



**QUEEN'S  
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**DOCTOR OF PHILOSOPHY**

**Strengthening breast cancer services in Vietnam  
Understanding context and challenges**

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*Award date:*  
2020

*Awarding institution:*  
Queen's University Belfast

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**Strengthening breast cancer services in Vietnam:  
understanding context and challenges**

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Submitted for the degree of  
Doctor of Philosophy (Medicine)  
Faculty of Medicine, Health and Life Sciences  
Queen's University Belfast

May 2020



*In memory of Professor Liam Murray*

## **Abstract Summary**

### **Strengthening breast cancer services in Vietnam: understanding context and challenges**

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Breast cancer is a growing public health challenge in Vietnam. Incidence rates have been rising consistently over the past decade. Stage of diagnosis tends to be late and multiple barriers prevent women from accessing screening, diagnostic, and treatment services. There has been little data systematically collected on breast cancer in Vietnam, with no integrated cancer registry. Data presented on breast cancer in Vietnam tends to be based on estimations and models, and from mortality rates in neighbouring countries.

The Vietnamese government has made significant strides in improving population health over the past two decades. New challenges, however, are emerging in the form of non-communicable diseases. Breast cancer creates specific challenges for both Vietnamese women and the health system that could be alleviated with targeted interventions and reforms. It is the aim of the studies presented in this thesis to contribute to developing an evidence-base to inform future decisions with the objective of improving outcomes for women with a breast cancer diagnosis.

Using a health systems approach and a broad range of research methodologies, this thesis enabled the production of a holistic overview on how the health system is currently structured and what challenges exist for breast cancer service delivery. The main results of the studies reported in this thesis show that:

1. There has been a lack of published research in both English and Vietnamese providing data on breast cancer or breast cancer service delivery in Vietnam. No qualitative studies on the experiences of women have been published.
2. A high amount of factual information on breast cancer is presented within the Vietnamese media. There is, however, a lack of visibility of women sharing their personal experiences of being diagnosed with and treated for breast cancer, and it is unclear whether information presented in the media has contributed to raising awareness about breast cancer.

3. Breast cancer service strengthening is required across all six of the WHO Health Systems Framework's 6 Building Blocks of (i) service delivery, (ii) health workforce, (iii) health information systems, (iv) access to essential medicines, (v) financing, and (vi) leadership/governance. Breast cancer services are predominately located in centralised and specialised hospitals in major metropolitan areas. Hospitals are overcrowded, creating challenges for healthcare providers, women with a breast cancer diagnosis, and their caregivers. Strengthening lower levels of the health system to provide screening and detection services may alleviate these pressures while also reducing access barriers for women living outside of major cities. Such service extension would need to be complimented with appropriate training for healthcare workers at lower levels of the health system. Health information systems require strengthening, given the lack of an integrated national cancer registry.
4. Beyond the Building Blocks, social determinants of health must be addressed to ensure breast cancer services are accessible and appropriate. Women experience multiple challenges in accessing breast cancer services, including geographic and cultural barriers, as well as out-of-pocket expenses relating to cost of treatment. Many households face financial catastrophe after women access breast cancer services. Reforms to the insurance system that increase coverage for screening and treatment services should be explored through future costing studies, and may have the potential to help downstage diagnosis. Equally, greater awareness of dynamics around breast cancer stigma, relationship breakdown, and other social phenomena experienced by women with breast cancer, is required for effective future health messaging and interventions. Barriers to accessing treatment should be addressed prior to the extension of screening programmes.
5. Caregivers provide an essential role within the health system and could be better supported and enabled through programmes providing them with information and skills to provide care for women with a breast cancer diagnosis. Services supporting the emotional and health needs of caregivers should be developed.

## Acknowledgements

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There are many people I wish to thank and acknowledge for their support in the production of this thesis. The thesis could not have been produced without the support of researchers at the Hanoi University of Public Health and other research institutions, hospitals, and patient and support groups across Vietnam. I'd like to thank all the women, carers, and healthcare professionals who gave their time to talk with me and the research team, and who shared their experiences and ideas. To the women who invited us into their homes, who baked for us and gave us gifts after our interviews, I truly hope that the evidence compiled in this thesis helps to support processes to reduce the burden of breast cancer in Vietnam. To the women who supported this research, and whom have since passed, your stories and experiences were always the motivation to complete this body of work.

I'd particularly like to thank Professor Hoang Van Minh for his guidance and support throughout the past three years, in supporting the design of research projects, and for enabling the research partnership that underpinned this thesis. I'd also like to specifically thank Tran Thu Ngan for her collaboration in many of the studies presented in this thesis. I learnt an incredible amount from our many conversations over coffee and dinner, and very much value the friendship we developed while working on this project.

I'd like to thank Nguyen Bao Ngoc and Ho Thi Hien for their partnership throughout the course of these studies. I'd like to particularly thank them for their hospitality in inviting me to their homes on more than one occasion to meet their families. I'd like to extend my gratitude to Le Thi Hai Ha, Dinh Thu Ha, Vu Tuyet Lan, Nghiem Le Phuong Hoa, Kim Bao Giang, Tran Tuan Anh, Tran Bich Phuong, Luu Ngoc Hoat, Luu Ngoc Minh and Nguyen Hoang Anh for all their support, friendship and hospitality throughout this project. Thank you for not only supporting this research with such enthusiasm and professionalism, but also for making me feel so welcome in Vietnam. I've made many friendships over the past three years, and value them all deeply.

I'd like to thank my supervisors Professor Michael Donnelly and Dr. Lynne Lohfeld for their encouragement, time and expertise that has supported this research and helped my development as an early-career researcher. I have learned a lot throughout this process and truly appreciate your support and guidance. I hope this is only the beginning of a long career of collaboration at the Centre for Public Health. I'd like to thank Dr. Olinda Santin at QUB's School of Nursing and Midwifery for all your support, partnership and friendship, and I'd like to mention the wider staff and student body at the Centre for Public Health whom I've learnt from immensely and who very much helped me feel part of the community even though my work frequently brought me away from Northern Ireland. I'd also like to thank both Dr. Paul Murphy and Professor Paul Fleming for their comments on chapter drafts and their support.

I'd particularly like to acknowledge Professor Liam Murray, and the support he gave me at the beginning of this process. Liam sadly died from pancreatic cancer in January 2018. Liam was driven and passionate about supporting global health research at the Centre for Public Health, and I truly hope that the relationships he developed (such as the one between CPH and the Hanoi University of Public Health) will continue to reap the rewards of his work and efforts. I regret not knowing Liam for longer. I have no doubt I would have learned a lot, and that his involvement would have strengthened this thesis. He took a risk in bringing me into a research post for which I had limited experience, and he supported the extension of that post to include postgraduate study. I am incredibly grateful for the opportunities he opened for me. In our short time together in Vietnam, we shared some good memories, good food, and a couple beers, for which I'm also grateful.

I'd like to thank my family for their continued support throughout this process. To my Mum and Dad, not only for their support throughout this study, but also in encouraging and supporting my work in global health over the past ten years even when that came with stress, worry and anxiety. Their support has been unwavering from early education through to this final step in my formal education journey. Finally, to my wife Savannah, thank you for your support and patience throughout this study, for supporting long periods of time in which I've been on the other side of the world, and for being on the end of skype call whenever I needed it. Rest assured, the support will be returned for your own Ph.D.

## Outputs

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### Papers:

- ‘Breast Cancer Services in Vietnam: a scoping review’ in *Global Health Action*. 2018. Vol .11. Issue. 1.
- ‘Strengthening breast cancer services in Vietnam: a mixed-methods study’ in *Global Health Research and Policy*. 2019. Vol. 4. Issue. 2.
- ‘Strengthening Screening and Detection Services for Breast Cancer in Vietnam’ in *Journal of Global Oncology*. 2018. Volume 4. Supplement 2. (Abstract).
- ‘Experiences of Accessing and Using Breast Cancer Services in Vietnam: A Descriptive Qualitative Study’ in *BMJ Open*. 2020.

### Reports:

- Summary of Research Project: Breast Cancer Services in Vietnam. A Collaborative Research Project between the Hanoi University of Public Health, Hanoi Medical University and Queen’s University Belfast, United Kingdom. Collaboratively produced for key stakeholders and policymakers symposium in Hanoi. 2018.
- Reports and Presentation of Results to Vietnam Ministry of Health and Hanoi University of Public Health Delegation at Queen's University Belfast. 2019.

### Oral Conference Presentations:

- ‘Strengthening breast cancer services in Vietnam’ at the International Health Congress, University of Oxford, June 2018.
- ‘Strengthening screening and detection services for breast cancer in Vietnam’ at a symposium for policymakers, Hanoi Fortuna Hotel, September 2018.
- ‘Strengthening screening and detection services for breast cancer in Vietnam’ at the World Cancer Congress in Kuala Lumpur, Malaysia, October 2018.

### Poster Presentations:

- ‘Evidence-based approach to evaluation and planning of breast cancer services in Vietnam’. Newton Projects Day, British Council. British Embassy, Hanoi. 16 November 2016.
- ‘Breast cancer services in Vietnam: a scoping study’. Centre of Excellence for Public Health Conference. Slieve Donard, Northern Ireland. 26 November 2017.

- ‘Strengthening and expanding breast cancer services in Vietnam: Recommendations from a mixed methods study’. Queen’s University Belfast Postdoc Symposium. Riddell Hall, Belfast. 26 March 2018
- ‘Strengthening and expanding breast cancer services in Vietnam: Recommendations from a mixed methods study’. Global Health Symposium 2018, Queen’s University Belfast. Riddell Hall, Belfast. 26-27 April 2018.
- ‘Research Collaborations between the Centre for Public Health (QUB) and the Hanoi University of Public Health 2016-2019’. Cancer Epidemiology Conference in memoriam of Prof. Liam Murray. Queen’s University Belfast. Riddell Hall, Belfast. 18 January 2019.

Lectures & Workshops delivered:

- Perspectives on Culture and Global Health. Delivered Spring 2019 with Dr. Desiree Schliemann to Medical Students, QUB.
- Ten Years of Global Health in Uganda and Vietnam: How to have an impact and build a career in global health. Delivered December 2018 to students from the Students Working Overseas Trust, QUB.
- Global Cancer Screening & Research in Low and Middle Income Contexts. Delivered in Autumn 2017, 2018 & 2019 to MPH and Medical Students (Cancer Screening Module), QUB.
- Scoping Reviews: Reflections on the process of analysis, writing, and publication. Delivered in March 2018 to MPH Students at the Hanoi University of Public Health.

## **Ethics**

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The study presented in Chapter 6, ‘Service Delivery Challenges from the Perspective of Healthcare Providers’, received ethical clearance from Institutional Review Board of Hanoi University of Public Health in Vietnam. No. 309/2017/YTCC-HD3. All participants in the study provided written consent, and were fully informed about how their information would be used.

The study presented in Chapter 7, ‘Understanding the Experiences of Women with Breast Cancer in Vietnam using the Pathways to Treatment Framework’ received ethical clearance from Institutional Review Board of Hanoi University of Public Health in Vietnam. No. 017-373/DD-YTCC. All participants in the study provided written consent, and were fully informed about how their information would be used. Given the sensitive content within this study, we contacted a counsellor in advance of our interviews to be available should any of the women in our study need professional support. All the women were informed of this option should they require it, but none requested it.

The study presented in Chapter 8, ‘Roles and Unmet Needs of Informal Cancer Carers in Vietnam’ received ethical clearance from Institutional Review Board of Hanoi University of Public Health in Vietnam. No. 018-442/DD-YTCC. All participants in the study provided written consent, and were fully informed about how their information would be used.

