

A Priority Setting Partnership for care improvement of Hypertensive Disorders of Pregnancy in Ghana - A National Research Agenda

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Abstract

Hypertensive Disorders of Pregnancy (HDP) are among the leading causes of maternal and perinatal morbidity and mortality in Ghana. Despite the high burden, research priorities have been historically shaped by academic, funding, policy and industry actors, with limited engagement patients/survivors of HDP, carers and clinicians whose lived experiences offer critical complementary research insights. Priority Setting Partnerships (PSPs) address this gap by involving these stakeholders in co-identifying future HDP research needs. This study aimed to identify research topics for improving HDP care in Ghana, based on the perspectives of HDP patients, carers and healthcare professionals.

A PSP was conducted by combining the James Lind Alliance (JLA) approach and the Research for Health Justice (R4HJ) Ethical Toolkit to ensure local relevance and ethical rigor. The process included establishing an Advisory Committee; administering surveys, reviewing the submitted uncertainties against existing literature and finalizing a shared Top 10 list of research priorities during a prioritization workshop.

Between February and August 2024, 238 HDP patients, carers and healthcare professionals across Ghana submitted a total of 774 research uncertainties, distilled into 51 areas. A second survey by 243 participants narrowed the 51 areas into 25 interim priorities, which were refined during the final prioritization workshop into 10 priorities. The Top 10 priorities encompassed diagnosis timing and accuracy, pathogenesis, care provision challenges, awareness, mental health and coping, shared decision making, preconception care and drug adverse effects.

Our integrated use of the James Lind Alliance method, Research for Health Justice Toolkit and extensive local engagement provides a model for ethically conducting PSPs in low- and middle-income settings and offers research priority recommendations from the key end-users.

Introduction

Hypertensive Disorders of Pregnancy (HDP), such as preeclampsia, gestational and chronic hypertension, account for approximately one in seven maternal deaths worldwide [1]. The heaviest burden of HDP lies in sub-Saharan Africa (SSA), where countries experience a relatively high HDP prevalence, case fatality rate and maternal mortality ratio (MMR) [2–4]. In Ghana, the MMR was 263 deaths per 100,000 live births in 2020, approximately 20 times higher than the average MMR in high income countries [4]. It is estimated that 18-37.3% of these maternal deaths can be attributed to HDP [5–8]. HDP furthermore contributes significantly to adverse perinatal outcomes, such as increased incidence of prematurity, birth asphyxia and other birth complications [9]. As such, addressing HDP can have profound, long-term effects on early childhood development in LMICs, as the health of a child during this critical stage can influence their growth, cognitive development, and overall quality of life [10].

Sustainable Development Goal (SDG) Target 3.1 and 3.2 aims to reduce the global average MMR to less than 70 deaths per 100,000 live births and the neonatal mortality rate to less than 12 per 1000 live births by 2030 [11]. Despite extensive investments in research and interventions to this end, in most SSA countries the declining MMR has stagnated in recent years [12]. One of the reasons for this stagnation is “waste” in biomedical research, as approximately only fifteen percent of global research investments in 2009 translated into improvements to clinical care [13]. This calls for more relevant, actionable and translatable research and

interventions that address the priorities and needs of the end beneficiaries. To achieve this, research agenda setting processes should move away from primarily engaging historical research drivers like the academic (medical) community, private sector, funders and policy makers, and instead include the end service users in priority setting [13, 14].

The James Lind Alliance (JLA) was established to encourage the transition towards more relevant and equitable research agenda setting [15]. The JLA method was designed to raise awareness of research questions that are of direct importance to patients, their carers and healthcare professionals and as a result drive a change in funding priorities. A step-by-step method to perform Priority Setting Partnerships (PSPs), in which patients, their caregivers and clinicians determine research priorities regarding a medical condition was therefore developed [16]. In line with this, the objective of this study was to conduct a similar PSP to identify and prioritize topics for future research leading to care improvement of HDP in Ghana, based on the views of HDP patients, their carers and healthcare professionals.

Methods

The methodology is described following the Reporting Guideline for Priority Setting of Health Research (REPRISE) reporting guideline [17]. The Hypertensive Disorders of Pregnancy Priority Setting Partnership (HDP PSP) project took place between 05 February until 03 August 2024, and the final report was published on October 3rd, 2024. Post-project dissemination and advocacy for the implementation of the priorities is still ongoing, mostly through the activities of the Ghanaian non-governmental organization (NGO) Action on Preeclampsia Ghana (APEGH).

Context and scope

The HDP PSP addressed care-related research priorities for HDP within Ghana. We used the definition for HDP as put forward by International Society for the Study of Hypertension in Pregnancy (ISSHP), including, but not limited to, gestational hypertension, preeclampsia, chronic (preexisting) hypertension, and chronic hypertension with superimposed preeclampsia [18]. Diagnostic criteria of these conditions are included in the **Supplementary Material 1**.

The HDP PSP focused on “uncertainties” regarding the diagnosis, treatment, prognosis, and causes and risk factors of HDP in Ghana (hereafter also summarized as care-related uncertainties). An “uncertainty” refers to a question or concern about HDP reported as a possible research priority by the study participant.

This PSP aimed to center the perspectives of “end users” of HDP research in Ghana: HDP patients/survivors, their carers and clinicians. To protect the stakeholder-led nature of this project and have research priorities reflect the full range of submissions, an Advisory Committee consisting of end-beneficiaries was established. This committee had the mandate to adjust the PSP process and scope based on local perspectives and “out-of-scope” responses received. Other stakeholders identified as essential to engage included policy making institutes/agencies (e.g. Ministry of Health (MOH), Ghana Health Service (GHS)), research funding institutes (e.g. Centers for Disease Control and Prevention, Research and Grant Institute of Ghana), research institutes (e.g. Noguchi Memorial Institute for Medical Research (NMIMR), University of Ghana), health insurance companies and pharmaceutical companies.

Framework for priority setting

The HDP PSP methodology entailed a four-phase mixed methods approach, including semi-structured surveys, interactive meetings and a deliberative final workshop (see **Figure 1**), largely following the JLA method [16]. In the JLA method, patients, carers and clinicians guide the process through forming a Steering Committee, they report and prioritize their uncertainties via two surveys and perform final prioritization during a deliberation workshop to establish a shared Top 10 research priority list.

To tailor the JLA process to the local Ghanaian context, available resources, and global health ethics considerations, we integrated the Research for Health Justice (R4HJ) Ethical Toolkit for priority setting processes into the methodology [19]. The R4HJ toolkit was developed to design priority setting processes in which power is shared with local stakeholders. It consists of four worksheets that researchers can use as a reflective guide towards an ethical and representative priority setting process [19]. The JLA method was modified based on the considerations resulting from these worksheets and recommendations from local collaborators, which are summarized in **Table 1**.

