancy, like to know about future health after a pregnancy complicated with blood pressure problems in pregnancy?
- What sort of information would you find essential and also helpful?
- How would you like this information presented? What would it look like?
- How/Where would you like to access it from?
- Discussing your history of high blood pressure in pregnancy with your healthcare provider (doctor, nurse, midwife) is important. What do you think may be helpful to assist women with this history during their conversation with a healthcare provider?
- Some women have suggested the doctor or nurse also talk about any health issues for you when you have your baby checked at the clinic or have vaccinations. How do you think this would work?
- Studies show that often women do not attend follow-up appointments with their doctors, due to other priorities of being a new parent. How can we improve the ability of women to be able to get to these appointments?
- Is there anything else you would like to tell us about management and education after PE or GH that you feel is important for us to consider when creating education?

Appendix 16: Demographics in Numbers and proportions of total survey versus interview participants

	Survey Total (HDP only) n(%)	Interview Total n(%)
Total n	**174 (100)**	**13 (100)**
AGE		
18-25	10 (6)	-
26-35	81 (47)	6 (46)
36-45	76 (44)	6 (46)
46+	7 (4)	1 (8)
ETHNICITY		
Caucasian	165 (95)	12 (92)
Asian	5 (3)	-
Aboriginal and Torres Strait Islander	1 (1)	1 (8)
*Other**	3 (2)	-
HIGHEST EDUCATIONAL ATTAINMENT		
Secondary School	23 (13)	-
Diploma/Trade Certificate	60 (35)	3 (23)
University Degree	90 (52)	10 (77)
Prefer not to answer	1 (1)	-
RELATIONSHIP STATUS		
In a relationship	162 (93)	13 (100)
Not in a relationship	11 (6)	-
Prefer not to answer	1 (1)	-
LAST HDP		
under 3 years ago	123 (71)	11 (85)
over 3 years ago	51 (29)	2 (15)
TYPE OF HDP		
PE	143 (82)	10 (78)
GH	15 (9)	2 (15)
CH	16 (9)	1 (8)

PE - preeclampsia, GH - gestational hypertension, CH - chronic hypertension

Appendix 17: Thematic table illustrating women's interview findings

Research aims	**Thematic framework/index**	**Category allocated (main category X and x if also linked to another category)**		
		Accessing evidence-based and comprehensive information	**Transitioning care from hospital to community**	**Fostering self-advocacy**
Content	What is HDP? / Definition of HDP?	**X**		x
	How will HDP affect my child?	**X**	x	x
	At what age/as of when will it affect my health?	**X**	x	x
	Explanation of the pathophysiology of HDP	**X**		x
	How can I mitigate risk? How can I reduce the risk?	**X**	x	x
	What is the recommended long-term follow-up? What do I need to have checked, how often and how long for?	**X**	x	x
	What are the long-term risks?	**X**	x	x
	What are the short-term risks?	**X**	x	x
	What are the signs and symptoms of long-term risks? When do I seek medical assistance?	**X**	x	x
	Information on medication safety	**X**		x
	Lack of knowledge/confusion displayed by interviewee	**X**		x

Format	Verbally from healthcare provider supported by information to take home	**X**		
	Structure, a program ready to follow and a recommended follow-up mapped out		**X**	
	Reminders like the Cervical Screening Registers or Gestational Diabetes Register notifications		**X**	
	Create a register like the diabetes register that I joined		**X**	
	Posters at the GP/Letter in the mail/ Something I can put on the fridge	**X**	x	
	Information in different languages including visual and auditory disability	**X**		x
	Easy access	**X**		
	A website/A smartphone application /A brochure/ t research papers to read	**X**		x
	Electronic so I can store it and access when needed	**X**		x
Access	Information from the healthcare provider	**X**	x	
	Push notifications / health advice- from GP or from a register (like Cervical Screening Registers or Gestational Diabetes Register) or from organisations (email, text or letter)		**X**	x
	Via organisations like Heart Foundation or Australian Action on Preeclampsia	**X**	x	x
	A website/A smartphone application /A brochure/ t research papers to read	**X**		x
	Research projects I can participate in	**X**	x	x
	Awareness day	x		**X**
	Social media (e.g. Facebook) - targeted interest groups (e.g. preeclampsia, premature birth)	**X**		x