## Abbreviations

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|           |   |
|-----------|---|
| AHRC..... | Arts and Humanities Research Council                  |
| BHGI..... | Breast Health Global Initiative                       |
| BMJ.....  | British Medical Journal                               |
| CBE.....  | Clinical breast examination                           |
| CPH.....  | Centre for Public Health (Queen’s University Belfast) |
| DFID..... | Department for International Development (UK)         |
| ESMO..... | European Society for Medical Oncology                 |
| FGD.....  | Focus group discussion                                |
| GCRF..... | Global Challenges Research Fund                       |
| GDP.....  | Gross Domestic Product                                |
| GIAA..... | Global Impact Accelerator Award                       |
| GNI.....  | Gross National Income                                 |
| GNP.....  | Gross National Product                                |
| HCMC..... | Ho Chi Minh City                                      |
| HCP.....  | Health care professional/provider                     |
| HDI.....  | Human Development Index                               |
| HIV.....  | Human Immunodeficiency Virus                          |
| HMU.....  | Hanoi Medical University                              |
| HN.....   | Hanoi   |
| HUPH..... | Hanoi University of Public Health                     |
| IARC..... | International Agency for Research on Cancer           |
| IDI.....  | In-depth interview                                    |
| LMIC..... | Low/Middle Income Country                             |
| MDG.....  | Millennium Development Goals                          |
| MOH.....  | Ministry of Health (Vietnam)                          |
| MRC.....  | Medical Research Council                              |
| NCD.....  | Noncommunicable disease                               |
| NIHR..... | National Institute for Health research                |
| ODA.....  | Official Development Assistance                       |
| OPP.....  | Out-of-pocket payments                                |
| QUB.....  | Queen’s University Belfast                            |
| SDG.....  | Sustainable Development Goals                         |
| SDH.....  | Social determinant of health                          |
| SHI.....  | Social Health Insurance                               |
| SOP.....  | Standard operating procedures                         |
| TB.....   | Tuberculosis  |
| VND.....  | Vietnamese Dong                                       |
| UKRI..... | UK Research and Innovation                            |
| UN.....   | United Nations  |
| UNDP..... | United Nations Development Programme                  |
| USD.....  | US Dollars  |
| WB.....   | World Bank  |
| WHO.....  | World Health Organisation                             |

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## Chapter 1: Introduction

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Vietnam shaped and has been shaped by some of the most significant geopolitical shifts in modern history: the Second World War; the end of colonialism and imperialism; and the Cold War. Contemporary Vietnam is home to over 90 million people. The country is on a remarkable upward trajectory in terms of its economic growth and its collective population health. Mortality rates from infectious diseases have plummeted in recent years. New health challenges have, however, emerged, principally in the form of non-communicable diseases (NCDs) (Hinh and Minh 2013b).

Vietnam is often understood, discussed, and mythologised through a historical lens. The wars the people of Vietnam experienced had an unquantifiable impact on the country, its population, and its political, social and cultural contexts. An understanding of the elements of this history (presented in Chapter 3) contributes to an appreciation of the decisions, political context and geographic variations that have influenced the contemporary delivery and organisation of public services, in this context, for breast cancer services.

It is important also to understand Vietnam through the prism of how Vietnamese people themselves understand their own history. Writing in English for a largely international audience, and as an author from a European context, there is a need to be cognisant of the portrayals of Vietnam within our popular culture, and actively seek to rebalance this understanding from a Vietnamese perspective. As the first ‘televised war’, Vietnam holds significant meaning for many who lived through that time, with some authors going as far as to suggest the word “Vietnam” itself holds a weight and resonance that defined a generation (Howard 1983). The proliferation of depictions of the Vietnam War through films from American perspectives, such as *The Deer Hunter*, *Apocalypse Now*, *Full Metal Jacket* etc. “were received not simply as movies but as important cultural events (and) as intellectually-respectable statements however ‘right’ or ‘wrong’ they may be” (Anderegg 1991). Vietnam has been “invented” and “reinvented” repeatedly within our popular discourse.

When trying to understand Vietnam today, it is important to recognise and critique these depictions, and their corresponding ideology. Vietnam is a country highly shaped by conflict, and the ideologies of nationalism and communism that developed alongside or in response to war. To focus solely on the historical and political level would be, however, a disservice to the complex and rich socio-cultural and economic evolutions and characteristics that also shape contemporary Vietnam, and are vital in our understanding of how people understand health.

The purpose of this thesis is to provide a contextual overview to better appreciate how breast cancer is conceptualised and experienced, and how breast cancer services are organised and delivered. The major contribution of this study is that it takes a holistic approach to understanding breast cancer service delivery in Vietnam including a detailed examination of 1) the health system and the user and provider experience of it; 2) social determinants of health including social structures and norms, and; 3) the wider context.

In an area in which little research, particularly international research on Vietnam published in English, has been undertaken, it is vital to understand the diverse, complex and interconnected themes that impact on how health is understood and experienced. A thorough understanding of these themes will then allow discussion and recommendations on how breast cancer services can be appropriately organised, delivered, and strengthened. Developing a deep appreciation for how the health system is structured, and the different factors impacting upon it, is crucial within initial context-setting research.

It is hoped that the contextual overview in this thesis provides useful findings not only for the strengthening and expanding of breast cancer services, but also key information for future health research and intervention development in Vietnam. Given the significant increases in international funding directed towards global health, this research aims to support international researchers and their Vietnamese colleagues by providing background, frameworks, and methodological reflections regarding the design of global health studies and the development of the appropriate partnerships to implement them effectively. As recently noted by a consortium of international health researchers:

Understanding the relationship between interventions and contexts is critical to understanding implementation success and failure, how interventions achieve impact, why their impacts vary and whether interventions can be sustained or successfully translated from one context to another (Craig, Di Ruggiero, and et. al. 2018).

The contemporary context in Vietnam is one not of the wars, conflicts and stereotypes previously highlighted, but rather one of expansion, growth, and success. This thesis aims to appreciate and build upon the successes that the Vietnamese government have had, and identify areas where future efforts could focus. Women's health in Vietnam has particularly improved over the past couple of decades. For example, maternal mortality has decreased from 233 per 100,000 live births in 1990 to 50 per 100,000 live births in 2015. Women's average life expectancy was 6 years higher than that of men in 2017 (H. V. Minh et al. 2018). NCDs, cancer, and breast cancer specifically have, however, been increasing. Recent data from GLOBOCAN indicates that in 2018 there were an estimated 15,229 new cases of breast cancer and an estimated 6,103 deaths related to breast cancer in Vietnam (GLOBOCAN 2018). Many LMICs such as Vietnam additionally face a double burden in which they experience the growth of NCDs while also still facing significant challenges in controlling and managing infectious and communicable disease (Boutayeb 2006).

These challenges of increased frequency of NCDs, and struggling to provide services to manage them, are not unique to Vietnam. As noted by Professor Ophira Ginsburg (New York University), cancer outcomes globally are highly dependent on a number of different factors. As Ginsburg stated in a recent article:

More than 2 million women worldwide are diagnosed with breast or cervical cancer, yet where a woman lives, her socioeconomic status, and agency largely determines whether she will develop one of these cancers and will ultimately survive. In regions with scarce resources, fragile or fragmented health systems, cancer contributes to the cycle of poverty. Proven and cost-effective interventions are available for both these common cancers, yet for so many women access to these is beyond reach (Ginsburg, Bray, et al. 2017).

Questions of access, quality, health system capacity, and health equity are recurrent themes within contemporary global health research. This thesis and the studies presented within it aim to contribute to promoting greater health equity, and supporting the growing field of women's health research in Vietnam. The picture presented within these chapters are of breast cancer services that are improving in scope and quality, but are still inaccessible to many women. There remains a lack of capacity and training of healthcare staff particularly at lower levels of the healthcare system to examine and refer for breast cancer diagnosis and treatment, coupled with a continued lack of awareness by many women concerning breast cancer symptoms. The purpose of this thesis is to examine how to strengthen breast cancer services, and argues that such strengthening needs to be understood holistically and within a health systems framework (WHO & Alliance for Health Policy and Systems Research 2009; WHO 2017).

An important point of departure is to understand what already exists to responsibly inform our recommendations. In other words, "We must know the system in order to strengthen it" (WHO & Alliance for Health Policy and Systems Research 2009). Chapters 3 and 4 of this thesis examine what research and data are already available on health and breast cancer systems in Vietnam through a contextual overview (Chapter 3) and a review of all published and grey literature in both English and Vietnamese at the time of writing (Chapter 4). Chapter 2 provides the methodological and theoretical framework that helps interpret and structure findings from the thesis.

Chapters 5 to 7 broaden the data available on how breast cancer services function, and how breast cancer is understood and experienced based on data from multiple stakeholder groups and sources. Chapter 5 explores how breast cancer is presented within the Vietnamese mass media, identifying issues related to the lack of visibility of personal stories and experiences of women with breast cancer. Chapter 6 provides data for the first time on the perspective of healthcare professionals on providing breast cancer services across all four levels of the Vietnamese health system. Chapter 7 provides in-depth qualitative data from women with a breast cancer diagnosis on their experiences of accessing and using breast cancer services; while Chapter 8 explores similar themes from the perspective of informal carers. Through providing diverse stakeholder primary data, this thesis makes an original contribution to the field of

global health, and provides important contextual information from which recommendations of service and system strengthening can be drawn.

Chapter 9 discusses how to translate research into action, identifies key interconnected findings presented throughout this thesis, and discusses the implications for future policy and research on breast cancer in Vietnam.

The strengths of this thesis are twofold. First is its presentation of data from multiple and diverse stakeholders on the delivery, organisation and use of breast cancer services. Within this thesis, data are presented from the perspective of women with a breast cancer diagnosis, healthcare providers, informal carers of women with a breast cancer diagnosis, as well as from mass media articles and from previously published literature. Second, this thesis has employed a broad range of research approaches and methods. It serves as an example of how to conduct far-reaching, needs-assessments in a context in which there has been little previous research. Qualitative and quantitative methodologies, using interviews, focus groups, surveys, and underpinned with reference to several models and frameworks, were used to ensure a wide range of data was collected from which to gain insight into the objectives of understanding how breast cancer services are delivered, what challenges exist in delivery, and how breast cancer is experienced by women in Vietnam.

The diversity of methods and stakeholders included in this thesis was a necessary component in producing an effective health systems and service delivery thesis. This work describes the context and provides primary data from which further research may be developed, and initial changes and adaptations to policy and planning can be recommended. It is a point of departure into the field of breast cancer research in Vietnam. It is intended to contribute to and support the long process of improving breast cancer service delivery for women in the country. As noted by ex-Director-General of the WHO, Dr Chan:

For the first time, public health has commitment, resources, and powerful interventions. What is missing is this: the power of these interventions are not matched by the power of health systems to deliver them to those in greatest need, on an adequate scale, in time. This lack of capacity arises, in part, from the fact that research on health systems has been so badly neglected and underfunded (Dr. Margaret Chan, Director-General, WHO).

October 2007) (WHO & Alliance for Health Policy and Systems Research 2009)

Breast cancer outcomes in Vietnam, despite improvements in the field of women's health, remain unacceptable. Too many women forego treatment or receive it too late to preserve health and dignity. Diagnosis is often late, with many women diagnosed at stages III and IV (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013; Dinh Nguyen 2011). Challenges in accessing services exist for women across the country, and are particularly stark for those who are poorer and living outside the metropolitan cities of Hanoi and Ho Chi Minh City. Providing evidence to change practice and policy, contribute to downstaging of breast cancer, and to improve health and quality of life of women and their families are the central objectives of this thesis. As outlined by prominent international development scholar and practitioner, Robert Chambers, it is a task that can appear challenging, but is by no means impossible or beyond us:

We accept the unacceptable, telling ourselves we are bowing to the inevitable. But the coexistence of extremes of wealth and poverty, or of power and vulnerability, is not inevitable. It is the result of innumerable human choices, actions and non-actions. We do not bow to physical diseases as inevitable – polio, measles, malaria, TB. Nor is there any reason to bow to social sicknesses and discords, as many millions of courageous and committed people show through the lives they live. The challenge, as with all that is not right, is to analyse, reflect and act to make things better (Chambers 1997).

## **Chapter 2: Methodology and Conceptual Overview**

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### **2.1 Objectives and Research Questions**

This thesis aims to provide a contextual overview to better appreciate how breast cancer is conceptualised and experienced by women in Vietnam, and how breast cancer services are organised and delivered.

The research questions throughout the different studies are:

- How is breast cancer conceptualised by women in Vietnam?
- How is breast cancer experienced by women in Vietnam?
- How are breast cancer services organised and delivered in Vietnam?
- To what extent are breast cancer services available and accessible to women with a breast cancer diagnosis in Vietnam?

### **2.2 Methodological Overview**

To answer these questions a broad range of methodologies and approaches were used throughout the studies presented in this thesis. Both quantitative and qualitative approaches were used to collect data via surveys, media-content analyses, in-depth individual interviews, and focus group discussions. Research approaches and methods were modified and culturally adapted for use in the Vietnamese context and the specific context of this research, while also being informed by well-established approaches such as mixed-methods frameworks (Cresswell and Plano Clark 2017) and media content analysis (Hilton, Patterson, and Teyhan 2012).