Table 1: Modifications to the JLA method

Element	Modification	Justification
Stakeholder engagement	The responsibilities of the Steering Committee were modified, changing from their operational tasks to focus on providing feedback. As a result, the committee was identified as an Advisory Committee considering the more advisory role assumed by the committee.	Necessary due to the limited time and financial resources. Through the R4HJ Ethical Toolkit, it was deemed necessary to adjust the level of participation of the committee to ensure continued involvement with the limited resources without overburdening the committee members.
	In addition to only patients, carers and clinicians, the Advisory Committee included a community representative and policy maker; these experts are not traditionally considered part of a Steering Committee as per the JLA guide.	Recommended by local team members. Per the local conventions, their inclusion early in the project as shared decision makers would improve support for the translation of the research agenda into actionable research, policy and interventions.
	Partnering with institutions was largely postponed to the dissemination phase, rather than done throughout the process.	Due to resource constraints and to prevent any influence on the involved patients, carers and clinicians due to the inherent power dynamics.
Surveys	Stakeholders with indirect experience (researchers, policy makers) were not actively excluded from the survey though the survey primarily targeted patients, carers and clinicians.	This change was made for the strategic purpose of increasing engagement with interested stakeholders. Their involvement would ultimately benefit the support for and/or endorsement of the agenda.
Data analysis	The literature search focused primarily on studies performed in Ghana or comparable socioeconomic or geographic contexts (i.e. West Africa, SSA, low- and middle-income countries).	The contextual determinants of health (care) in Ghana were considered highly relevant and often more applicable than global research findings.
Final Workshop	Participants were provided with an online form to rank shortlisted priorities before the workshop. Follow-up contacts were made until each participant had completed the form. This was a prerequisite for attending the workshop.	This was done to ensure all participants were familiar with the question list in advance to the workshop. This was deemed especially important for equitable participation and also helped ameliorate low punctuality.
Administrative	No official JLA Advisor was involved in the process. Rather, experts in community engagement were consulted during the process.	This was decided due to limited resources and in order to have flexibility to tailor the process to the Ghanaian context and integrate the R4HJ toolkit.
	The protocol is not published on the JLA website.	This was due to resource constraints and because we adjusted the original JLA process.

Governance and team (*Phase one*)

The HDP PSP project was initiated by the Severe Preeclampsia adverse Outcome Triage (SPOT) study group, the Ghanaian NGO APECGH, the Greater Accra Regional Hospital (GARH) and the Korle-Bu Teaching Hospital (KBTH). The core research team consisted of a final year medical student from the UMCU (Principal Investigator (PI)), a PhD-student from the UMC Utrecht (UMCU, co-investigator), the CEO of APECGH (co-investigator), a maternal health research fellow from the Ghanaian institute NMIMR (supervisor) and an associate professor in global health from the UMCU (supervisor). A qualitative researcher with expertise in participatory research

methods provided guidance regarding stakeholder engagement. This team performed most of the operational tasks with co-investigators from GARH, KBTH, GHS involved where appropriate.

An Advisory Committee consisting of local HDP end beneficiaries (patients, carers, clinicians) was established to provide input and feedback to ensure cultural appropriateness of the process. To ensure an equitable representation and involvement of this Advisory Committee, Phase One started with an extensive stakeholder analysis based on recommendations from co-investigators, a careful deliberation within the core project team and a review of ethical considerations from Worksheet 1 and Worksheet 4 of the R4HJ toolkit [19]. The Advisory Committee invitees were chosen with a twofold aim: (1) to achieve optimal representation of HDP patients, carers and clinicians, including various communities and vulnerable groups, and (2) to ensure broad support for the research agenda in the different levels of society. The Advisory Committee consisted of five HDP survivors with diverse backgrounds (such as being a nurse, having a comorbidity or running a patient advocacy organization); two carers (one husband and one sister of HDP survivors); a community representative (a Queen mother recognized for advocating for women's rights and girl education) ; and five healthcare professionals (ranging from a community health nurse to an obstetrician-gynecologist and a policy maker). All except for one member were from the Greater Accra Region. An in-person Advisory Committee meeting was held on March 7th, 2024, at the Greater Accra Regional Hospital to introduce the project protocol, establish respectful engagement principles, and agree on strategies for disseminating the project survey. Subsequent monthly meetings were conducted as the project progressed. An APECGH linguist was available to support translation of all communication (both in-person and online) for Advisory Committee members more comfortable with the local dialect. The Advisory Committee members were compensated for their involvement by covering food and transportation costs during in-person meetings, and mobile data usage during online meetings.

Identification of research priorities (*Phase two*)

A first survey was developed and disseminated to gather care-related evidence uncertainties regarding HDP from patients, carers and healthcare professionals.

Inclusion criteria for survey participation were age of at least eighteen years; the willingness and ability to provide informed consent; and having direct experience with HDP in Ghana. This could be lived experience (i.e. HDP patients, survivors, carers, family or friends), or professional experience (any healthcare practitioner in the field of obstetrics and gynecology (OBGYN). Though not explicitly targeted, researchers and policy makers in the field of HDP were not excluded from participating in the survey.

The survey consisted of two sections, one with demographic questions and an open-answer section to write out questions and concerns about HDP. Two versions of the survey were created: a patient/carers version and a healthcare professional version. The versions only differed in terms of the language and use of medical jargon based on a review by the advisory committee and respondents had the ability to choose for themselves which version they filled out. Paper and online versions were offered to broaden accessibility. The survey can be found in the **Supplementary Material 1**. Through the APECGH network, the survey was also actively disseminated during visits to health facilities and communities, social media, via calls and voice messages. Survey responses were collected from March 25th until April 31st, 2024. Interim evaluation of the survey responses was performed by the Advisory Committee, and the survey dissemination strategy was adapted to increase the number of respondents across the country. An overview of the dissemination locations is depicted in **Figure 2**.

Responses to the first survey were analyzed following a five-step process. First, the data was downloaded and cleaned. Second, “out-of-scope” submissions (evidence uncertainties that did not cover a topic regarding the diagnosis, treatment, prognosis, causes or risk factors of HDP in Ghana, or that could not be understood as an uncertainty) were excluded. Third, uncertainties were categorized into the following main groups: diagnosis, treatment, prognosis, and causes/risk factors. Uncertainties in these main groups were further subcategorized iteratively. The WHO Network for Improving Quality of Care for Maternal, Newborn and Child Health Framework was also used as a guide in this phase [20]. Fourth, duplicate and similar uncertainties from the same sub-category were summarized into clear, unambiguous questions (hereafter referred to as “indicative questions”). When possible, two versions of the indicative question were developed—one with and one without medical jargon. Finally, literature and guidelines were reviewed to evaluate the existing knowledge base of each indicative question. Databases used were PubMed, The Cochrane Database of Systematic Reviews, Scopus (for social science questions), the Ghana Health Service Standard Treatment Guidelines and the International Society for the Study of Hypertension in Pregnancy Guidelines [21,22]. Level of evidence was determined based on availability of review articles such as systematic reviews. Regarding geographical scope, reviews including Ghana were prioritized, and where necessary expanded to West Africa, sub-Saharan Africa, LMICs and finally global in the case of few search results.

Prioritization of indicative questions (*Phase three*)

Prioritization of the indicative questions resulting from the data analysis was completed in two steps: a second survey, followed by a final prioritization workshop.