Enablers	Knowledgeable healthcare provider	x	**X**	
	If my own knowledge is good it will enhance conversation with healthcare provider and my search for information	x	x	**X**
	I am in charge of my health and should be proactive in my health approach and seeking assistance (but I need knowledge for this)			**X**
	Hear information repeated often, at all HCP contact points	**X**		
	The right timing for the risk discussion		**X**	
	The right help (the right HCP or service to assist with mitigating risk e.g dietician)		**X**	x
	The specialist writing a letter to my GP	x	**X**	
	To have a plan of care - what is the plan - what now?	**X**	x	
	Have something written down by my healthcare provider about my HDP	**X**	x	x
	Follow up more structured like post-diabetes		**X**	
Barriers	Psychological sequelae - identified and stated by the women or demonstrated by their answers (e.g. recurrent focus on birth, diagnosis, why? how? what? Rather than looking into future health)	**X**	x	x
	Does my healthcare provider know about this topic? Do I trust my healthcare provider?	x	**X**	x
	I should not have to explain this to my GP What if I don't explain it correctly to the GP, will they believe me? I feel weird/intimidated informing my GP of my health risks, I would not bring it up		**X**	x
	Need more information, what happened, no one really explained or maybe I didn't understand?	**X**	x	x

GP- general practitioner, HCP- healthcare provider, HDP - hypertensive disorders of pregnancy

Appendix 18: Long-term health after gestational hypertension or preeclampsia - Healthcare Provider Survey

LONG TERM HEALTH AFTER GESTATIONAL HYPERTENSION OR PREECLAMPSIA - Health Care Provider Survey

Introduction to survey, contact details & Ethics

You are invited to take part in a survey to gain insight into what healthcare providers know about long term health in women who have experienced gestational hypertension or preeclampsia. The study is being conducted by the University of NSW (UNSW), University of Technology Sydney (UTS) and the Sydney Partnership for Health, Education, Research and Enterprise (SPHERE). The study is being undertaken by:

- Dr. Amanda Henry - Senior Lecturer in Obstetrics UNSW & SPHERE member
- Distinguished Professor Caroline Homer - UTS, Midwifery Faculty of Health & 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.

You can complete the survey if you are a currently practicing healthcare provider in Australia. We would like you to reflect on your knowledge and practice over the last three (3) years.

If you are willing to take part in the study, please click on the link and then complete the online survey. This should take about 5-10 minutes to complete and will involve answering questions about you, your current practice and your understanding of long term health in women who have experienced gestational hypertension or preeclampsia.

Participation in this study is entirely voluntary. 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 results will be published in a research thesis study, 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 at the end of the survey. The results will be available one (1) year after conclusion of

the survey.

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 would like any further information about the study please contact the Principal Investigator, Dr. Amanda Henry on 02 91132315 or via email Amanda.henry1@health.nsw.gov.au.

If you experience any distress or concern as a result of completing this survey, please contact Dr. Amanda Henry (details above) or 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.

☐ Enter survey

LONG TERM HEALTH AFTER GESTATIONAL HYPERTENSION OR PREECLAMPSIA - Health Care Provider Survey

ABOUT YOU

These first few questions are to find out about you, your background, and occupation.

2. What is your gender?

○ Female
○ Male
○ Other (please specify)
○ Prefer not to answer

3. Which health professional are you? (Please check the most relevant/current practice answer if more than one apply)

○ General Practitioner
○ Qualified Obstetrician and Gynaecologist, practice gynaecology only
○ Qualified Obstetrician and Gynaecologist, practice obstetrics only
○ Qualified Obstetrician and Gynaecologist, practice both obstetrics & gynaecology
○ Physician with substantial obstetric practice
○ Other (please specify)
○ Cardiologist
○ Physician (other than cardiologist or obstetric physician)
○ Midwife
○ Community/child and family health nurse

4. How long have you been practising in your current profession in Australia?

○ <5 years
○ 5-10 years
○ 11-15 years
○ >15 years
○ Prefer not to answer

5. What state or territory of Australia are you currently practising in?

○ NSW
○ VIC
○ ACT
○ QLD
○ NT

○ SA
○ TAS
○ WA
○ Prefer not to answer

LONG TERM HEALTH AFTER GESTATIONAL HYPERTENSION OR PREECLAMPSIA - Health Care Provider Survey

ABOUT YOUR DAILY PRACTICE

These next questions address your daily practice with regards to treating women with a history of gestational hypertension or preeclampsia.