Each chapter in this thesis describes a specific sub-study, each of which used different types of data, gathered using different methods and from different participants. The specifics of the methodological approach taken in each sub-study will be described within each relevant chapter.

The main contribution of the thesis is to provide empirical data and evidence from which policymakers in Vietnam can understand the current context, challenges, and implications for policy, practice and health promotion. Given the lack of data on breast cancer in Vietnam, this thesis is intended as a starting point from which further

research streams can be developed, and from which interventions can be designed and tested. By providing answers to the questions presented at the beginning of this section, future intervention development can be informed by an evidence-base.

### **2.3 Conceptual Approach**

A number of conceptual frameworks were used to help structure and interpret the results presented in this thesis. Context is understood broadly throughout the thesis, and incorporates a thorough understanding of the multiple factors such as historic, socio-economic, cultural, geographic, political, and institutional factors (Craig, Di Ruggiero, and et. al. 2018). No comprehensive frameworks currently exist for the systematic evaluation of breast cancer services in low and middle income countries (LMICs), however, the Breast Health Global Initiative (BHGI) is currently developing models and tools for situational and contextual analysis to support research in this area (forthcoming in Cancer, 2020). In the absence of such frameworks for breast cancer services, this thesis has adapted existing frameworks for evaluating health systems and the wider context, and applied that to the investigation of a single specific service.

One frequently used model is the WHO's Health Systems Framework, and its six building blocks of the health system (Figure 2.1) (WHO 2017, 2000). The building blocks include: (i) service delivery, (ii) health workforce, (iii) health information systems, (iv) access to essential medicines, (v) financing, and (vi) leadership/governance. This framework offers a starting point of the main elements to consider when evaluating how a system or service operates and is organised. Each of the building blocks identifies core elements that are essential in ensuring that a health system functions and is able to provide services across a range of morbidities.

The Framework's strengths are in its recognition of the interconnected nature of health systems, and how changes in one area may affect other areas of the system. The Health Systems Framework, however, has limitations. For the purposes of analysing the wider context, and the different factors that enable or prevent access and use of different health services, a much wider and holistic model and framework is required.

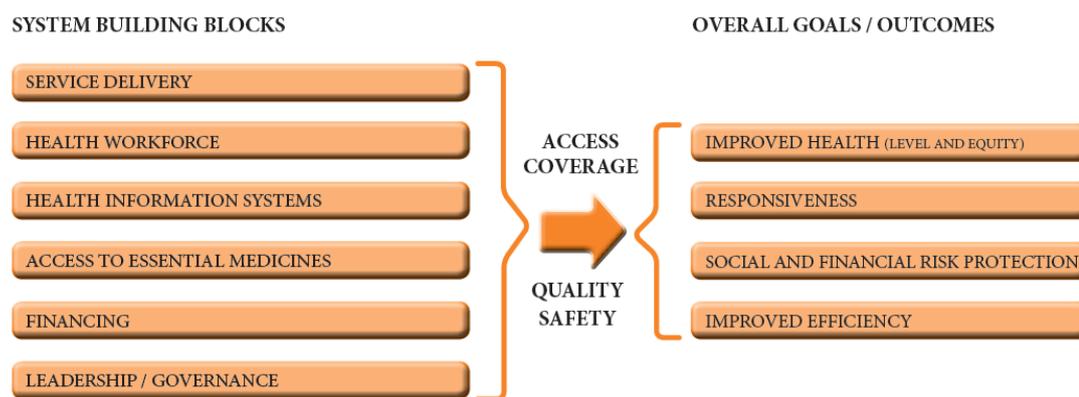


Figure 2.1: Six building blocks of health systems, taken from (WHO 2010).

Within this thesis, the WHO Health Systems Framework helps to situate and organise findings on how breast cancer services are delivered (for example in Chapter 6, examining capacity to deliver breast cancer services across health facilities within the Vietnamese health system). It is unable, however, to holistically address the different social determinants, cultural belief models (both discussed in chapter 7), and the existence of wider networks of healthcare delivery and support (for example, carers, as discussed in Chapter 8) that are required to understand wider dynamics regarding access to services and experiences of living with breast cancer.

Sacks et al. developed a wider framework that helps address these considerations (Figure 2.2). Building on the WHO’s Health Systems Framework, Sacks recognises that good health requires the involvement of diverse and multiple stakeholders, including the community and individuals using specific services. In addition, the quality of health services needs to be matched by a wider context in which services are accessible and in which social determinants of health are addressed. Sacks highlights that “community health depends on (1) delivery of high quality, evidence-based services (*service delivery*), (2) *household production of health* and (3) *social determinants of health*. All three determinants influence each other” (Sacks et al. 2019).

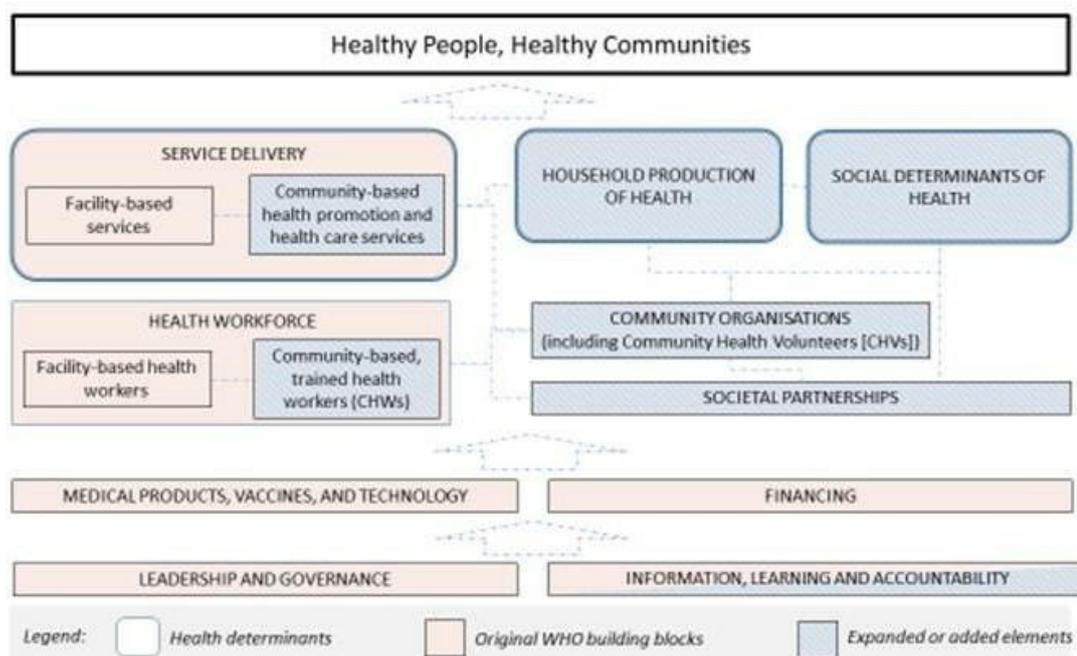


Figure 2.2: *Beyond the Building Blocks Framework in (Sacks et al. 2019).*

These frameworks are referenced throughout the thesis, and are used as discussion aids for findings presented in the different chapters. Additional theoretical models, such as Scott’s Framework for Patient Pathways to Treatment (Scott et al. 2013), and phenomenological approaches (Taylor 2013; McWilliam 2010), were additionally used to complement the analysis within specific chapters, and are introduced within the following chapters. Both frameworks and approaches add the additional crucial element of ensuring that the voice of women affected by breast cancer are included when understanding challenges in accessing and using breast cancer services in Vietnam.

These models and frameworks are used in combination throughout this thesis to help situate findings and stimulate discussions. None of the frameworks take precedence over others, as none are able to sufficiently address all the questions of this thesis.

## 2.4 Originality of the Thesis

The candidate’s role in the studies presented within this thesis was to shape the design of each study, design data collection tools and consent forms, and train researchers in how to use them. He was centrally involved in piloting data collection tools in field visits to Dong Thap and Bac Giang provinces, as well as supporting the collection of qualitative data in both Hanoi and Ho Chi Minh city. The candidate took a lead on all

analysis while maintaining a collaborative approach. He led the writing of all the chapters presented in this thesis and the subsequent papers produced from them.

The candidate was brought into the project as a Research Assistant once funding for the project had been secured. The candidate was centrally involved in initial meetings between the Centre of Public Health at Queen's University Belfast and the Hanoi University of Public Health to conceptualise, design and plan the research project. After a year of working as a Research Assistant, the role was expanded to support the candidate in undertaking a PhD and further lead on the development of the studies presented within this thesis. All the studies presented in the thesis were identified and designed by the candidate, with support from the wider research team.

The candidate's background is largely in social sciences, having undertaken a BA in Politics from the University of Nottingham and a Masters in Development from the Institut de hautes études internationales et du développement in Geneva, Switzerland. Professionally and voluntarily, he worked in malaria prevention in Uganda, HIV and Hepatitis testing and prevention in Thailand, and as a community engagement officer in Northern Ireland on peace, reconciliation and education programmes. This background helped to inform the qualitative nature of many of the studies presented in this thesis.

In some interviews, it was felt that the candidate's positionality may compromise the quality of data collected, or that his presence wouldn't be seen as appropriate given the sensitive nature of the content of the interviews. In these interviews, the candidate was not present. In other interviews, for example with healthcare professionals or within focus groups with carers, the candidate was present and would contribute questions in support of the lead Vietnamese researcher (through simultaneous translation). Positionality is discussed in more depth in the next section.

## **2.5 Reflexivity and Positionality**

Reflection and reflexivity as concepts and practices concern the ability to examine one's own beliefs and behaviours. They concern the environments and contexts in which we live and work, and offer an opportunity to take stock, redefine and move in new directions, as well as allowing us to better understand the dynamics of contexts in which we work. "At its simplest, reflexive practice is the ability to be aware of the dynamics of our social and professional environments, reflecting on how these shape

our own behaviour and the impact that this has on other people. It means looking at one's own practice with a view to understanding and then potentially transforming it – and thus learning to change and improve the quality of our relationships with others” (Eyben 2006).

Terms such as reflection, critical reflection, and reflexivity are often used interchangeably. However, there are subtle yet important differences among them. Reflexivity involves questioning one's own knowledge, belief, approaches and practice, considering knowledge itself as data that can be analysed and scrutinised. Researchers can be reflexive about how their positionality impacts upon the research, and equally how their research impacts upon them as researchers (Attia and Edge 2017). Scholars writing about reflexivity often argue that knowledge is not objective, but rather is socially created and intricately tied to power, positionality and lived experiences.

Reflection, or critical reflection, is often considered a practice, in which professionals attempt to view their work, knowledge, and positionality with a degree of objectivity (D’Cruz, Gillingham, and Melendez 2006). The purpose is to acquire learning that can then be applied to work and future projects. Fleming defines reflection as “the ability to gain understanding by reflecting on specific issues in practice through critically contextualizing, observing and analysing to generate new knowledge and insights which can enhance practice” (Fleming 2006). For Fleming, reflection applied to health promotion projects should be applied in three main domains: the self, the context, and processes. The ‘self’ relates to individual roles, skills and values, as well as team dynamics; ‘context’ to social, cultural, political, economic and institutional dynamics impacting on the project; and ‘processes’ relating to the planning and implementation of projects. An examination of a project along these three domains gives space for researchers and a research team to reflect broadly on the characteristics of a project, while also examining assumptions and structural context that may have impacted upon their work (Fleming 2007).

The candidate attempted to maintain both a reflective and a reflexive approach throughout the research project. Being aware of positionality throughout the project was important not only in creating a collaborative and effective research project, but also to ensure that data quality was not determinately affected by the involvement of

the candidate in the studies. “Positionality refers to the stance or positioning of the researcher in relation to the social and political context of the study—the community, the organization or the participant group” (Coghlan and Brydon-Miller 2020). As a white man and non-Vietnamese speaker the candidate’s positionality would have been likely been a barrier to gathering in-depth sensitive data, particularly from women with a breast cancer diagnosis. As a result, data collection, as well as other aspects of this research project, were therefore highly collaborative and conducted in partnership.