In the second survey, respondents were asked to select four to ten questions they personally found important out of the full list of indicative questions that were provided. Respondents were then asked to choose their top 3 out of their selected questions, to help resolve ties where necessary. The question list was organized under the main category headings: diagnosis, treatment, prognosis, and causes and risk factors. As with the first survey, two versions were created based on use of medical jargon and reviewed by the advisory committee. The surveys are available in the **Supplementary Material 1**. In the online survey, the categories and associated questions were randomized for each respondent to avoid question order bias. The survey was open from June 25th until July 23rd, 2024. Inclusion criteria were the same as the first survey. Survey dissemination followed the same strategy as the first survey with dissemination occurring at different facilities. The distribution of these locations is shown in **Figure 2**. An interim priority list was generated based on the second survey responses. These indicative questions were ranked based on the number of responses adjusted according to the type of respondent (patient/carer versus healthcare professional).

The Final Prioritization Workshop was held on August 2nd, 2024, at the Centre for Biodiversity Conservation Research, University of Ghana. This workshop served to reach consensus among HDP patients, carers and healthcare professionals about the final Top 10 research priorities for HDP in Ghana. The workshop participants (N=24) were primarily patients, carers and healthcare practitioners including the Advisory Committee members. Two other stakeholders (one representative from the Ghana Health Service and one representative from the Society of Obstetricians and Gynecologist of Ghana, SOGOG) were included as workshop participants to promote buy-in and support for the resulting agenda. The workshop followed 3 sessions in which a facilitator supported by an APECGH volunteer facilitated a group of 6 participants to review the interim list of 25 questions. Each small group was carefully put together during each session for an equitable and open

collaboration to achieving the objective for that session. In the first small group session, participants shared their individual preferences and tallied up the preferred questions. In the second session, each group extensively discussed the 25 questions and prepared a top 20 list of questions. After this session, a preliminary composite ranking from the four groups was calculated and presented. In the third session, this composite ranking was reviewed, and the final composite ranking was created and approved. After the workshop, the research team reviewed the final list and presented it to the Advisory Committee. The full workshop program and activities can be found in the **Supplementary Material 1**.

Dissemination and implementation (*Phase four*)

The final Top 10 research priorities were integrated into a report, which was launched via an online meeting on October 3rd, 2024 [21]. and subsequently published on the APECGH website. Additional strategies for the dissemination of the final Top 10 research priorities include dissemination on both research platforms such as publication and presentations at conferences, symposia and other (scientific) meetings as well as and non-research platforms via APECGH's engagement activities and local media with a focus on promoting partnering with research, funding and policy making institutes, to encourage the translation of the Top 10 into actual research projects.

Ethical approval

Ethical approval for this project was obtained from the Ghana Health Service Ethics Review Committee on February 12th, 2024, reference number 063/06/22.

Funding and conflict of interest

This study was funded with an Utrecht University Open Science seed grant. No conflicts of interest were reported in this project.

Results

Identification of indicative questions

The first survey was completed by a total of 292 respondents. After exclusion of 54 incomplete surveys, 238 complete surveys remained. The respondents consisted of 87 HDP patients or survivors, 17 carers, 124 clinicians and 10 other health professionals. Most respondents were women of reproductive age (n=217, 91%), living or working in an urban setting (n=196, 82%). Among the patients and carers, the majority had completed tertiary education (n= 56, 53%) and were traders (n= 24, 23%), midwives (n= 15, 14%) or teachers (n= 14, 14%) by profession. Most of the healthcare professionals were nurses and midwives (n=85, 63%) and worked at a secondary or tertiary health facility (n=101, 75%). 80% (n=190) of the respondents had their last experience with HDP less than five years prior to the survey, showing that the research priorities were based on recent experiences. Detailed baseline characteristics of the survey respondents can be found in **Table 2** and **Figure 3**. An overview of the involved stakeholders and the number of uncertainties at each process stage is depicted in **Figure 4**.

The survey yielded a total of 774 individual submissions, of which 310 from patients and carers, and 464 from healthcare professionals. 161 submissions were classified as not containing any research uncertainty (see

Supplementary Material 3 for the full list). Of the remaining 613 uncertainties, 114 (15%) questions were regarding diagnosis, 193 (25%) regarding treatment, 87 (11%) regarding prognosis, and 219 (28%) regarding causes and risk factors. There were no uncertainties reported outside the project scope. See the **Supplementary Material 3** for categories and sub-categories identified. A total of 55 indicative questions were formulated after categorizing and consolidating similar uncertainties.

Table 2: Baseline characteristics of the survey respondents

Characteristic	First survey (uncertainty identification)			Second survey (interim prioritization)		
	Patients/carers	Professionals	Total	Patients/carers	Professionals	Total
	n=104 (44)	n=134 (56)	n=238 (100)	n=96 (40)	n=147 (60)	n=243 (100)
Sex						
• Female	100 (96)	102 (76)	202 (85)	94 (98)	126 (86)	220 (91)
• Male	4 (4)	32 (24)	36 (15)	2 (2)	21 (14)	23 (9)
Age						
• 18-24	10 (10)	5 (4)	15 (6)	6 (6)	15 (10)	21 (9)
• 25-35	43 (41)	59 (44)	102 (43)	46 (48)	64 (44)	110 (45)
• 35-45	47 (45)	53 (40)	100 (42)	38 (40)	56 (38)	94 (39)
• 45 and above	4 (4)	17 (13)	21 (9)	6 (6)	12 (8)	18 (8)
Living/work setting	Living:	Work:		Living:	Work:	
• Urban	87 (84)	109 (81)	196 (82)	82 (85)	127 (86)	209 (86)
• Rural	17 (16)	25 (19)	42 (18)	14 (15)	20 (14)	34 (14)
Highest finished education						
• No formal	14 (14)	-	-	5 (5)	-	-
• Primary	19 (18)	-	-	25 (26)	-	-
• Secondary	15 (14)	-	-	18 (18)	-	-
• Tertiary	56 (53)	-	-	44 (46)	-	-
• Unknown	0 (0)	-	-	4 (4)	-	-
Work at health facility level						
• Primary	-	28 (21)	-	-	20 (14)	-
• Secondary	-	53 (39)	-	-	90 (61)	-
• Tertiary	-	48 (36)	-	-	33 (22)	-
• Other facility	-	5 (4)	-	-	4 (3)	-
Patient/carers professions						
• Trader	24 (23)	-	-	23 (24)	-	-

• Midwife	15 (14)	-	-	13 (14)	-	-
• Teacher	14 (14)	-	-	4 (4)	-	-
• Nurse	4 (4)	-	-	11 (12)	-	-
• Tailor	7 (7)	-	-	9 (9)	-	-
• Student	5 (5)	-	-		-	-
• Hairdresser	4 (4)	-	-	4 (4)	-	-
• Farmer	5 (5)	-	-	3 (3)	-	-
• Housewife	5 (5)	-	-	6 (6)	-	-
• Other	20 (17)	-	-	20 (21)	-	-
Healthcare professions						
• Nurse/Midwife	-	85 (63)	-	-	113 (77)	-
• Medical doctor	-	37 (28)	-	-	23 (16)	-
• Physician assistant	-	1 (1)	-	-	0 (0)	-
• Community health nurse	-	1 (1)	-	-	6 (4)	-
• Researcher	-	2 (2)	-	-		-
• Pharmacist	-	2 (2)	-	-	1 (1)	-
• Medical student	-	3 (2)	-	-	0 (0)	-
• Other	-	3 (2)	-	-	4 (3)	-
Relation to HDP						
• Patient/survivor	87 (84)	-	-	70 (73)	-	-
• Partner	7 (7)	-	-	3 (3)	-	-
• Relative	6 (6)	-	-	13 (14)	-	-
• Friend/colleague	4 (4)	-	-	10 (10)	-	-

Legend: values depicted as absolute numbers (percentages). Due to rounding of the separate characteristics, percentages do not always tally up to exactly 100.