DEFINITIONS:
You may find these useful in order to more easily understand and answer the next questions about the blood pressure conditions addressed in this survey.

Gestational hypertension: the new onset of hypertension (≥140 mmHg systolic or ≥90 mmHg diastolic) after 20 weeks gestation but where the woman is otherwise well (that is, high blood pressure only but no effect on her baby's growth or on her organs).

Preeclampsia: when hypertension (≥140 mmHg systolic or ≥90 mmHg diastolic) is diagnosed after 20 weeks gestation and one or more of the following new-onset conditions are present: (1) Proteinuria (2) Other maternal organ dysfunction such as renal insufficiency, liver involvement, neurological complications, haematological complications (3) Uteroplacental dysfunction and hence potential fetal growth restriction.

6. Do you see/treat women with a history of gestational hypertension or preeclampsia?

○ Yes

○ No

○ I am not sure

ABOUT YOUR DAILY PRACTICE

7. In your usual clinical practice, do you routinely ask women about their pregnancy history including whether they had gestational hypertension or preeclampsia?

○ Always

○ Often

○ Sometimes

○ Never

LONG TERM HEALTH AFTER GESTATIONAL HYPERTENSION OR PREECLAMPSIA - Health Care Provider Survey

ABOUT YOUR DAILY PRACTICE

8. Do you ever refer women with a history of gestational hypertension and preeclampsia to another health care provider regarding their long-term health because of this specific history?

○ Yes

○ No

○ I am not sure

LONG TERM HEALTH AFTER GESTATIONAL HYPERTENSION OR PREECLAMPSIA - Health Care Provider Survey

ABOUT YOUR DAILY PRACTICE

9. Where do you refer women to (e.g. dietician, cardiologist, obstetric or renal physician)? Please write as many as apply.

LONG TERM HEALTH AFTER GESTATIONAL HYPERTENSION OR PREECLAMPSIA - Health Care Provider Survey

LONG-TERM HEALTH RISKS AFTER GESTATIONAL HYPERTENSION OR PREECLAMPSIA

This section looks at comparing the potential long-term health risks for women with a history of gestational hypertension or preeclampsia with women who had no blood pressure complications in pregnancy.

<u>You will be provided with an accurate risk profile at the end of the survey</u>.

10. Do you think that there is an increased risk of developing future cardiovascular disease after gestational hypertension or preeclampsia?

○ Only preeclampsia increases the long-term health risks

○ Only gestational hypertension increases the long-term health risks

○ Both, gestational hypertension and preeclampsia increase the long-term health risks

○ Neither gestational hypertension or preeclampsia increase the long-term health risks

○ I am not sure

LONG TERM HEALTH AFTER GESTATIONAL HYPERTENSION OR PREECLAMPSIA - Health Care Provider Survey

11. Compared to a woman who did not have blood pressure problems in pregnancy, how likely is it that women who did have a history of preeclampsia (PE) will develop the following:

	The PE group has a LOWER likelihood of developing it	The PE group has a THE SAME likelihood of developing it	The PE group has a HIGHER likelihood of developing it	I do not know
Chronic hypertension	○	○	○	○
Diabetes	○	○	○	○
Renal disease	○	○	○	○
Breast cancer	○	○	○	○
Cardiac death	○	○	○	○
Ischaemic heart disease/heart attack	○	○	○	○
High blood pressure in another pregnancy	○	○	○	○
Stroke	○	○	○	○
Peripheral vascular disease	○	○	○	○
Leukaemia	○	○	○	○
Seizures	○	○	○	○
Overall mortality risk	○	○	○	○

12. Compared to a woman who did not have blood pressure problems in pregnancy, how likely is it that women who did have a history of gestational hypertension (GH) will develop the following:

	The GH group has a LOWER likelihood of developing it	The GH group has a THE SAME likelihood of developing it	The GH group has a HIGHER likelihood of developing it	I do not know
Chronic hypertension	○	○	○	○
Diabetes	○	○	○	○
Renal disease	○	○	○	○
Breast cancer	○	○	○	○
Cardiac death	○	○	○	○
Ischaemic heart disease/heart attack	○	○	○	○
High blood pressure in another pregnancy	○	○	○	○
Stroke	○	○	○	○
Peripheral vascular disease	○	○	○	○
Leukaemia	○	○	○	○
Seizures	○	○	○	○
Overall mortality risk	○	○	○	○