## **2.6 Partnership Development and Research Context**

Partnerships are unequivocally considered important in the production of quality research. The number of collaborative research partnerships for global health has increased significantly in recent years, often dictated by requirements of funders that partnerships constitute a core part of funding applications and proposals (Herrick and Reades 2016). Larkan describes research partnerships as “contextually relevant peer-to-peer collaborations which offer a platform for sharing knowledge and growing expertise globally, working towards a common goal, across disciplines and perspectives” (Larkan et al. 2016). This definition brings together many commonly expected characteristics within global health research partnerships, namely: collaboration; capacity-building; common objectives; and multi/inter-disciplinarity.

A key objective of the research presented in this thesis was to gain a thorough understanding about the context in which Vietnamese breast cancer services are organised and delivered. Understanding context, however, must also include an appreciation and analysis of the context in which that research was produced. The recognition of the global epidemiological transition from communicable to noncommunicable burden of disease (highlighted particularly by the WHO’s Global Plan for NCD Prevention and Control 2013-2020 (WHO 2013)) has resulted in new funding streams to support research in this area. While the degree to which communicable and non-communicable disease differs, and whether the different categorisations are redundant (many frame NCDs are socially communicable diseases) (Adjaye-Gbewonyo and Vaughan 2019), the categorisation of NCDs as a distinct health challenge has arguably increased their visibility and allowed funding to be directed towards research and programme delivery within this area.

Significant and new funding streams are being made available and protected for global health research. For example, the UK government has ring-fenced 0.7% of its GNI (Gross National Income) for official development assistance (ODA) at a time when other budgets have been cut. Much of this budget is administered through funding bodies such as the National Institute for Health Research (NIHR), the UK Research & Innovation (UKRI), the Newton Fund, and the Global Challenges Research Fund (GCRF) to support research and development through UK university partnerships. In her 2019 Annual Report, 'Health, our global asset: partnering for progress', England's Chief Medical Officer Professor Dame Sally Davies, highlights that research has been one of the UK's strongest contributions to improving global health, and that the development of North-South partnerships are essential for continued success. In her recommendations she states that research funders should continue to "promote the growth of equitable partnerships between researchers in the Global North and Global South, including in lower-income countries" (Davies 2019).

The studies presented in this thesis were conducted within an collaborative partnership between the Centre for Public Health, Queen's University Belfast, and the Hanoi University of Public Health. A Newton Fund Institutional Links Grant to support partnership building between institutions from high and lower income settings was awarded to Queen's University Belfast and the Hanoi University of Public Health in March 2016. The research collaboration was initially conceptualised between Professor Liam Murray of the Centre for Public Health at Queen's University Belfast and Professor Hoang Van Minh at the Hanoi University of Public Health. The aim was to explore guidelines and treatment outcomes related to breast cancer in Vietnam. In initial meetings in Hanoi in December 2016 it became clear that there needed to develop a deeper understanding of the context around breast cancer and breast cancer service delivery. Furthermore, treatment in centralised oncology hospitals appeared to follow much of the Breast Health Global Initiatives (BHGI) guidelines for LMICs.

In light of this, the candidate felt it would be of more use to focus on the factors impacting on whether people were able access services and the challenges faced in terms of breast cancer service delivery across all levels of the health system; an approach that was agreed with the wider team. In addition to the support from the Newton Grant, the team were awarded additional funds from the MRC-AHRC (Medical Research Council & Arts and Humanities Research Council), GCRF (Global

Challenges Research Fund) and the GIAA (Global Impact Accelerator Awards) to support, deepen and expand these studies.

This partnership expanded over time to include additional partners such as Hanoi Medical University (HMU), the Institute for Anthropology in Hanoi, the Vietnam Women's Academy, Queen's University Belfast's School of Nursing and Midwifery and the School of Arts, English and Languages, as well as Ulster University's Belfast School of Arts.

The research collaboration attempted to emulate the eight key principles noted by the Tropical Health and Education Trust (THET) as important to promoting effective research partnerships. Partnerships should be (1) strategic; (2) harmonized and aligned; (3) effective and sustainable; (4) respectful and reciprocal; (5) organized and accountable; (6) responsible; (7) flexible, resourceful, and innovative; and (8) committed to joint learning (THET 2019). Characteristics that contribute to ineffective and unequal partnerships can readily be described with antonyms for the concepts previously highlighted, such as distrust, lack of collaboration, poor communication, etc.

This research collaboration attempted to emulate these key principles to produce high quality and collaboratively implemented studies. To ensure a reflexive, reflective and responsive approach to our collaboration, a series of reflective conversation were held within the research team. Within these conversations, there was consensus on benefits of both the Vietnam/UK collaboration and global health research partnerships more broadly. Participants, however, highlighted previous difficulties in working within international partnerships, and challenges regarding how global health research is produced. Contextual challenges were described as administrative and bureaucratic, structural (in terms of funding), and practical (such as communication, travel etc.). The team discussed ways of addressing these barriers within our own work, and identified the key factors and values that allowed such barriers and challenges to be overcome.

Consistently, the research team highlighted the importance of leadership; the need for both good planning but also flexibility; and the importance of good communication skills to circumvent challenges of working across language and different institutional, social and cultural norms. Other themes raised by the research team related to equity,

and Vietnamese team members additionally highlighted the importance of training within global health research partnerships.

In the three years since the partnership commenced, several demonstrable outcomes have been achieved, indicating the success of collaborations to date. Outcomes include the publication of papers in peer-reviewed and open-access global health journals (Global Health Action, Global Health Research and Policy, and BMJ Open); the presentation of research findings at international conferences (World Cancer Congress, Malaysia and the International Health Congress Oxford, UK); the presentation of key findings to policymakers in Hanoi; and the award of two PhD places at the Centre for Public Health (QUB). A number of grants have additionally been awarded to the collaboration to undertake research, further develop the institutional partnership, and to expand into new areas of mutual interest. An approximate total of £400,000 has been awarded to the partnership since 2016, with high-level delegation visits from HUPH and the Vietnam Ministry of Health to QUB in 2019.

Published literature consistently cites the importance of partnerships when conducting global health research. The research collaboration underpinning the studies presented in this thesis highlight that while significant institutional and structural barriers exist impacting on research partnerships, communication, trust-building, and leadership can overcome many of these barriers. More broadly, this partnership facilitated significant personal learning noted by virtually all team members, and was deemed essential to producing quality and rigorous findings presented in the following chapters.

## **2.7 Contributions of the Research Team**

The studies presented in this thesis would not have been possible without the support of a multidisciplinary and international research team (Photo 2.1 & 2.2). Luu Ngoc Minh, Tran Tuan Anh and Ngo Tri Tuan helped support the sourcing and translation of articles in Vietnamese for use within the Scoping Study presented in Chapter 4. Le Thi Hai Ha, Dinh Thu Ha and Vu Tuyet Lan provided support in sourcing and translating data from Vietnamese mainstream media, presented in Chapter 5, along with supporting analysis and corroborating key findings. I owe a huge debt of gratitude



*Photo 2.1: Some of the research team working on the MRC AHRC ‘Harnessing the Arts and Storytelling to Reduce the Impact of Breast Cancer in Vietnam’ Project in Hanoi in April 2017.*

to Tran Thu Ngan and Nguyen Bao Ngoc who were central with data collection of studies presented in Chapters 6 and 7. Both Ngan and Ngoc played significant roles in shaping the interview guides and initial data analysis, as well as leading interviews in Vietnamese with both healthcare providers and women with a breast cancer diagnosis. Ho Thi Hien and Nghiem Le Phuong Hoa supported data collection through conducting focus groups and interviews with carers presented in Chapter 8.

A number of senior Vietnamese academics including Kim Bao Giang and Luu Ngoc Hoat supported conceptualisation of this studies and analysis of data presented within the Scoping Review in Chapter 4. Prof. Hoang Van Minh has been integral as a supervisor throughout all the studies, along with colleagues in Queen’s University Belfast: Liam Murray, Michael Donnelly, Lynne Lohfeld and Olinda Santin.



*Photo 2.2: Candidate with Tran Thu Ngan (right) and Nguyen Bao Ngoc (left) following a dissemination of results conference in Hanoi in 2018*

## Chapter 3

### Vietnam: Context, Politics, and Health

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This chapter aims to provide a contextual overview of the historical, political, socio-cultural and economic determinants of health in Vietnam. The chapter will provide a synopsis of recent Vietnamese history, showing how it has influenced the current delivery and organisation of health services, before examining current health trends and indicators in Vietnam. The chapter will discuss how health services are contemporarily organised throughout the country. Understanding the structure of the health system is crucial in interpreting the findings of the studies presented within this thesis and their implications for policy and planning of breast cancer services. Having an in-depth knowledge of the wider political context is equally important for appreciating the necessary advocacy options for ensuring this research achieves its objective of having an impact on policy and planning with the goal of improving services for women with breast cancer.

#### 3.1 Political History and Economic Overview

Vietnam has had a turbulent political history, having been at the centre of wars, colonisations and occupations with and by China, France, and more recently the United States of America. Much of recent Vietnamese history has been shaped by occupation and oppression, and as such it is perhaps unsurprising that the ideology of Communism and Nationalism (and until recently, Isolationism) feature so centrally in recent Vietnamese political history. As stated by the revered Vietnamese historical scholar, Nguyễn Khắc Viện, “Capitalism (and thus globalisation) only evoked memories of a long colonial past with all its injustices, atrocities, and the horrors of merciless war” (Viện 2015).

Vietnam has historically been a victim of geography, having the Chinese empire as a neighbour. For one thousand years (111 BC to 938 AD), Vietnam was occupied by different Chinese dynasties, and for the following thousand years China continued to exert influence in Vietnam through language, culture, legal structures, and the introduction of Confucianism.

By the middle of the nineteenth century, the rapidly expanding European powers had secured footholds in India, the Philippines, Java, Singapore, and Hong Kong. Driven by the need and desire to grow and exploit the international market to support the economies and industries of Europe, Britain, France, Spain and Holland invaded territories across South East Asia. In 1858, France and Spain landed in Danang (central Vietnam) under the guise of fighting against the repression and persecution of Catholics in the country. After nearly a decade of fighting, the Mekong Delta in the South of Vietnam was eventually surrendered to France in 1867 (Jamieson 1995). French forces continued to push into the North of Vietnam, before the Franco-Vietnamese Treaty was signed in 1874, giving France sovereignty over the Mekong Delta and trading rights across all of Vietnam. In 1884 France extended their claim of sovereignty to both Northern and Central Vietnam (Jamieson 1995), creating the French colony state of French Indochina (Vietnam, Laos & Cambodia).

Vietnamese resistance to French occupation continued over the following decades. However, it was the end of the Second World War, and the politically and economically devastating defeat of France by Germany in 1940, that provided the opportunity for a renewed push for Vietnamese independence (Dunn 1990). Following the defeat of France, an increasingly expansionist Japan gained control of the whole of French Indochina, before their own defeat in August 1945. The Potsdam Declaration, outlining the terms of Japanese surrender, superficially divided Vietnam at the 16<sup>th</sup> Parallel, with the intention of Chinese forces disarming Japanese forces in the North, and British forces disarming the Japanese in the south. France was then to resume its administration and control over Indochina (Dunn 1990).

The Viet Minh, a nationalist independence movement led by Ho Chi Minh, however, resisted the French re-entry into Vietnam, and on 2 September 1945 proclaimed independence as the Democratic Republic of Vietnam. As China ceded control in the North of Vietnam following negotiations with France, French forces and the Viet Minh vied for control in what became variously known as the Indochina war, the French War, or the First Vietnam War (1946-1954). The war came to end with Vietnam provisionally split along the 17<sup>th</sup> Parallel, with the north controlled by the Viet Minh under Ho Chi Minh, and the South by Bao Dai, the last emperor of the Nguyễn Dynasty and closely aligned with the French. In 1955 Bao Dai was replaced

by Prime Minister Ngo Dinh Diem, a Catholic nationalist and anti-communist, with support from the United States of America (Ruane 1998).

The following decade saw a further escalation of conflict, with communist-supported insurgencies in the south of Vietnam, and eventual intervention by the American military, motivated by the fear of the spread of communism and of a domino effect in the region should Ho Chi Minh's communists have been successful in uniting the country. The war, variously known as the Second Indochina War, The Vietnam War, or the American War, ended with an estimated 1,118,000 deaths in Vietnam alone (not including deaths in Laos and Cambodia) (Guenter 1978). Estimates of the death toll vary greatly, with some estimating as many as 3 million people killed (Ruane 1998). The war represented a human, political, military, economic and moral disaster for the United States. US Secretary of Defence, Robert McNamara in his personal account *In Retrospect*, reflected, "People are human; they are fallible. I concede with painful candor and a heavy heart that the adage applies to me and to my generation of American leadership regarding Vietnam. Although we sought to do the right thing – in my judgement, hindsight proves us wrong" (McNamara and VandeMark 1995).