Literature review was conducted to identify questions that had been broadly answered. Of the 55 questions, two questions under the category “diagnosis” were excluded as they were deemed sufficiently addressed through local and international treatment protocols, national health surveys and research papers (See **Supplementary**

Material 2; Questions D_02 and D_07). In addition, per feedback from the Advisory Committee, it was determined to merge two pairs of questions (See **Supplementary Material 2;** Questions D_04 and D_04A) and rephrase one question into a more relevant version based on the evidence found. The findings and justification for the decisions made during the literature review stage can be found in the **Supplementary Material 2**. The 51 remaining questions for the second survey consisted of twelve (12) for diagnosis, nineteen (19) for treatment, ten (10) for prognosis and ten (10) for causes/risk factors. See the **Supplementary Material 3** for these questions and their associated domains.

Prioritization of indicative questions

The second project survey was completed by 243 people (96 HDP patients or survivors, 24 carers, 142 clinicians and 5 other healthcare professionals). Similarly to the first survey, its respondents were mainly women of reproductive age (n=225, 93%) living or working in an urban setting (n=209, 86%) in Western or Greater Accra Region (n=169, 70%). The largest share of patient and carer respondents finished tertiary education (n=44, 46%), common professions were trading (n=23, 34%), midwifery (n=13, 14%) and nursing (n=11, 12%). Most of the healthcare professionals were nurses and midwives (n=113, 77%) working at a secondary health facility (n=90, 61%). 72% of the healthcare professionals had over two years of professional experience with HDP, underlining that their reported uncertainties were based on extensive experience. Full baseline characteristics of the second survey respondents can be found in the right columns of **Table 2**. A total of 908 individual submissions were received from patients and carers (average of 9 submissions per respondent), and for healthcare professionals 1221 submissions (average of 8 submissions per respondent). **Table 3** shows the top 25 questions selected in the interim prioritization survey. The detailed ranking process can be found in the **Supplementary Material 3**. There were no ties in ranking during the interim prioritization process.

Table 3: Interim priority list including separate ranking of patients/carers and healthcare professionals

Question	Ranking		
	Overall	Patients/ carers	Professional
How can we create awareness about the severity and complications of HDP in Ghana?	1 st	4 th	1 st
What are the causes and risk factors of HDP in Ghana?	2 nd	1 st	7 th
How adequate are healthcare professionals' knowledge and skills regarding HDP complications and prognosis in Ghana?	3 rd	6 th	4 th
What are strategies to improve antenatal care attendance in Ghana?	4 th	24 th	2 nd
Is prevention of HDP possible and if so, how?	5 th	4 th	7 th
What are the adverse effects of commonly used HDP medication in Ghana?	6 th	1 st	36 th
What is the accuracy of screening and diagnosis of HDP among women in Ghana, and how can this be improved?	7 th	3 rd	26 th
What role do patients' partners play in the treatment of HDP in Ghana?	8 th	6 th	12 th
What coping strategies do preeclampsia patients, their partners and relatives use in Ghana?	9 th	12 th	5 th
To what extent can complications be prevented through accurate and timely diagnosis of HDP in Ghana?	10 th	18 th	3 rd
What are the challenges for healthcare professionals in Ghana in diagnosing HDP?	11 th	12 th	14 th
What is the current level of awareness about HDP in Ghana, and how can this be increased?	12 th	6 th	21
What education needs to be provided to HDP patients in Ghana about their prognosis, and how should this be done?	13 th	11 th	18 th
What are the possibilities for early diagnosis of HDP in Ghana (before presence of symptoms)?	14 th	21	12 th
To what extent do healthcare professionals in Ghana educate HDP patients about their treatment, and how can this be improved?	15 th	12 th	21 st
What are the challenges for healthcare professionals in Ghana regarding the provision of adequate treatment for HDP?	16 th	16 th	18 th
What is the emotional and psychological impact of HDP in Ghana?	17 th	6 th	33 rd
What are biomarkers for risk prediction in HDP, and how reliable are these in Ghana?	18 th	12 th	26 th
What is the risk of recurrence of HDP in Ghana?	19 th	21 st	15 th
What is the role of patient involvement, risk communication and shared decision making regarding HDP in Ghana?	20 th	33 rd	5 th

How can we best address myths or misconceptions about the causes and risk factors of HDP in Ghana?	21 st	18 th	31 st
What is the financial burden of diagnostic tests for HDP patients in Ghana, and how can this be improved?	22 nd	21 st	26 th
What are the existing inequities in screening, diagnostic criteria, timing and accuracy of HDP diagnosis in Ghana, and how can these be improved?	23 rd	18 th	33 rd
What non-pharmacological options could support HDP treatment in Ghana?	24 th	16 th	36 th
How can preconception management be integrated into the standard maternal health services in Ghana?	25 th	33 rd	10 th

Table 4 depicts the final Top 10 research priorities for the management of HDP in Ghana as concluded after the Final Prioritization Workshop (see the **Supplementary Material 3** for the plain language version). The small group rankings and interim collated ranking are included in the **Supplementary Material 3**. The priorities include questions regarding early and accurate diagnosis, pathogenesis, barriers in service delivery, awareness of the general public, impact on mental health and coping, patient education and autonomy, preconception care and drug side effects.

Three questions out of top 10 research priorities do not correspond to the top 25 questions submitted for the final prioritization workshop. This is a result of the feedback provided by participants during the workshop, in which it was suggested to combine two pairs of questions into overarching questions, and another triplet of questions into a single question (see the **Supplementary Material 3** for more details). As a result, the questions ranked 11-13 eventually ended in the final Top 10 list as question 8, 9 and 10.

Seven out of ten questions in the final Top 10 list were also ranked high in the interim priority list, which represents alignment between the smaller group of workshop participants and the much larger second survey respondents. However, during the workshop, the participants emphasized the necessity for research beyond the Top 10 list of questions. It was therefore agreed during the workshop to include any remaining questions from the interim priority list in the dissemination process.

Table 4: Final Top 10 research priority list

RANK	QUESTION
1	What are the possibilities for earlier diagnosis of HDP in Ghana to prevent complications?
2	What are the causes and risk factors of HDP in Ghana?
3	What are the challenges for healthcare professionals in Ghana regarding the diagnosis, knowledge of prognosis and complications, and provision of adequate treatment for HDP?
4	What is the current level of awareness about HDP in Ghana, and how can this be increased?
5	What is the accuracy of screening and diagnosis of HDP among women in Ghana, and how can this be improved?
6	What is the emotional and psychological impact of HDP in Ghana?
7	What are strategies to improve patient involvement, risk communication and shared decision making regarding HDP in Ghana?
8	How can preconception management be integrated into the standard maternal health services in Ghana?
9	What coping strategies do preeclampsia patients, their partners and relatives use in Ghana?
10	What are the adverse effects of commonly used HDP medication in Ghana?