13. Compared to a woman who did not have blood pressure problems in pregnancy, how likely is it that women who did have a history of preeclampsia (PE) will develop the following:

	The PE group has a LOWER likelihood of developing it	The PE group has a THE SAME likelihood of developing it	The PE group has a HIGHER likelihood of developing it	I do not know
Chronic hypertension	○	○	○	○
Diabetes	○	○	○	○
Renal disease	○	○	○	○
Breast cancer	○	○	○	○
Cardiac death	○	○	○	○
Ischaemic heart disease/heart attack	○	○	○	○
High blood pressure in another pregnancy	○	○	○	○
Stroke	○	○	○	○
Peripheral vascular disease	○	○	○	○
Leukaemia	○	○	○	○
Seizures	○	○	○	○
Overall mortality risk	○	○	○	○

14. Compared to a woman who did not have blood pressure problems in pregnancy, how likely is it that women who did have a history of gestational hypertension (GH) will develop the following:

	The GH group has a LOWER likelihood of developing it	The GH group has a THE SAME likelihood of developing it	The GH group has a HIGHER likelihood of developing it	I do not know
Chronic hypertension	○	○	○	○
Diabetes	○	○	○	○
Renal disease	○	○	○	○
Breast cancer	○	○	○	○
Cardiac death	○	○	○	○
Ischaemic heart disease/heart attack	○	○	○	○
High blood pressure in another pregnancy	○	○	○	○
Stroke	○	○	○	○
Peripheral vascular disease	○	○	○	○
Leukaemia	○	○	○	○
Seizures	○	○	○	○
Overall mortality risk	○	○	○	○

15. How many years after gestational hypertension or preeclampsia do you think the various signs and symptoms of the above potential risks may start to manifest?

○ < 10 years after pregnancy
○ 10-15 years after pregnancy
○ 16-20 years after pregnancy
○ > 20 years after pregnancy
○ Not sure/don’t know

16. If you have spoken to the women in your care about increased risks of cardiovascular disease after gestational hypertension or preeclampsia, what has been your advice? (please tick all applicable)

☐ Assess cardiovascular risk
☐ Medication
☐ Other (please specify)
☐ Lifestyle adjustments
☐ I have not spoken to women in my care about increased health risks after GH or PE

17. If you would like to leave any comments about this topic:

LONG TERM HEALTH AFTER GESTATIONAL HYPERTENSION OR PREECLAMPSIA - Health Care Provider Survey

POST-SURVEY OPTIONS AND SUMMARY OF RISK PROFILE

18. **FOCUS GROUP/INTERVIEW OPPORTUNITY-**
(participation certificate provided)

Focus groups (one off - 2hrs max at St George Hospital, Sydney) or more in-depth telephone interviews (one off 30mins max) will be held. The aim is to establish appropriate education content and distribution about long term women's health after hypertensive pregnancy.

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

Name

Email Address

Phone Number

19. Please leave your email address if you wish to receive results from this study (in approx. 1 year). Your details will not be used for any other purpose.

Email Address

CONTACT

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

There are, unfortunately, some long term health risks associated with having had hypertension in pregnancy.

Women who have had hypertension during pregnancy are about 3 to 4 times more likely to develop **chronic hypertension** than women who did not have a hypertensive 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 previously hypertensive pregnancy compared to women who have not. Therefore, if they have had a hypertensive pregnancy, 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 or preeclampsia. All of these cardiovascular problems are about **twice as likely** to eventually happen to a woman who has had gestational hypertension or preeclampsia compared to a woman who has not.

Kidney problems are about **5 to 10 times** more common after preeclampsia in particular. Although the **relative risk** of developing renal disease is substantially higher after preeclampsia, the **absolute risk** of long-term renal 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 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

Appendix 19 - Risk factor knowledge by profession and by pregnancy HDP (PE or GH) in numbers and proportions

CHRONIC HYPERTENSION

	Midwives n=171		General Practitioners n=71		Obstetricians n=178		Cardiologists n=26	
	PE **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**
Lower likelihood	0 (0)	2 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Same likelihood	7 (4)	12 (7)	1 (2)	1 (1)	3 (2)	3 (2)	0 (0)	0 (0)
Higher likelihood	142 (83)	132 (77)	62 (87)	64 (90)	166 (93)	162 (91)	26 (100)	26 (100)
I do not know	10 (6)	6 (4)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Did not answer	12 (7)	19 (11)	8 (11)	6 (8)	9 (5)	14 (8)	0 (0)	0 (0)