In 1975, the Northern Vietnamese communist forces entered Saigon, bringing with them a final victory, and securing the reunification of Vietnam. The years following saw Vietnam invade Kampuchea (Cambodia) in response to attacks from the Khmer Rouge regime and to overthrow the Pol Pot administration, and a short conflict with China (The Sino-Vietnamese War or the Third Indochina War). The country entered a period of relative isolationism throughout the following decade, deepened by its continued occupation of Cambodia until 1989 (Bernkopf Tucker 1990). In isolation, Vietnam sought to rebuild itself under the guidance of communist dogma and ideology, emphasising the development of heavy industry, collectivization of agriculture, and suspension of private trade. The five year plan from 1976-1980, however, failed to stimulate economic growth in the post-war period (Palmujoki 1997).

Vietnam began to relax and revise its policies on collectivisation following economic crisis in 1986, introducing liberalising measures on private trade, and encouraging a more outward looking economic model and approach (Tien et al. 2011; Palmujoki 1997). These economic changes known as *doi moi* (renovation) also corresponded

with the movements of *perestroika* (restructuring) and *glasnost* (openness) implemented by Mikhail Gorbachev in the Soviet Union. Vietnam's economy saw significant growth following the adoption of *doi moi* reforms. In 1990, total gross domestic product in Vietnam was 6.47bn (USD), and by the year 2000 had reached 31.18bn (USD) (World Bank 2018d). Despite the economic reforms, however, political pluralism was rejected by the country's ruling class. To this day, the country remains a Communist one-party state. Vietnam's economic growth continued throughout the past two decades, with GDP reaching 245bn (USD) in 2018 (World Bank 2020) (Figure 3.1).

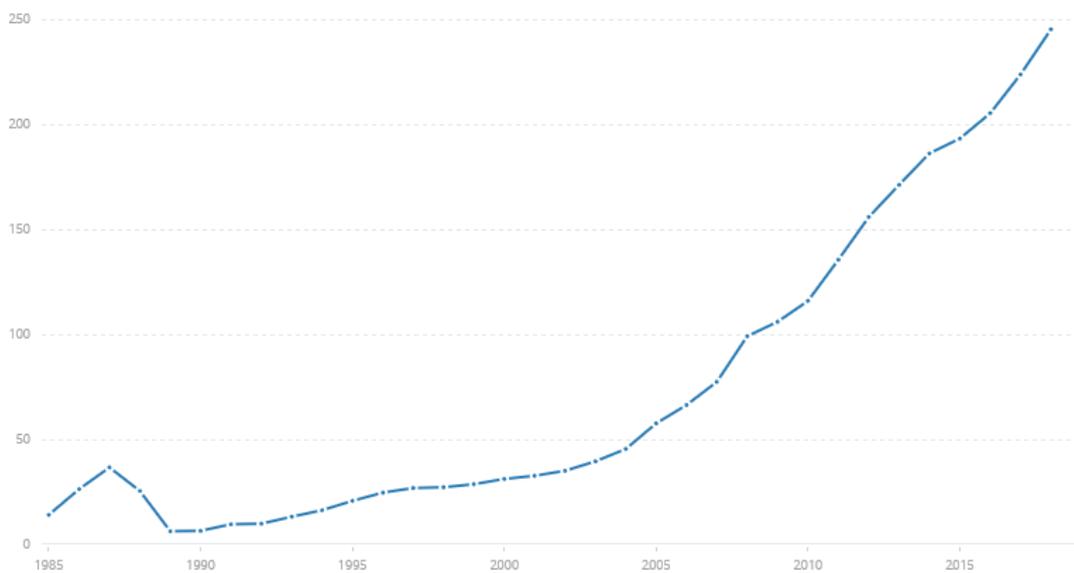
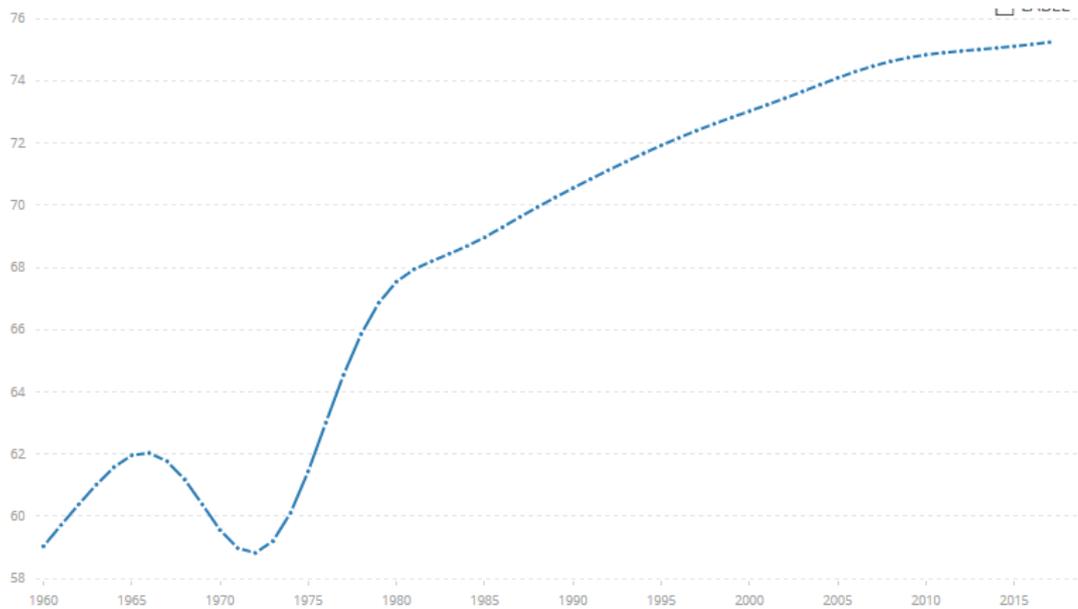
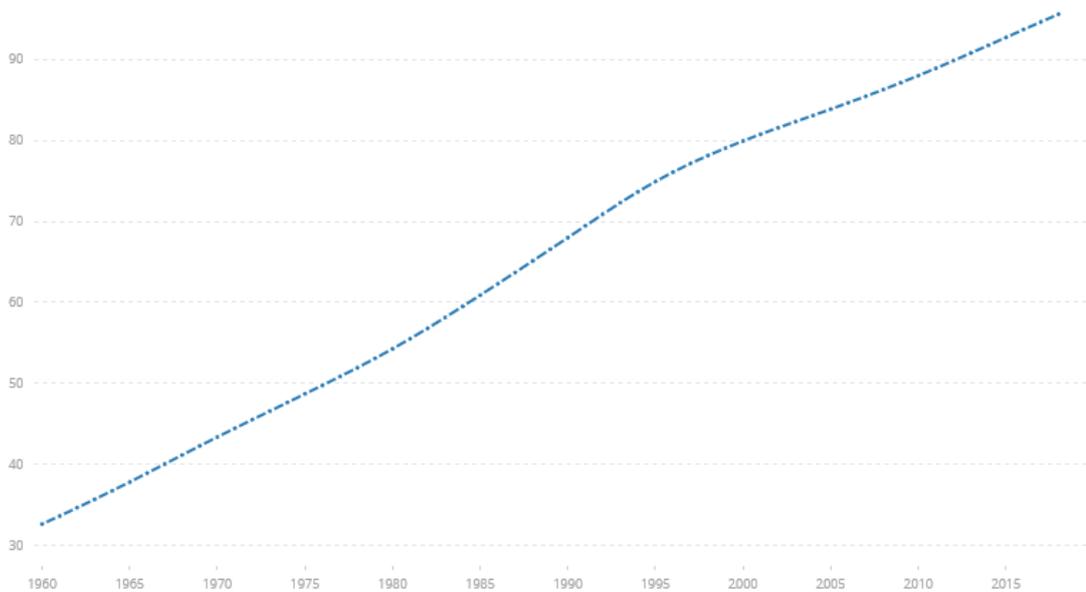


Figure 3.1: GDP growth in Vietnam (USD in Billions) (World Bank 2020)

Today, Vietnam has a total population of 93,448,000 (WHO 2018), making it the 15<sup>th</sup> largest country in the world by population (World Bank 2018b) (Figure 3.3). Vietnam's population remains largely young, with 22.7% of the population under 15 years of age, and 9.6% (2013 data) over 60 years of age (WHO 2018). Life expectancy has increased consistently over the past half century, as shown in Figure 3.2. Life expectancy at birth in Vietnam is currently 75 years (Figure 3.2).



*Figure 3.2: Life expectancy in Vietnam (World Bank 2020).*



*Figure 3.3: Population growth in millions (World Bank 2020)*

An estimated 65% of the population still resides in rural areas (World Bank 2018c), however population density is highest around the metropolitan centres of Hanoi and Ho Chi Minh City and the coastline (Figure 3.4). Vietnam currently ranks 115 out of 188 countries on the Human Development Index (HDI) (UNDP 2018). HDI attempts to assess and rank countries on a more holistic scale than solely economic growth and

development, and is described as a “measure of average achievement in key dimensions of human development: a long and healthy life, being knowledgeable and have a decent standard of living” (UNDP 2018). Consequently, it is a more effective index for comparing countries, especially in regards to health systems, outcomes and expectations, than gross national product or gross domestic product. Vietnam scores 0.683 on the HDI. The global average in 2015 was 0.717 (UNDP 2018). Vietnam is categorised as being within a cohort of countries of ‘Medium Human Development’ out of four categories, ‘Very High Human Development’; ‘High Human Development’; ‘Medium Human Development’; and ‘Low Human Development’.

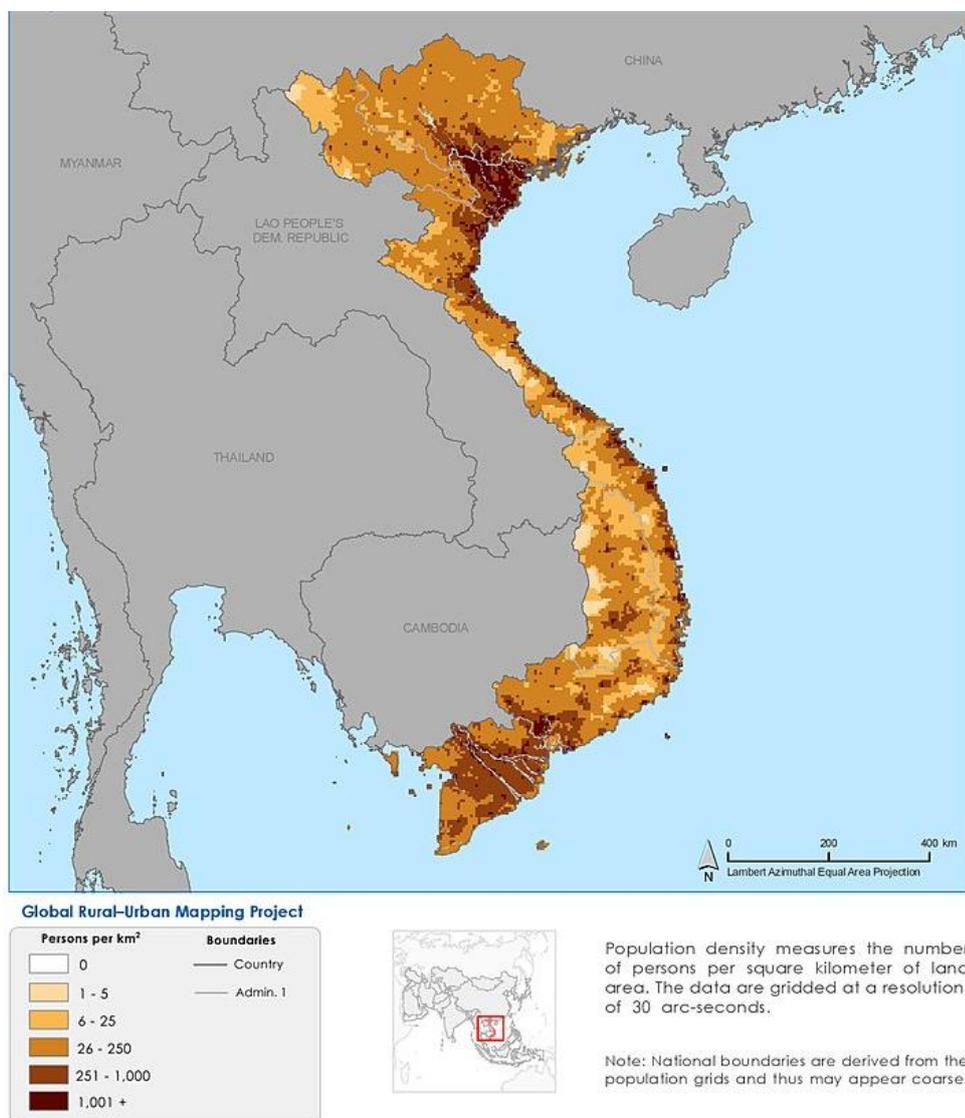


Figure 3.4: Population Density Map of Vietnam from year 2000 (more recent graphics not available) (SEDAC (Socioeconomic Data and Applications Centre) 2000).