Discussion and conclusion

Principal findings

We conducted a Priority Setting Partnership to identify care-related research priorities for HDP in Ghana, based on the views of over 500 HDP patients, carers and clinicians. The Top 10 priority list covers a wide range of topics related to the care for patients with HDP, which reflects the diverse challenges that patients, carers and clinicians in Ghana face. Beside more broad priorities regarding accurate diagnosis and the pathogenesis of HDP, context-specific challenges to quality and respectful care were reflected in the list in the questions about shared decision-making (Question 7), involvement of male partners (Question 9), myths and traditional beliefs (Question 2 and 4) and inequities in healthcare access (Question 3 and 8).

With assistance of the R4HJ toolkit and extensive local stakeholder engagement and expertise, the JLA PSP method was adapted to address contextual factors such as the strong presence of hierarchy, importance of traditional leadership and community structures, and resource and internet access challenges [22].

Findings in relation to literature

The Top 10 priorities of the HDP PSP correspond with commonly found question types in PSPs: PSP exercises are more likely to prioritize education and training, service delivery, psychological interventions, exercise, complementary interventions and diet. This is in contrast with the majority of topics studied in (industry or sponsor-driven or investigator-driven) trials [23]. All HDP PSP priorities except for the 5th and 10th, fall within

these categories. The HDP PSP furthermore did not include questions regarding specific pharmacological and surgical therapeutic interventions, which constitute the vast majority of trials on this topic [23]. Instead, diagnostic testing and drug safety was a priority identified in this project as evidenced by the 5th and 10th priority. Their presence in the HDP PSP priority list can be understood in the context of specific Ghanaian healthcare system challenges such as delays in accurate diagnosis, expensive or lack of access to medicine and dissatisfaction and disrespectful maternal care [24].

GHS, the largest health service delivery arm under auspice of the Ministry of Health, published priorities for maternal health in their strategic plan for 2020-2025 [25]. This national strategic plan prioritizes health system strengthening, tracking and the implementation of audits for maternal health among others, which were not explicitly identified as priorities in the HDP PSP. However, alignment is observed in issues such as availability of skilled healthcare professionals as seen in the 1st, 3rd and 5th priority in our Top 10. It is also worth noting that the average patient, carers and frontline healthcare workers may not necessarily be familiar with the more systemic factors and terminologies within the healthcare system that define the quality of care such as regular audits, effective clinical guidelines, health information system and robust referral processes. From patients' perspective, these factors are perceived downstream in the form of suboptimal availability and accessibility of skilled healthcare workers, medicine and other equipment which defines the quality of care for them.

A number of similarities can also be identified between this HDP PSP and the JLA PSP on HDP conducted in the UK between 2018 and 2019 [26]. As visually summarized in **Table 5**, the top 3 priorities in Ghana (early diagnosis, pathogenesis and needs of healthcare professionals) are also included in the UK HDP PSP. HDP screening, mental health effects and psychological needs of patients' and families are also featured in both Top 10s. This suggests that the priorities of HDP patients, carers and healthcare professionals are potentially universal and recognized in different settings. However, it is observed that Ghana HDP PSP included a stronger focus on awareness, mental health effects and access to adequate diagnosis and care, whereas the UK HDP PSP prioritized (long-term) management and prognosis. These differences likely reflect contextual challenges in Ghana such as persisting barriers in primary (mental) healthcare which results in the most "fundamental questions" still remaining unaddressed for many patients. Additionally, limited health literacy and low awareness of long-term health implications of HDP on future pregnancies and overall health could be another factor driving the difference in priorities identified between the UK

Table 5: Comparison between the Top 10s of the HDP PSP in Ghana and the UK.

RANK	Ghana HDP PSP	UK HDP PSP (Ho et al., 2020)
1	What are the possibilities for earlier diagnosis of HDP in Ghana to prevent complications?	What are the long-term physical and mental health consequences of pregnancy hypertension (including pre-eclampsia) for the woman, baby and family?
2	What are the causes and risk factors of HDP in Ghana?	How can we predict and prevent shorter term complications of pregnancy hypertension (including stillbirth, fetal growth restriction, neonatal death, progression to pre-eclampsia)?
3	What are the challenges for healthcare professionals in Ghana regarding the diagnosis, knowledge of prognosis and complications, and provision of adequate treatment for HDP?	What is the best screening test for pre-eclampsia?
4	What is the current level of awareness about HDP in Ghana, and how can this be increased?	Following pregnancy hypertension, what is the best way to prevent future long-term problems?
5	What is the accuracy of screening and diagnosis of HDP among women in Ghana, and how can this be improved?	What is the cause of pregnancy hypertension (including pre-eclampsia)?
6	What is the emotional and psychological impact of HDP in Ghana?	How can pregnancy hypertension (including pre-eclampsia) be prevented in a subsequent pregnancy?
7	What are strategies to improve patient involvement, risk communication and shared decision making regarding HDP in Ghana?	What are the educational needs of healthcare professionals managing women with pregnancy hypertension?
8	How can preconception management be integrated into the standard maternal health services in Ghana?	What is the best way to diagnose pre-eclampsia promptly?
9	What coping strategies do preeclampsia patients, their partners and relatives use in Ghana?	What is the best way to manage pregnancy hypertension (including optimal antenatal and postnatal antihypertensive medication and optimal timing of delivery)?
10	What are the adverse effects of commonly used HDP medication in Ghana?	How can we provide better support for women with pregnancy hypertension and their families?

Legend: solid line = strong similarity, dashed line = weak-moderate similarity

HDP PSP and the Ghana HDP PSP [27-29].

To the best of our knowledge, this PSP is the second JLA PSP on HDP worldwide (one performed in the United Kingdom in 2018-2019) and the first JLA PSP on HDP to be conducted in Africa [26,30]. The only other JLA PSPs conducted in LMIC contexts are currently taking place in Ethiopia (on women's genital prolapse and incontinence), Uganda (on maternal and newborn health) and Tanzania (on adolescent mental health) [31-33]. Their outcomes are not available yet, but an interim report was published in which the Ethiopian team describes their experiences with applying the JLA method in their context [33]. Most of their experiences correspond to this HDP PSP, such as the need to administer the survey in person to achieve sufficient inclusivity, the importance of access to an existing local network, issues with language barriers, and challenges with second survey respondents not reviewing the full list of questions. Both PSPs also narrowed down the geographical range of their literature searches to ensure contextually relevant information to guide the shortlisting of the summary questions. The PSP in Ethiopia visited rural health clinics and patients' homes, which we could not do due to resource constraints. We addressed these potentially missed groups through local survey dissemination by APEC Ghana's regional coordinators, community health nurses and other volunteers. Similarly to the Ethiopian team that translated the written questions into Amharic, we also chose to provide Twi translation of the second survey during in-person administration as Twi is a largely spoken language. This illustrates the

importance of critically evaluating the optimal strategy for each individual context, rather than using a set approach for “the LMIC setting”. Lastly, the Ethiopian PSP team noticed that the uncertainties identified during the first survey did not resonate with the second survey participants. Our team experienced the opposite, as the topics included in the second survey were complimented by the respondents for covering all of their personal concerns and further aligned with the ranking during the final prioritization workshop.