DIABETES

	Midwives n=171		General Practitioners n=71		Obstetricians n=178		Cardiologists n=26	
	PE n (%)	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**
Lower likelihood	1 (1)	2 (1)	1 (1)	0 (0)	1 (1)	2 (1)	0 (0)	0 (0)
Same likelihood	48 (28)	54 (32)	21 (30)	20 (28)	68 (38)	60 (34)	3 (12)	5 (19)
Higher likelihood	61 (36)	51 (30)	29 (41)	31 (44)	76 (43)	73 (41)	21 (81)	17 (65)
I do not know	49 (29)	45 (26)	12 (17)	14 (20)	22 (12)	29 (16)	2 (8)	4 (15)
Did not answer	12 (7)	19 (11)	8 (11)	6 (8)	11 (6)	14 (8)	0 (0)	0 (0)

RENAL DISEASE

	Midwives n=171		General Practitioners n=71		Obstetricians n=178		Cardiologists n=26	
	PE n (%)	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**
Lower likelihood	2 (1)	2 (1)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)	0 (0)
Same likelihood	9 (5)	27 (16)	1 (1)	9 (13)	11 (6)	20 (11)	0 (0)	1 (4)
Higher likelihood	128 (75)	102 (60)	61 (86)	53 (75)	152 (85)	133 (75)	26 (100)	23 (89)
I do not know	20 (12)	20 (12)	1 (1)	3 (4)	5 (3)	11 (6)	0 (0)	2 (8)
Did not answer	12 (7)	20 (12)	8 (11)	6 (8)	10 (6)	13 (7)	0 (0)	0 (0)

CARDIAC DEATH

	Midwives n=171		General Practitioners n=71		Obstetricians n=178		Cardiologists n=26	
	PE n (%)	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**
Lower likelihood	1 (1)	3 (2)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)	0 (0)
Same likelihood	13 (8)	20 (12)	1 (1)	8 (11)	4 (2)	17 (10)	1 (4)	3 (12)
Higher likelihood	110 (65)	93 (54)	57 (80)	50 (70)	149 (84)	130 (73)	23 (89)	21 (81)
I do not know	34 (20)	35 (20)	5 (7)	7 (10)	14 (8)	17 (10)	2 (7)	2 (7)
Did not answer	13 (8)	20 (12)	8 (11)	6 (8)	11 (6)	13 (7)	0 (0)	0 (0)

ISCHAEMIC HEART DISEASE/HEART ATTACK

	Midwives n=171		General Practitioners n=71		Obstetricians n=178		Cardiologists n=26	
	PE n (%)	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**
Lower likelihood	1 (1)	3 (2)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)	0 (0)
Same likelihood	16 (9)	21 (12)	1 (1)	4 (8)	8 (4)	15 (8)	1 (4)	1 (4)
Higher likelihood	113 (66)	97 (57)	57 (80)	58 (82)	155 (87)	140 (79)	25 (96)	24 (92)
I do not know	29 (17)	30 (18)	5 (7)	3 (4)	6 (3)	9 (5)	0 (0)	1 (4)
Did not answer	12 (7)	20 (12)	8 (11)	6 (8)	9 (5)	13 (7)	0 (0)	0 (0)

HDP NEXT PREGNANCY

	Midwives n=171		General Practitioners n=71		Obstetricians n=178		Cardiologists n=26	
	PE **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**
Lower likelihood	0 (0)	3 (2)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)	0 (0)
Same likelihood	12 (7)	20 (12)	0 (0)	4 (6)	0 (0)	15 (8)	1 (4)	1(4)
Higher likelihood	146 (85)	100 (58)	63 (89)	58 (82)	169 (94)	140 (79)	25 (96)	24 (92)
I do not know	1 (1)	29 (17)	0 (0)	3 (4)	0 (0)	9 (5)	0 (0)	1 (4)
Did not answer	12 (7)	19 (11)	8 (11)	6 (8)	9 (5)	13 (7)	0 (0)	0 (0)