As shown, Vietnam has undergone rapid economic growth. The pace of development, as highlighted by its rapid economic growth, is such that this contextual overview will soon be out of date. However, it is clear looking at the recent history of Vietnam that the country is on a sharp upward trajectory. This makes this research all the more important: unlike some other developing nations, Vietnam's government has the capacity to respond to the findings in this thesis and associated papers, and has the opportunity to invest in interventions and services that have the potential to greatly improve health and wellbeing.

### **3.2 Social and Cultural Context in Vietnam**

Equally important to understanding the political determinants of health and how health services are organised and administered, is an understanding of the different social and cultural determinants that affect health seeking behaviours, decisions around health, and how health is viewed across society. Understanding how these determinants impact on breast cancer is a central component of this thesis' qualitative studies exploring the use of breast cancer services by women with a breast cancer diagnosis, but is worth also exploring more broadly in this introductory chapter.

Vietnamese family structures often have nuanced and complex gender roles that shape healthcare choices and decision-making. For example, it is common practice within the majority Kinh community (the largest ethnic group) and other ethnic groups for a woman to move to her husband's family home after marrying. After this transition many of the woman's most important responsibilities (care and domestic obligations) often transfer from her biological family to her husband's family (Malarney 2003). Little research has examined the implications of this transition and associated responsibilities and how they may affect women's health-seeking behaviour. These themes are explored most explicitly in Chapters 7 and 8 of this thesis.

More broadly, Vietnam has created numerous legislative frameworks that attempt to protect women and promote gender equity, underpinned by the work of Vietnam Women's Union and the National Committee for the Advancement of Women (Schuler et al. 2006). However, Vietnam still scores only modestly within country-comparative reports such as the Global Gender Gap Report 2017 (World Economic Forum 2017), in which Vietnam is ranked 69<sup>th</sup> out of 144 countries. Vietnam scores particularly poorly in 'health and survival', ranked at 138<sup>th</sup> out of 144. 'Health and

survival' collates data from two indicators: sex-ratio at birth (intended to highlight the issue of 'missing women'), and the gap in healthy life expectancy between men and women (accounting for violence, disease etc.) (World Economic Forum 2017). Despite improvements within the area of women's health, particularly related to maternal health, a number of challenges remain. These include the continuing burden of HIV and other communicable disease (particularly in migrant communities), high prevalence of sexual violence, and increasing cervical cancer incidence aligned with low levels of HPV vaccination (H. V. Minh et al. 2018).

As described in the introduction to this thesis, women's health has largely been improving in Vietnam, and several strong statutory and advocacy groups (like the Women's Union) ensure women's health is a visible area of priority. The Vietnam Women's Union, with an estimated membership of over 11 million women, is one of the largest unions of women in the world (Schuler et al. 2006). It supports a wide range of policy development and programme implementation work across several issues from health promotion, economic development, educational support and cultural activities. The union has branches in every village of the country (Communes), and is largely viewed as being an important vehicle for achieving other indicators of gender equity, namely economic participation and opportunity (ranked 33<sup>rd</sup> out of 144 countries) (World Economic Forum 2017).

Despite being officially a secular state, a number of different religions are presently practiced and observed in Vietnam. Buddhism is the majority religion; however, it has evolved and intertwined with other belief systems over hundreds of years to form a particular Vietnamese variation of Buddhism: "Over many centuries, Taoism, Buddhism, and Confucianism had become intertwined, simplified, and Vietnamised to constitute – along with vestiges of earlier animistic beliefs – A Vietnamese folk religion shared to some extent by all Vietnamese" (Jamieson 1995). Jamieson discusses the influence of Taoist beliefs surrounding *yin and yang* and contends that the belief in balance and harmony influences how people may view their health.

Health, in this sense, is traditionally viewed as the body in balance. Treatment of illness is concerned with the restoration of this balance. The types of food ('hot' foods or 'cold' foods) consumed often was, and is still, seen as central in ensuring restoration of balance in the body (Jamieson 1995). While there is limited research on the

connections between these traditional beliefs and contemporary Vietnamese conceptualisation of health, the themes of nutrition and diet (and their role in breast cancer treatment) were consistently raised by women with breast cancer and their informal carers in interviews and focus groups conducted as part of this thesis.

Traditional beliefs in the power of non-biomedical remedies are maintained across Vietnam, although to what extent they are considered as alternative therapies as opposed to complementary is not widely understood (Shillabeer 2016). From research presented in this thesis, the majority of women interviewed in our studies described using traditional and home remedies only as a complement to, and not instead of, biomedical interventions. Elements of Confucianism and Buddhism, and the belief in karma and multiple lives, may also impact upon some health seeking behaviours. For example ill health can often be considered directly related to transgressions in previous lives, and the shame and denial of being sick associated with such beliefs may strongly affect health-seeking behaviours (Shillabeer 2016).

Despite the long history of conflict and occupations outlined in the previous section of this chapter, Vietnam has retained a distinct language, cultural characteristics and sense of national identity over time. To present a homogenous view of any culture and national identity is, however, problematic. As stated by Van Huy and Kendall, Vietnamese society is comprised of different “ages, ethnicities, occupations and circumstances” and “is a society of both urban and rural people who are ethnically diverse and live in geographically varied and socially diverse circumstances” (Van Huy and Kendall 2003).

Vietnam has 54 officially recognised ethnic groups, 31 of whom are located in the northern mountainous areas of the country (Michaud, Turner, and Roche 2002). The largest ethnic group is the Kinh people, representing 86% of the total population of Vietnam. In contrast, 34 of the 54 official ethnic groups have populations of less than 100,000 people each (UNFPA 2011). Significant inequalities exist between the majority groups and minority ethnic groups across many indicators. For example, infant mortality and under-five mortality are lowest among the Kinh ethnic group (13 per 1000 live births, and 19 per 1000 live births respectively) compared to other ethnic groups (Mong: 46 per 1000 live births, and 72 per 1000 live births respectively), and life expectancy across both sexes is highest among Kinh people (UNFPA 2011).

Inequalities between the Kinh and minority groups have been growing in recent decades across indicators such as educational access and attainment, literacy, education enrolment, standards of living, health outcomes, and income (Baulch et al. 2007; UNFPA 2011; Partnership for Action in Health Equity 2013). As noted by a statement by the United Nations Population Fund, “Although many government programmes have been designed to address this disparity over the years, it appears that significant efforts are still required” (UNFPA 2011).

A limited amount of research exists on factors affecting or influencing access to and use of health services by ethnic minority groups. Research has indicated that on certain service utilisation, disparities are significant. For example, in 2006 women from ethnic minority groups were estimated as being five times less likely to give birth in a health facility than women from Kinh and majority ethnic groups (Doan et al. 2016; Målqvist et al. 2013).

### **3.3 Health in Vietnam: Governance, Financing and Trends over Time**

Significant progress has been made in improving health outcomes in Vietnam since the turn of the century. Vietnam achieved or exceeded many of the Millennium Development Goals, particularly around child mortality and child nutrition. It has also made progress towards achieving universal health coverage (Partnership for Action in Health Equity 2013). As of 2017, social Health Insurance (SHI) covered approximately 87% of the population, rising from 60% in 2010 (WHO 2019b; Ministry of Health, Vietnam 2017).

The provision of health services in Vietnam has changed and evolved dramatically over the past few decades. The provision of health is highlighted in Articles 39 and 61 of the country’s 1992 Constitution, which declare that, “The State invests in, develops and ensures the unified administration of people's health protection”, and “Citizens are entitled to health care” (Socialist Republic of Vietnam 2001). Although issues related to health only appear in two of the Constitution’s 147 articles, the years following *doi moi* saw the development of a number of policies and strategies aiming to improve access to health services for the poorest, including user exemption fees (Tien et al. 2011) and enshrining the responsibility and role of the state to manage and provide health services across the country.

Vietnam's health infrastructure has similarly expanded significantly over the past few decades. Before the 1980s there is little evidence of systematic, population-based approaches to health care delivery, arguably due to the persistence of the conflicts that engulfed the country for the previous century (Shillabeer 2016). The economy developed rapidly throughout the 1990s and into the new millennium, and the saw the parallel development of a health system to meet the demands of the growing population.

Initially health delivery focused on preventative care, treatment of diseases affecting the young, and infectious disease control and treatment. Vietnam, however, is going through an epidemiological transition similar to many LMICs. Since 2002, the Vietnamese Ministry of Health (MoH) developed strategic plans for the control and treatment of NCDs and specifically cancer (Harper 2011; MoH, Vietnam 2015b, 2015d; B. D. Nguyen 2011). However, mechanisms for evaluating the progress made within these plans and strategic objectives remain limited.

NCDs are on the rise in Vietnam. The World Health Organisation (WHO) estimates that 75% of all deaths in Vietnam are now caused by NCDs, with 430,000 deaths from NCDs identified in their 2008 review (WHO 2011). Among the deaths caused by NCDs, an estimated 40% are attributable to cardiovascular diseases, 14% from cancer, 8% from chronic respiratory diseases, and 3% from diabetes. Recent data estimate there were 164,671 new cases of cancer and 114,871 cancer-related deaths in 2018 (GLOBOCAN 2018). The most common cancers associated with mortality were liver (23.48%), lung (19.14%), stomach (13.92%), and breast (5.64%). These challenges are compounded by the continued existence of communicable and infectious disease (e.g. large Measles outbreaks in 2014 and Dengue Fever outbreaks in 2017), in what is sometimes referred to as the 'double burden' of the epidemiological transition (Boutayeb 2006).

The Vietnamese health system consists of a four-tiered healthcare structure, shown in Figure 3.5. This structure corresponds with a dual system of categorisation, in which each facility is categorised into a specific 'class', based on a composite score the facility receives based on factors such as infrastructure and equipment; human resources; services offered; size; and location; and 'level' of the facility largely based on scale and location (national, provincial, district or commune).

Facilities are administered by either the Ministry of Health (central and special levels), or by provincial Departments of Health. As with most health systems, specialised services are provided at central and national levels, often in urban settings. Commune health stations and general district hospitals are entry points into the health system, providing examinations, referrals and in some cases treatment. A 2010 audit showed there were 36 central level hospitals (managed directly by the Ministry of Health), 273 provincial-level hospitals, and 559 district-level hospitals (Partnership for Action in Health Equity 2013).

Very little information exists on how the different levels of the health system operate in reality. A key criticism from the WHO and others has been the vertical disease-specific nature of the organisation of services for NCDs including cancer (WHO 2011), making it difficult to achieve integrated and multi-sectoral approaches to disease control, prevention and treatment. The mixed methods study presented in Chapter 6 attempts to deepen understanding of how each level of the Vietnamese health system operates in the delivery of cancer services, providing specific empirical data on the provision of breast cancer services. Research on service delivery for other NCDs is limited, however, two studies suggest that primary health centres lack both sufficient human resources, training and equipment to adequately provide NCD prevention and management services (Van Minh et al. 2014; Vu Duy et al. 2018). Lack of capacity in lower levels of the health systems are also reported in relation to maternal and neonatal services (Heo et al. 2020).

In relation to human resources in the health system, the WHO estimates that there are 1.19 doctors per 1,000 of the Vietnamese population (based on 2013 statistics) (WHO 2018), however statistics from the General Office of Statistics in Hanoi, would indicate that this number is inflated, reporting 775,000 doctors working in the country in 2016, equating to 0.83 physicians per 1,000 of the population (General Statistics Office of Vietnam 2018).