Finally, as is the case in most research activities in LMIC settings, the Advisory Committee involvement was limited due to constraints on financial compensation, and the short project timeline limited the amount of feedback that could be collected at each stage. The involvement of stakeholders with a historically powerful role in agenda settings (policy makers, research institutes, funding institutes and insurance companies) was largely postponed to phase three and four. This made it possible to amplify the voices of patients, carers and clinicians first in the project. However, these influential stakeholders are also crucial for the translation of the priorities into research projects. Involving them late in the process may have a negative effect on the implementation of the research agenda; however, this must be weighed against the deliberate space created for patients and carers to share their voices.

Strengths and limitations

The main strength of this study is its transdisciplinary and inclusive nature, including stakeholder and community engagement in all stages of the process. The network and expertise of APECGH were crucial to realize this - their professional network provided opportunities for collaboration with healthcare facilities and their invested follower and volunteer bases allowed for survey coverage throughout the country among non-English speakers and community members. Furthermore, APECGH’s expertise was crucial to consider cultural factors such as appropriate community entry strategies, endorsement of the research agenda through involvement of traditional leaders and the inclusion of non-clinicians in some project stages. This contributed significantly to the broad representation and reduced the time required to reach the final research priority list considering the limited budget and timeline (six months, compared to twelve to eighteen months as recommended by the JLA [14]).

A last strength of this study was the incorporation of the R4HJ Toolkit into the PSP process. Worksheet 1 in particular provided useful reflections for the stakeholder analysis, and the ethical considerations in Worksheet 4 helped to decrease hierarchy and build trust among the Advisory Committee members, which was consequently also observed during the final workshop. In this way, the use of the R4HJ also helped to compensate for the absence of an official JLA Advisor in the project, who normally ensures a constructive group dynamic.

The limitation of this study is that risk of bias could not be prevented. While this may be due to a lack of resources, selection bias could have also been introduced in the convenience sampling via APECGH’s and co-investigators’ networks. Women with challenges accessing healthcare, low literacy or no formal education, people with a disability and partners of survivors were likely more difficult to reach with our dissemination strategy. Low inclusion of partners, inhabitants of rural areas and people with no formal education is also represented in the baseline data (**Table 2**). Yet, the high degree of overlap in the uncertainties reported in the first survey, the final workshop rankings and everything in between provides confidence in the potential generalizability of these findings.

A second limitation might have arisen based on an observation of a local midwife who reported that pregnancy complications are a taboo in Ghanaian culture, which may have led to selection bias as well [24, 34]. Since the suspected missed groups are populations that generally face more or different challenges accessing care, the missed input possibly translated to skewed results. As such, any future research projects should aim to consult these groups during the translation of the priority (domains) into specific research projects. Specific attention should be also given to adolescents below eighteen years, who were excluded from this survey. Since adolescents often face more stigmatization, their priorities may also differ from those of the general HDP patient population. Self-reporting bias may have occurred by the self-reported identity of HDP patient/carer or professional in the survey. A remarkably large number of reported HDP patients or carers were also clinicians (see **Table 2**), and there were instances reported where a clinician identified themselves as “carer” when the study intended to identify them as “healthcare provider”. Thereby, the actual share of healthcare professionals may be larger than reported in this article. The high number of double patient-clinician roles may however also be a sign that personal experience is a motivation for these clinicians to participate in HDP research. Bias may have also been introduced when providing the four main categories in the first survey as it may have directed respondents towards reporting only in-scope uncertainties. However, the scope was already set to cover a wide spectrum of topics including those important to the respondents. Lastly, the fact that literature review was executed by a single reviewer may have impacted the objectivity of the results. The limitation was addressed by regular meetings between the reviewers to consider decisions made by individual reviewers as well as consulting the full research team and Advisory Committee where necessary.

Conclusion, implications and recommendations

The HDP PSP project successfully identified care-related research priorities of HDP patients, carers and clinicians in Ghana. An extensive local network, stakeholder engagement and use of the R4HJ ethical toolkit enabled an agenda that adequately represents these populations, despite the limited resources. We believe that research on the resulting priorities can lead to more conscientious allocation of local research funds for HDP, and thereby improvements in maternal and perinatal health in Ghana. To ensure its effect, advocacy for the incorporation of this list into the national research agenda is crucial as well as an active dissemination to and engagement with academic, funding, policy and industry actors to guide future direction and funding for future research in maternal healthcare.

The HDP PSP priority list provides a broad direction for future research, but focused research questions will need to be formulated within the priority areas. We highly recommend consulting (vulnerable) groups that were underrepresented in our project during this process. This study provides valuable insight into the perspective and expectations of end users such as patients, carers and clinicians with regards to maternal health research. However, it is recommended for future research to focus on how these priorities identified are translated into research projects, interventions and changes in policy and funding schemes. Furthermore, as maternal health policies, strategies and interventions sponsored by foreign donors frequently have multinational reach and impact, additional PSPs are recommended across Sub-Saharan Africa to provide a more comprehensive understanding of patient perspective and expectations. Finally, additional studies in patient and community engagement in research is recommended to enhance equitable partnerships in research agenda design and implementation.

Declarations

Acknowledgements

This project, due to its multicultural and transdisciplinary nature, was a team effort. We would like to use this space to express our appreciation to those who supported this project behind the scenes: Mr. Emmanuel Asare Adjei for the operational and moral support, Irene Dansoa Amankwah and Naana Egyiroba Idun-Acquah for their help with the survey administration, Comfort Adwubi Appiah for her administrative support, Divine Nkrumah for reaching out to his network in media, the coordinators of the campus tour (Samantha Katsande, Bryony Brookman-Eshun and Mavis Nsiah Asante) for all their preparatory work towards survey administration in different health facilities, the local healthcare workers for facilitating the administration, all the APEC regional coordinators for their help in disseminating the surveys in different regions, and to the final workshop facilitators and note-takers. Without you, this project would not have been possible. We would also like to express our appreciation to all the health facilities and departments who created an opportunity for us to reach out to patients and carers.