STROKE

	Midwives n=171		General Practitioners n=71		Obstetricians n=178		Cardiologists n=26	
	PE **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**
Lower likelihood	1 (1)	3 (2)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)	0 (0)
Same likelihood	17 (10)	19 (11)	1 (1)	6 (8)	12 (7)	22 (12)	1 (4)	1 (4)
Higher likelihood	121 (71)	105 (61)	57 (80)	54 (76)	150 (84)	128 (72)	24 (92)	23 (89)
I do not know	20 (12)	24 (14)	5 (7)	5 (7)	7 (4)	13 (7)	1 (4)	2 (8)
Did not answer	12 (7)	20 (12)	8 (11)	6 (8)	9 (5)	14 (8)	0 (0)	0 (0)

PERIPHERAL VASCULAR DISEASE

	Midwives n=171		General Practitioners n=71		Obstetricians n=178		Cardiologists n=26	
	PE n (%)	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**
Lower likelihood	1 (1)	3 (2)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)	0 (0)
Same likelihood	23 (13)	21 (12)	3 (4)	9 (13)	25 (14)	29 (16)	3 (12)	4 (15)
Higher likelihood	96 (56)	84 (49)	44 (62)	38 (54)	109 (61)	100 (56)	19 (73)	17 (65)
I do not know	37 (22)	44 (26)	16 (23)	17 (24)	37 (21)	32 (18)	4 (15)	5 (19)
Did not answer	14 (8)	19 (11)	8 (11)	7 (10)	7 (4)	16 (9)	0 (0)	0 (0)

OVERALL MORTALITY

	Midwives n=171		General Practitioners n=71		Obstetricians n=178		Cardiologists n=26	
	PE n (%)	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**
Lower likelihood	1 (1)	2 (1)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)	0 (0)
Same likelihood	11 (6)	16 (9)	0 (0)	10 (14)	7 (4)	13 (7)	0 (0)	2 (8)
Higher likelihood	124 (73)	104 (61)	58 (82)	50 (70)	147 (83)	133 (75)	24 (92)	23 (89)
I do not know	23 (13)	28 (16)	5 (7)	4 (6)	15 (8)	18 (10)	2 (8)	1 (4)
Did not answer	12 (7)	21 (12)	8 (11)	7 (10)	9 (5)	13 (7)	0 (0)	0 (0)

BREAST CANCER

	Midwives n=171		**General Practitioners n=71**		**Obstetricians n=178**		**Cardiologists n=26**	
	PE n (%)	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**
Lower likelihood	4 (2)	4 (2)	0 (0)	0 (0)	4 (2)	3 (2)	0 (0)	0 (0)
Same likelihood	56 (33)	56 (33)	32 (45)	31 (44)	90 (51)	87 (49)	11 (42)	13 (50)
Higher likelihood	5 (3)	5 (3)	0 (0)	2 (3)	1 (1)	5 (3)	3 (12)	2 (8)
I do not know	94 (55)	86 (50)	31 (44)	32 (45)	73 (41)	69 (39)	12 (46)	11 (42)
Did not answer	12 (7)	20 (12)	8 (11)	6 (8)	10 (6)	14 (8)	0 (0)	0 (0)

LEUKAEMIA

	Midwives n=171		**General Practitioners n=71**		**Obstetricians n=178**		**Cardiologists n=26**	
	PE n (%)	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**	**PE n (%)**	**GH n (%)**
Lower likelihood	2 (1)	3 (2)	1 (1)	0 (0)	2 (1)	2 (1)	0 (0)	0 (0)
Same likelihood	58 (34)	56 (33)	24 (34)	28 (39)	86 (48)	86 (48)	12 (46)	13 (50)
Higher likelihood	3 (2)	3 (2)	0 (0)	0 (0)	1 (1)	1 (1)	1 (4)	1 (4)
I do not know	96 (56)	90 (53)	38 (54)	35 (49)	79 (44)	74 (42)	13 (50)	12 (46)
Did not answer	12 (7)	19 (11)	8 (11)	8 (11)	10 (6)	15 (8)	0 (0)	0 (0)