State spending within health care budgets in 2016 were estimated at 5.60% of total expenditure. This shows a small increase since 2005 and 2007 (no data for 2006), when state expenditures were 2.90% and 4.11% respectively (General Statistics Office of Vietnam 2018). There is a disparity with WHO figures, which state that government

expenditure on health as a percentage of total government expenditure was 9.3% in 2013, and 6% of GDP (WHO 2018).



*Figure 3.5. Overview of the structure, class categorisation and functions of different levels of the Vietnamese health system (MoH, Vietnam 2013a). Adapted from Shillabeer (2016) (Shillabeer 2016).*

*Doi moi* created the opportunity for the liberalisation and privatisation of health services. Vietnam’s model of health financing shifted from a tax-based model to a social insurance model; user charges were introduced; private healthcare providers were permitted to operate; and the pharmaceutical market was opened (Tien et al. 2011; Somanathan et al. 2014). Significant challenges came with this political shift, as out-of-pocket payments (OPP) accounted for 71% of total health care expenditure in 1993, and rising to 80% by 1998 (Tien et al. 2011).

The result of these reforms at government level has been the extension of social health insurance (SHI) coverage to approximately 87% of the Vietnamese population. Challenges remain, however, with significant OPPs and catastrophic financial health expenditure for many families. According to a 2011 estimate, OPPs still account for 57% of total health care expenditure (Tien et al. 2011). Reasons for continued high

prevalence of OPPs has been attributed to increases in costs for health services; increases in coverage leading to higher utilization of health services and thus higher spending; provision of unnecessary services; and cost-recovery by health care providers (Somanathan et al. 2014).

SHI does not cover all health conditions and services, especially in relation to NCDs which are often more costly to treat. The Ministry of Health's 2015 National Strategy for the Control of NCDs states, "Health insurance does not cover certain NCD prevention services. No health insurance billing guidelines are made available for screening a number of diseases under the Health Insurance Law, and payment for consultancy services is not applicable" (MoH, Vietnam 2015c).

Levels of financial catastrophe and impoverishment from healthcare costs are particularly high in Vietnam. Financial catastrophe exists when health costs equal or exceed 40% of a household's capacity to pay, while Impoverishment concerns when a non-poor household is impoverished by healthcare costs (WHO 2005). In Vietnam, in 2013 an estimated 862,661 and 563,785 households were pushed into financial catastrophe and impoverishment respectively (Partnership for Action in Health Equity 2013). Households at the greatest risk of such financial crises were headed by older adults, in rural areas and of lower economic status (Partnership for Action in Health Equity 2013). A recent study of the financial burden of healthcare costs surveyed 1,141 cancer patients households in Hanoi. Results showed that 37.4% of the households had been impoverished by the treatment costs for cancer (H. Minh et al. 2017). Other studies have estimated financial catastrophe could be as high as 73% for patients undergoing surgery (R. Sullivan et al. 2015). Not having insurance has also been shown to be a significant indicator for lower health service utilisation according to a recent study in a rural district in the north of Vietnam (Van Minh et al. 2018).

Patient pathways are designed as linear and hierarchical. To access and comply with health insurance regulation patients are required to enter the health system at either commune or district levels, and be referred upwards if required (MoH, Vietnam 2015a). In reality, it is unclear to what extent this occurs, with patients bypassing the lower levels of the health system either due to lack of confidence in service providers or beliefs that the services they require are not available at lower levels of the system (as discussed in Chapter 6). Often patients will receive a diagnosis at a higher-level

facility and pay for this service out-of-pocket. They then re-enter the system at a lower-level facility so they can receive health insurance coverage thereafter. Not only does this potentially create unnecessary out-of-pocket costs for families, but also contributes to duplication of services and overcrowding common in higher-level facilities.



*Photo 3.1: The records room in a provincial oncology hospital (photo: Savannah Dodd, 2017).*

An enduring obstacle to effective planning of health services is the lack of an integrated and systematic approach for recording, compiling and collating patient data (Photo 3.1). In terms of cancer, only nine hospital-based registries exist across the health system. There is no electronic, integrated system for collecting and storing data (Thuan et al. 2016). As described by Shillabeer, "One major barrier to the application of any form of evidence-driven healthcare is the lack of consistent, clean and structured data. Systems are often little more than data collection points that are used to input incomplete data, frustrate medical professionals and negatively impact upon the potential for health analysts and policymakers to provide value where it is critically needed" (Shillabeer 2016).

Data sets for Vietnam (GLOBOCAN 2018) are based on estimates and modelling often relying on data from neighbouring countries, and are at risk of being incomplete or misleading. The implications of a lack of integrated data collection will be explored further in chapters specifically looking at the lack of, and inconsistencies within, data on breast cancer in Vietnam.

## Chapter 4

### Breast Cancer Services in Vietnam

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#### 4.1 Contextual Overview

The purpose of the following chapter is to move from a description of the Vietnamese health system as a whole, to a more focused description and analysis of breast cancer services specifically. To date, there have been few targeted studies on breast cancer in Vietnam and the few studies that exist have never been reviewed in either English or Vietnamese. This chapter collated, analysed, and reviewed existing studies. Given the iterative nature of this thesis, the results of this review were used to inform and underpin the design of mixed-methods and qualitative studies presented later in this thesis.

In Vietnam, breast cancer incidence has more than doubled over the last two decades from an age-standardised rate of 13.8 per 100,000 women in 2000 to 29.9 per 100,000 women in 2010, with an estimated 12,533 new (reported) breast cancer cases per year across the country (Dieu, Duc, and Thuan 2012) in 2010. There is variation in the estimated number of new cases. Estimates from the International Agency of Cancer Registries (IARC) indicated a decline in the breast cancer age-standardised incidence rate in Vietnam to 23.0 per 100,000 in 2012 (or 11,067 new cases). However recent GLOBOCAN data show an increase in estimates of breast cancer cases to 15,229 new cases per year, accounting for 20% of cancer incidence in women. There are an estimated 6,103 deaths in Vietnam from breast cancer annually (GLOBOCAN 2018).

These trends have been matched with a growth in research on NCDs generally and on breast cancer in particular. This is reflected in the fact that most of the studies in this review were published in or after 2013. No studies have been conducted to review this body of evidence in order to understand their implications for future breast cancer research in Vietnam. Situating this research within a wider context of global efforts to reduce the impact of breast cancer; incidence of breast cancer in Vietnam remains quite low in comparison to higher income contexts, despite increasing incidence rates and likely high levels of underreporting. Globally, breast cancer is the most commonly

diagnosed cancer in women, with over 1 million cases diagnosed annually (Jacques Ferlay et al. 2010). In the UK, with a population of two-thirds that of Vietnam, 55,222 new cases were recorded in 2014 (Cancer Research UK 2017), while across Europe there is an age-standardised rate of 94.2 per 100,000 women (J. Ferlay et al. 2013).

This chapter focuses on charting and analysing available literature on breast cancer services in Vietnam. The methodology of a scoping review was chosen instead of a systematic review as there was not sufficient literature on breast cancer in Vietnam to warrant a systematic review. A scoping review additionally allowed the inclusion of multiple data types, including grey literature, which provided a more comprehensive overview of the current context regarding breast cancer and breast cancer service delivery in Vietnam. By working closely with two Vietnamese colleagues at the Hanoi University of Public Health and the Hanoi Medical University, Vietnamese literature was incorporated into this review. The inclusion of Vietnamese literature within this review ensures that the picture presented in this chapter is comprehensive in terms of both its scope and breadth. The chapter focuses on the organisation and delivery of breast cancer detection, diagnosis and treatment services with the aim of identifying themes relevant to health systems strengthening. The results provide essential context-setting data and information critical to understanding issues relevant to this study area and the design of future research projects.

## **4.2 Scoping Review Methodology**

This scoping review followed the five-stage framework developed by Arksey and O'Malley (Arksey and O'Malley 2005): identifying the research or review question(s); identifying relevant studies; selecting the studies for review; charting the data from them; and collating, summarising and reporting results. According to Mays, Roberts and Popay (Mays, Roberts, and Popay 2001), scoping reviews 'can be undertaken as standalone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before [and in order] to map the key concepts underpinning a research area and the main sources and types of evidence available'.

A scoping review of published and grey literature was deemed to be the most appropriate methodology for this project due to the lack of analytical reviews on breast cancer services in Vietnam. Common themes and gaps were identified and charted regarding the detection, diagnosis, and treatment of breast cancer.

Literature published in English was systematically searched in the MEDLINE, Web of Science, and JSTOR databases from 2002 (when the Vietnamese National Cancer Control Strategy was published) to 2017 using the keywords ‘Vietnam’ and ‘Breast Cancer’. Eligible articles were papers and publications that reported empirical data about breast cancer detection, diagnosis and/or treatment services including articles about cancer in Vietnam that referred to breast cancer and breast cancer services (initial searches indicated that few studies examined breast cancer in isolation). The systematic search indicated that there has been no previously published review on breast cancer in Vietnam.

Following this initial search of articles in English, two colleagues at the Hanoi University of Public Health searched the electronic databases at the Hanoi Medical University Library, the Hanoi University of Public Health Library, the Vietnam Oncology Journal (K Hospital), and the Institute for Preventive Medicine and Public Health Library in Vietnam using the Vietnamese keyword equivalent of ‘Breast Cancer’ and the same inclusion criteria noted above. Data was collaboratively charted and synthesised in Vietnamese before translating the results into English and combining them with the findings from the search of English language literature.

Grey literature was identified through an online search. Websites of Vietnamese governmental ministries, international organisations and non-governmental organisations were searched to source government reports and guidelines, strategic and operational-related documents, organisational reports and statistics. The same inclusion criteria as noted above was applied and used in earlier steps.

All sources were appraised and excluded if they did not meet criteria of appropriateness and relevance to the study objectives. The final step was to ‘chart’ all eligible documents using three organisational categories: screening and detection, diagnosis, and treatment. Relevant details (including contextual information such as socio-economic data, demographics and incidence rates) were extracted and charted to assist with analysis of the findings. During this process, international guidelines were consulted from the WHO (WHO 2013), the Breast Health Global Initiative (BHGI) (Benjamin O. Anderson et al. 2008), the European Society for Medical Oncology (Senkus et al. 2015), the Asian Oncology Summit (Lertkhachonsuk et al. 2013), and key articles in journals on global surgery and cancer control in LMICs

(Gelband et al. 2015; R. Sullivan et al. 2015). The recommendations from these guidelines were compared with the results from the review to identify discrepancies, gaps and implications for systems strengthening for breast cancer services.

### **4.3 Results**

Six articles and two abstracts published in English and five journal articles published in Vietnamese met our criteria and were included in the review. A further seven articles were included that focused specifically on risk factors for breast cancer in order to provide contextual and demographic information including articles on NCDs, global surgery and general cancer control in Vietnam. A search and review of grey literature produced eight documents comprising reports from government, public agencies and non-governmental organisations (Figure 4.1).

#### ***Screening and Detection***

Information was not broadly available on how breast cancer is detected in Vietnam. While some studies provide data on the numbers of women screened under various programmes (Full Results Appendix Table 4A), there are very little data concerning how these programmes were organised and what methods were used. There is also very little information on patient management guidelines regarding, for example, patient referral for diagnostic confirmation and treatment after the detection of an abnormal lump or identification of other symptoms.

The study found evidence of at least three large-scale localised, provincial, and regional screening programmes implemented in Vietnam. Between 2008 and 2015, the National Cancer Control Programme screened an estimated 100,000 women aged 30-54 for breast and cervical cancer (Thuan et al. 2016). The National Cancer Control Programme offers free screening for all women using clinical breast examination (CBE), ultrasound, and mammography in case of referral. However, information was not found on either its broader coverage or strategies for scaling up existing programmes.