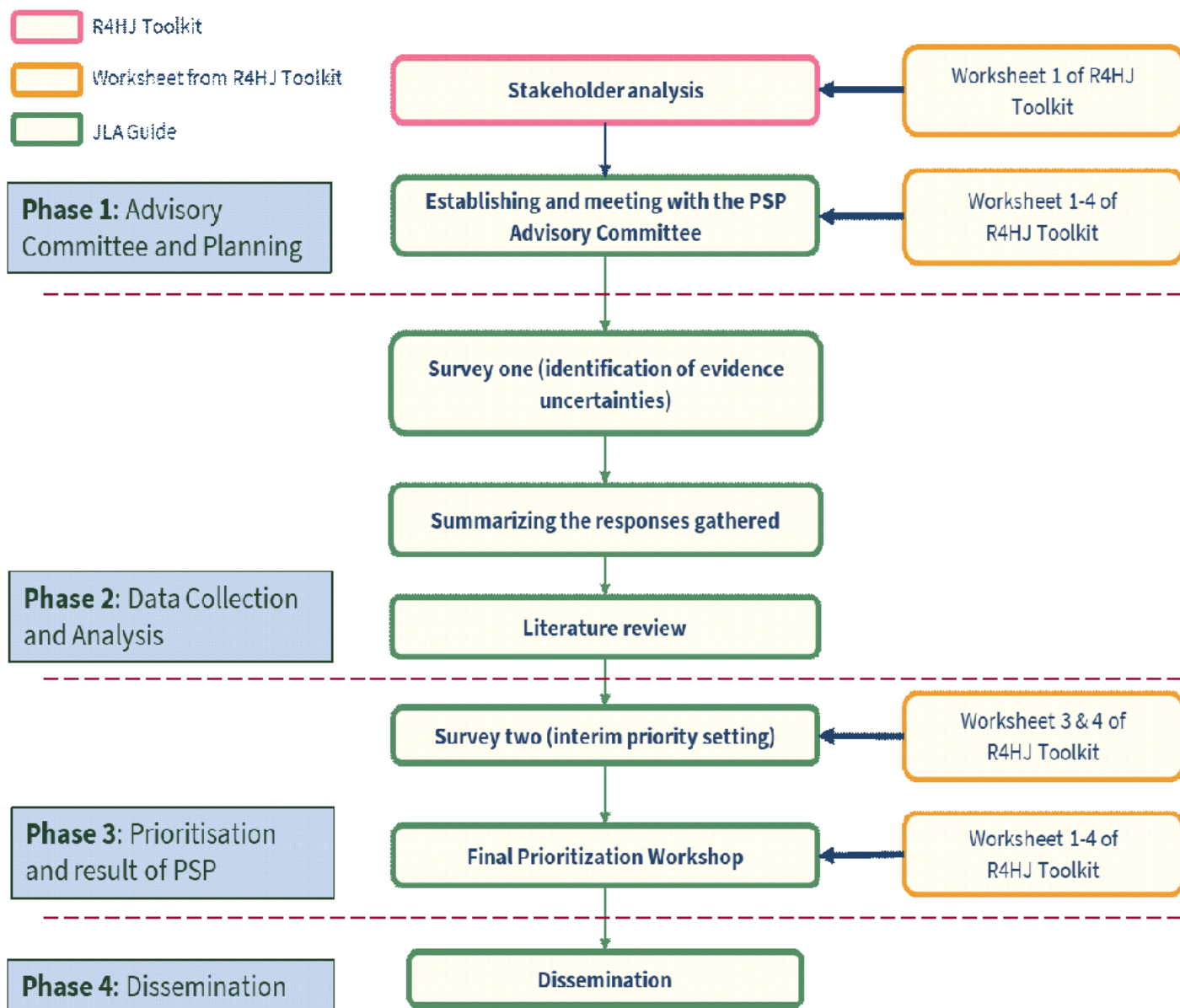
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Figures



- Worksheet 1: Selecting a Partner
 Worksheet 2: Deciding to Partner
 Worksheet 3: Deciding to Engage with the Wider Community
 Worksheet 4: Designing Priority-setting

Figure 1

Phases and activities of the HDP PSP process

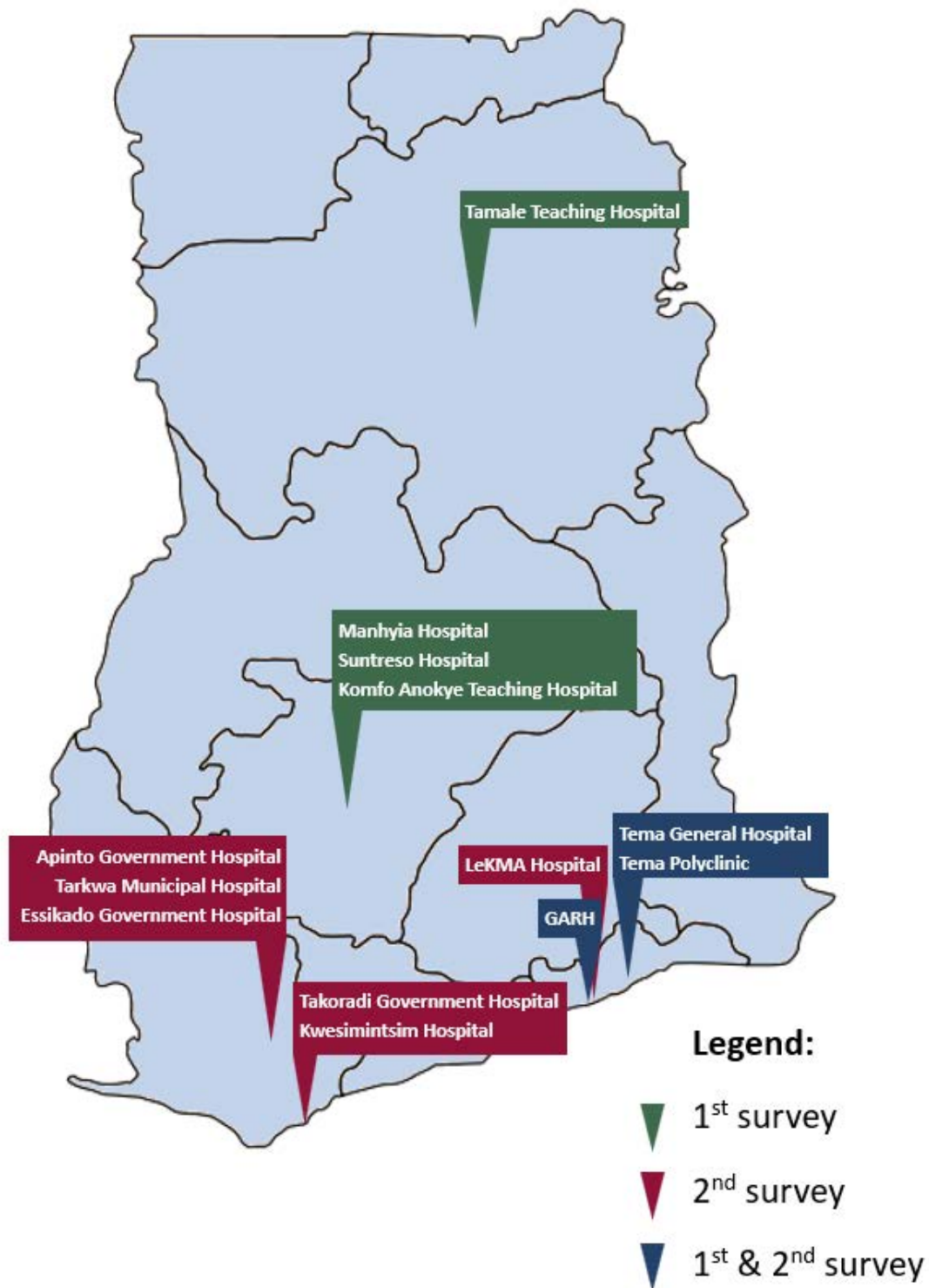


Figure 2

Regional distribution of survey dissemination. (Wikimedia Commons)