SEIZURES

	Midwives n=171		General Practitioners n=71		Obstetricians n=178		Cardiologists n=26	
	PE **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**	**PE** **n (%)**	**GH** **n (%)**
Lower likelihood	1 (1)	2 (1)	0 (0)	0 (0)	3 (2)	3 (2)	0 (0)	0 (0)
Same likelihood	33 (19)	51 (30)	25 (35)	37 (52)	83 (47)	86 (48)	7 (27)	9 (35)
Higher likelihood	49 (29)	28 (16)	12 (17)	5 (7)	20 (11)	10 (6)	9 (35)	7 (27)
I do not know	74 (43)	70 (41)	26 (37)	23 (32)	62 (35)	64 (36)	10 (39)	9 (35)
Did not answer	14 (8)	20 (12)	8 (11)	6 (8)	10 (5)	15 (8)	0 (0)	1 (4)

Appendix 20: Post-survey interview questions for healthcare providers

- In your experience, what are essential ingredients to a successful risk discussion?
- What information do you feel is necessary to share with women about their long-term health after hypertensive disorder of pregnancy (both, PE and GH)?
- Would there be any resources or information in any format be useful for you to have access to in order to support your discussions with women on this topic?
- How do your referral pathways work? Who do you refer women to if necessary and do other healthcare providers refer women to you. If so, how and what is included in the referral letter.
- What type of content would you like to see in an educational/information unit/package covering information on long-term health after HDP?
- What format do you think it should be in? What do you find works within your professional setting, what has proven to be most attended/well received/optimal learning context?
- How would you like to access it? What would be most practical for your profession?
- Is there anything else you would like to tell us about management and education after HDP that you feel is important?

Appendix 21: Thematic table illustrating healthcare provider interview findings

Research aims	**Thematic framework/index**	**Category allocated** (main category **X** and x if also linked to another category)			
		Obtaining evidence-based information for own learning	**Optimising the referral process from hospital to community health services**	**Facilitating women's health literacy**	**Seizing educational opportunities**
Content	What is HDP? / Definition of HDP?	**X**		x	
	Clinical signs and symptoms	**X**		x	
	Explaining the link between HDP and future health risks	**X**	x	x	
	Statistics on long-term risk factors	**X**		x	
	What advice should be given about follow-up	**X**	x	x	
	Who is responsible for the risk discussion	**X**	x	x	x
	Content relating to referral	**X**	x		x
	What are the short-term risks?	**X**	x	x	x
	Helpful resources	**X**	x	x	x

Format	Clinical meetings	**X**			
	Case discussions	**X**	x		x
	Hospital lectures/in-services/education sessions/grand rounds	**X**		x	x
	Workshops/education days	**X**	x	x	x
	Conferences	**X**	x		
	Webinars	**X**	x		
	Other online learning	**X**			
	Educational videos	**X**			
	Clinical practice guidelines	**X**	x	x	
	Podcast	**X**			
	Awareness campaign	**X**	x	x	
	Journal articles and professional bulletins	**X**			
	Fact sheets	**X**		x	
	Smartphone applications	**X**	x	x	x
	Multi-disciplinary	**X**	x	x	
	Education that is short and ‘snappy’ / has momentum	**X**			x
	Interesting, engaging, informative	**X**			
	Education in a variety of formats	**X**		x	
	Current and referenced	**X**	x	x	
	Practical/clinical application/hands-on/interactive	**X**		x	
	Variety of formats	**X**	x		
	National versus just state based	**X**	x		

Access	Subscriptions (podcast, journals, google alerts)	**X**	x		x
	Social media (Twitter, Facebook)	**X**			x
	Self-initiated database searches/journal search	**X**		x	x
	Professional colleges	**X**	x		x
	Obtain information from Specialists (colleagues)	**X**	x		x
	Regional and International societies	**X**	x		
	Conferences	**X**	x		
	Primary Health Network	**X**	x		
	Hospital initiatives	**X**	x		x
	Health Organisations	**X**			
	University	**X**			
	National register	**X**	x	x	x
Enablers	**Acquisition of knowledge**				
	Self-initiated learning	**X**			x
	Technological literacy	**X**	x		
	Professional Colleges	**X**	x		x
	Learning from other disciplines	**X**	x		
	Rewards (CPD points)	**X**			
	Easy access to evidence-based information	**X**	x		
	Professional conscience/awareness of impact and importance	**X**	x		
	Environment with regular hours in order to capture more/all staff	**X**			