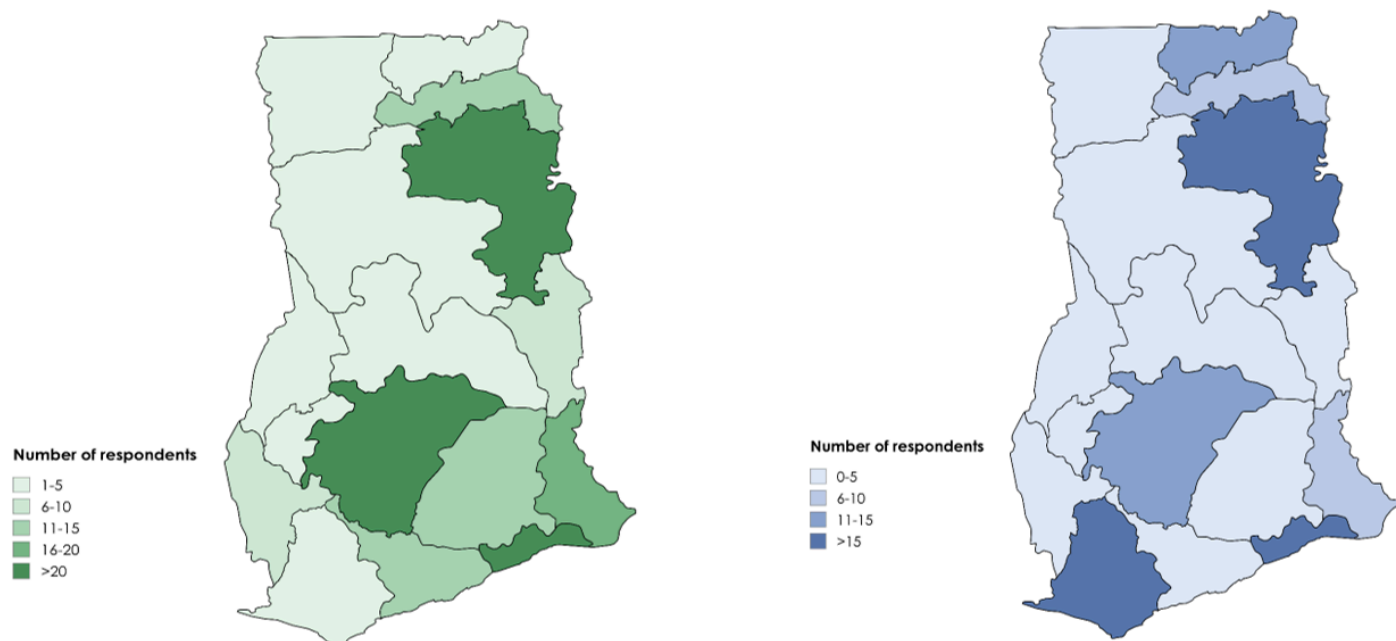


Figure 3

Regional distribution of respondents of the first survey (left) and second survey (right)

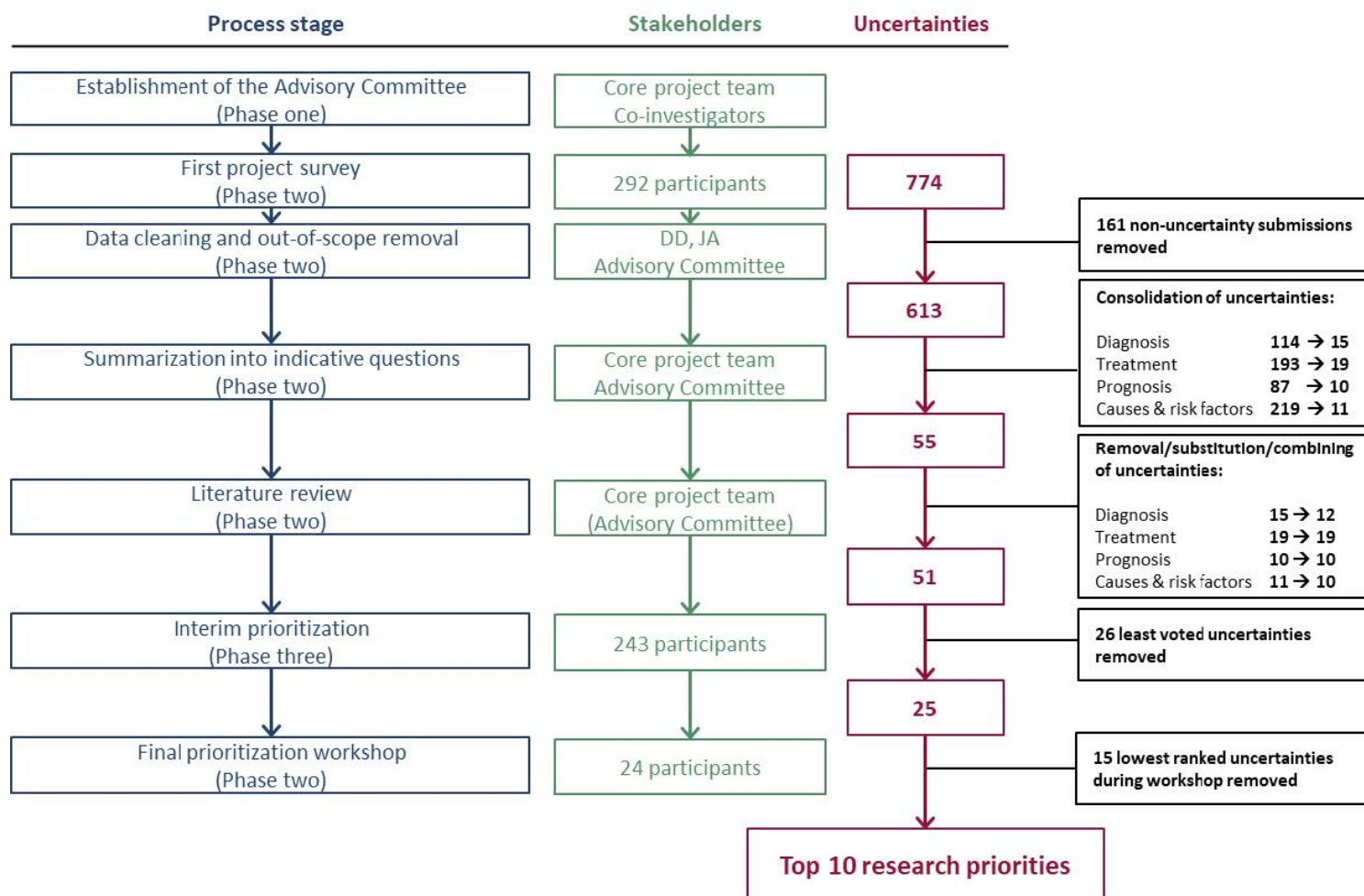


Figure 4

Summary of the HDP PSP stakeholders and uncertainties per process stage. Uncertainties = the number of uncertainties left at the end of the according stage, stakeholders = the stakeholders involved in producing the result of the according stage.

Supplementary Files

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