	Electronic records to aid follow-up (eg clinical software reminders)	**X**	x		
	Working in public health vs private health	**X**	x		
	Transmission of knowledge				
	Resources prepared for women to support in risk discussion	x	x	**X**	x
	Continuity of care		**X**	x	x
	Relationships of trust/good therapeutic relationship with the woman		**X**	x	x
	Taking obstetric history		**X**	x	x
	Clear documentation		**X**		
	Variable factors dependent on the woman (e.g. timing of follow-up, health literacy, self-determination)		x	x	**X**
	Using screening tests to discuss relevant preventive health topics			x	**X**
	Opportunistic counselling		x		**X**
	Resources available to the institution/work place		**X**		**x**
	Interprofessional transmission of knowledge/being on the same page		**X**	x	

Barriers	**Acquisition of knowledge**				
	Professional scope (legal and philosophical)	**X**			
	Lack of regional/international guideline promotion/awareness	**X**			
	Working solo/not part of a wider team/limitations of independent learning	**X**			
	Variable IT skills amongst HCP and student HCP	**X**			
	Variable learning styles amongst HCP and student HCP	**X**			
	Old clinical beliefs	**X**			
	Disjointed health system - state regulation	**X**			
	Lack of centralised access to GPs	**X**			
	Speed of new research emerging in specialty fields	**X**			
	Cost or ability to access information/education	**X**			
	Dichotomy of university teaching and current clinical practice/the missing link	**X**			
	Lack of time for education/interruptions/other priorities/topics of interest	**X**			
	Over requirement of mandatory learning (distracting from learning other clinically relevant topics)	**X**			
	Lack of interdisciplinary collaboration/position statements	**X**	x		
	Lack of topic presence	**X**			
	Transmission of knowledge				

	Lack of continuity of care		**X**	x	x
	Health- literacy of the women			**X**	x
	Cultural and language diversity of the women		**X**		x
	Women’s trust in HCP affected by past experience		**X**	x	
	Conflicting advice from various HCP		**X**	x	x
	Women’s accuracy of recall of information/obstetric history			x	**X**
	Women’s variation of interpretation of the information shared with them		x	x	**X**
	HCPs selectively downplaying or withholding information so as not to scare women			x	**X**
	Too many (or none set up) software reminders/pop ups		**X**		x
	Not using educational opportunities during routine visits/screening tests				**X**
	HCP unaware of the link between HDP and future risk	**X**	**x**	x	**x**
	Passing the buck (for the risk-discussion)				**X**
	Missing the boat - missed opportunities for preventive health discussion				**X**
	Limiting education to PE only (no other HDPs)				**X**
	Timing of appointment (since birth) for women				**X**
	Issues around referral		**X**		
	Information overload for women			x	**X**
	Women prioritising their children (not presenting)				**X**

	The word wide web (women googling)			x	**X**
	Language used in risk discussion and how it affects women’s perceived risk		X	x	

CPD - continuing professional development, GP - general practitioner, HCP - healthcare providers, HDP - Hypertensive disorder of pregnancy, IT- information technology, PE- preeclampsia

Appendix 22: Demographic details of participants grouped by profession

State or Territory	Profession*	Area of practice	Gender
ACT/NSW	Midwife	Academic	female
ACT/NSW	Midwife	Midwifery Group Practice- Public	female
ACT/NSW	Midwife	Maternity services - rotational	female
ACT/NSW	Midwife	Day Assessment Unit - Public	female
VIC	Midwife	Maternity services - rotational	female
ACT/NSW	Midwife	Clinical Midwifery Educator - Public	female
WA	Midwife	Midwifery Educator - Public	female
WA	Midwife	Maternity services - rotational	female
ACT/NSW	Midwife	Maternity services - rotational	female
ACT/NSW	Midwife	Midwifery Group Practice - Public	female
ACT/NSW	Midwife & CFHN	Public, research	female
ACT/NSW	Specialist obstetrician	Private practice	male
QLD	Specialist obstetrician	Academic/public hospital	male
ACT/NSW	Specialist obstetrician	Public/Private practice	male
VIC	Specialist obstetrician	Private	female
TAS	Specialist obstetrician	Public/Private practice	male
WA	GP with OBGYN Diploma	Private practice	female
ACT/NSW	GP with OBGYN Diploma	Private practice	male
VIC	GP with OBGYN Diploma	Private practice	female
VIC	Cardiologist	Public/Private practice	male

* Not listed in order of interviews conducted

VIC -Victoria, NSW - New South Wales, WA -Western, Australia, TAS - Tasmania, CFHN - Child and Family Health nurse, GP - general practitioner, OBGYN- obstetrics/gynaecology