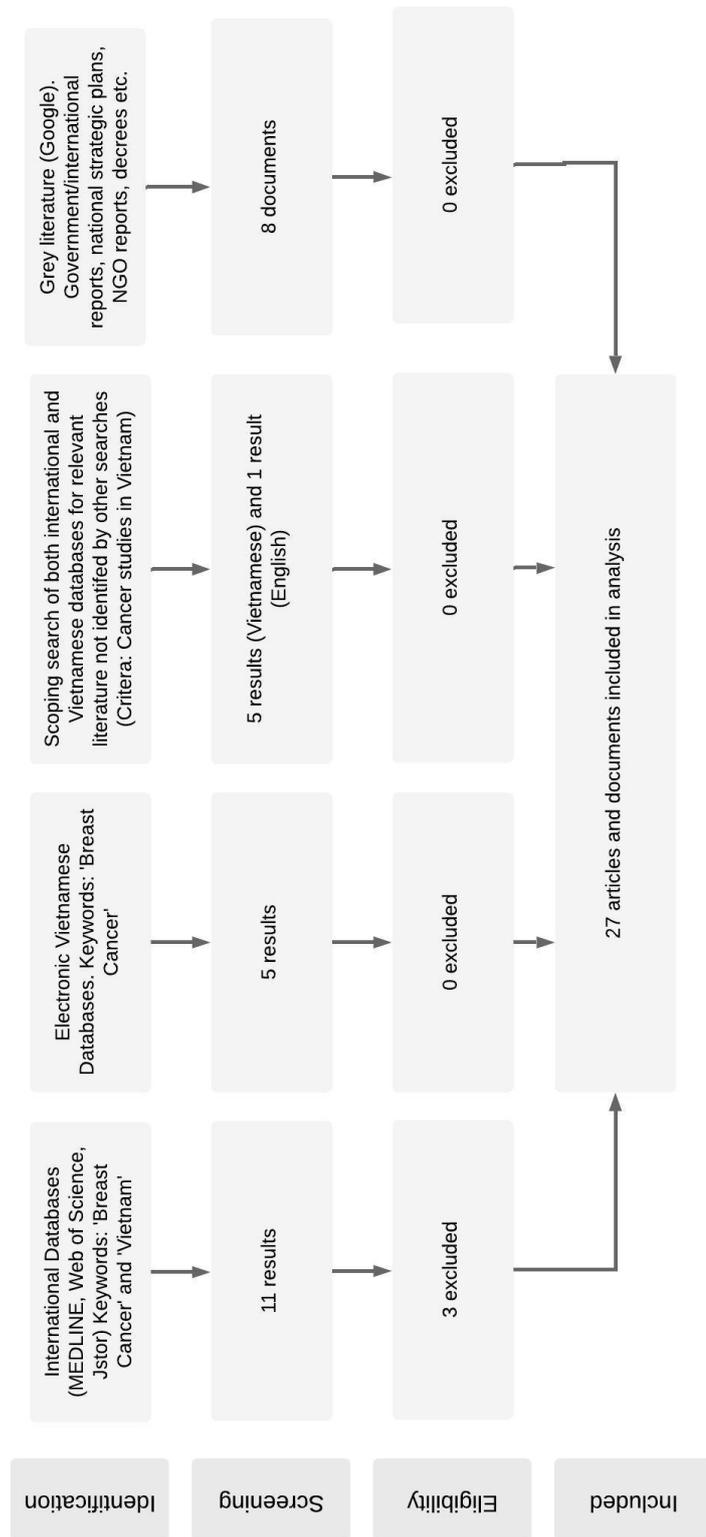


Figure: 4.1: Flow chart showing process for screening and selecting articles included within the review.

The Vietnamese Joint Annual Health Review is an annual report that focuses on one sector of the country's health care system. The 2014 issue stated that over 120,000 women have been screened for breast cancer nationwide (predominately in Hanoi and Ho Chi Minh City) between 2008 and 2013 (MoH, Vietnam 2015b), and recommended ways to better prevent and control non-communicable diseases (NCDs), including cancer. The 'Early detection of breast cancer and cervical cancer in women' programme was also implemented in Hanoi between 2012 and 2014 by the Committee for the Advancement of Women in Hanoi, and reportedly screened 50,000 women. However, information was sparse about how these screening programmes were conducted. Furthermore, evaluations about their outcomes appeared to be absent, although the review noted 'a shortage of trained personnel, (a) lack of appropriate diagnostic equipment, and the lack of health insurance reimbursement for screening services' (MoH, Vietnam 2015b).

The 'We Care for Her' campaign, implemented by the Cancer Patient Support Fund, Bright Future, and supported by the Swiss Embassy in Vietnam and the Roche Group, also reported providing free breast screening for an estimated 4,000 women across five provinces in 2013-2014. These services were expanded to reach 12,000 women in Hanoi, Da Nang, and Ho Chi Minh City in 2015-2016 (We Care for Her 2017).

Given the localised nature of these interventions, and the lack of systematic national screening, it has been estimated that less than 10% of eligible women nationally receive appropriate annual breast (and cervical) screening (Harper 2011). Screening activities are not covered under social health insurance (MoH, Vietnam 2015b), and furthermore, the majority of programmes report screening activities in large cities, perhaps exacerbating inequality in access between rural and urban areas. Vietnam remains a largely rural country, with an estimated 65% of its population (2016) still residing in rural areas (World Bank 2018c).

Beyond a lack of systemic capacity, the low numbers of women using screening and detection services may be related to low levels of public awareness and education about detection, symptoms, where to access services, and how to conduct self-examination. Systems barriers and low population awareness of symptoms were commonly noted reasons for late presentation by women with breast cancer in Vietnam (Thuan et al. 2016; Tiep et al. 2015; Trieu, Mello-Thoms, and Brennan 2015).

Knowledge on the need for early diagnosis is relatively low. One study reviewed reported only 40.8% of 900 subjects cited knowledge on the need for early detection (Vach, Thuy, and Anh 2010). The Vietnam Women's Union (who have representatives in every commune in Vietnam) has been active in running programmes to increase awareness about breast cancer. They reportedly have increased monthly breast self-examination among women across five provinces between 2013-2015 from 7.7% of surveyed women to 88% (Vietnam Women's Union 2017). However, in-depth information was lacking on which specific elements of these programmes contributed to success, and how this programme was evaluated.

A study was also completed on the cost-effectiveness of CBE as a screening method in Vietnam with the aim of reducing mortality and morbidity from breast cancer (N.H. Lan, Laohasiriwong, Stewart, Wright, et al. 2013). The authors describe how CBE has been the primary screening and detection method across six provinces where cancer registries were established in 2008. A costing simulation (Markov Model) showed that CBE screening and detection were very cost-effective when compared to the WHO criteria and guidelines, with the cost-effectiveness of the screening program estimated to be US \$994.96 per life-years saved. More detailed information on CBE programmes in Vietnam was, however, not available, such as how often CBEs were conducted by doctors (e.g. through opportunistic screening) or the level of training that health staff had received on how to conduct a CBE.

### *Diagnosis*

The Ministry of Health of Vietnam developed guidelines for breast cancer diagnosis and treatment in 2013 outlining the location and facility type (level) where examinations, diagnostics and treatment are to be provided (MoH, Vietnam 2013b). Diagnostic capacity has increased across the country, with the development of six specialist oncology hospitals (public sector) and 43 oncology units in general hospitals. However, a number of challenges for diagnostics remain. A survey of the 63 provincial hospitals in 2008-2010 found that nine (14%) hospitals had no functioning pathology departments, and pathological confirmation in other hospitals could be slow and at times inaccurate (B. D. Nguyen 2010).

Six of the eight English-language articles reviewed highlighted that the overwhelming pattern is for women to be diagnosed at later stages and at younger ages than in

European countries. In one study of 129 eligible patients, 56.6% were diagnosed at Stage II, 27.1% at Stage III and 9.3% at Stage IV. About one-third (36.4%) of the women were diagnosed between the ages of 40-49 years, and another 32.6% between 50-59 years of age (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013). Similar results were shown in two articles based on the same data set of 1,584 patients (Nguyen H. Lan, Laohasiriwong, and Stewart 2013; Trieu, Mello-Thoms, and Brennan 2015). Later diagnosis was also predominant in another study where 64.2% of 4,715 new breast cancer cases diagnosed in five provinces were found at Stage III or stage IV (Dinh Nguyen 2011). Two further papers, including one retrospective study on stages of diagnosis across five hospitals in 2009, found that 49.5% of the women were diagnosed with Stage III or IV breast cancer (Thuan et al. 2016), while 67.7% in the second study were diagnosed at Stage II (J. Nguyen et al. 2016).

Stage of diagnosis is strongly correlated with treatment outcomes, with women diagnosed at earlier stages having better survival rates and fewer complications from treatment. In one study, although no significant difference was found for cost of treatment between those diagnosed at an early versus late stage of disease, the survival times were significantly longer for those women diagnosed at an earlier stage (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013).

Specific information on how breast cancer was defined across studies is limited and can be an important reason for variation in study results. In Vietnam the main means of detecting breast cancer cited in the literature include ultrasound, hemotogram, CA 15.3, tumour biopsy, or cytological tests (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013) with some women having mammography and estrogen-receptor tests, progesterone receptor tests, and Her 2-Neu tests.

### ***Treatment***

Treatment for breast cancer in Vietnam is provided largely at the national and provincial levels. Two national level hospitals, one in Hanoi (K Hospital) and the other Ho Chi Minh City (HCMC Oncology Hospital), provide the majority of specialised cancer treatment. The Ministry of Health issued guidelines in 2013 (MoH, Vietnam 2013b) that mandates that most surgical interventions should take place at provincial and national level facilities, with benign tumours treated at district level facilities.

Surgery, either stand-alone, or in combination with other treatment modalities, represented the most common form of treatment for breast cancer in the studies examined. In one study of 3,684 breast cancer cases treated between 2004 and 2008, 94% of the patients underwent mastectomy (Dinh Nguyen 2011). This finding is echoed in other studies (Nguyen H. Lan, Laohasiriwong, and Stewart 2013; N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013) that cite surgery (complete mastectomy or breast-conserving surgery) as the most common treatment, often in combination with chemotherapy, radiation therapy, and hormone therapy. Preoperative chemotherapy has also become more widely used in Vietnam to reduce tumour size prior to surgery and breast-conserving surgery. This approach has been shown to reduce recurrence rates and increase the 5-year survival rate in Vietnam from 40% to 75% (Duc 2015).

Another study revealed that 79% of the 948 women completing the study received surgery while 10% received chemotherapy (primary treatment) (Nguyen H. Lan, Laohasiriwong, and Stewart 2013). Surgery was also the main modality used for 73% of the 636 patients lost to follow-up compared to 11% who received chemotherapy as their primary treatment. Hormone therapy was offered to 75% of the group finishing the study over the five years after receiving their primary treatment (Nguyen H. Lan, Laohasiriwong, and Stewart 2013). Another study reported that tamoxifen was the most common hormone therapy (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013) although trastuzumab has also been considered as cost-effective in combination with standard treatment for metastatic HER2-positive breast cancer women in Vietnam (T. T. C. Nguyen and Nguyen 2014).

Capacity at provincial hospitals greatly varies; however, with administrators in 10 of 63 (15.8%) of provincial hospitals surveyed between 2008 and 2010 stating they could not admit and treat patients for cancer because they lacked the necessary radiotherapy equipment (B. D. Nguyen 2010). Treatment options across the country widely vary depending on geographic location, with a strong rural/urban difference (Trieu, Mello-Thoms, and Brennan 2015). Although most provincial hospitals officially provide surgical services, as of 2008 (more recent information not found), 10 of them stated that they could not offer this service and regularly referred patients elsewhere (WHO 2011).

Two studies reported a high rate of treatment non-completion, as well as a large proportion of participants who received no treatment. In one study 10.2% of eligible patients received no treatment after diagnosis (Nguyen H. Lan, Laohasiriwong, and Stewart 2013). Being married and frequent migration were two contributing factors, with marital status strongly linked to poor treatment success rates. This may relate to family dynamics, roles and expectations as outlined in Chapter 1, although further research is required. Lack of health insurance was also cited as a possibly significant predictor of treatment dropout, with 26.2% uninsured women abandoning treatment compared to 5.9% of those with health insurance (Nguyen H. Lan, Laohasiriwong, and Stewart 2013; N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013).

Health insurance coverage varies based on age and on other factors such as employment status and income level. Those working in the informal sector (34% of the workforce aged over 15) are the most likely to not have health insurance (MoH, Vietnam 2015b). In 2013 an estimated 31.5% of the population was not covered by health insurance (MoH, Vietnam 2015b). Of the 68.5% who are covered by insurance, 26% of that proportion is considered poor or 'near poor' and are in receipt of State subsidies to support their premiums (MoH, Vietnam 2015b). Sullivan et.al. examined treatment discontinuation, financial catastrophe, and out-of-pocket costs in 4,585 patients receiving surgical treatment in LMICs, including Vietnam. They reported that 73% of patients in Vietnam faced possible financial catastrophe due to costs related to receiving surgical treatment. Partial health insurance coverage, which meant women had enough coverage to begin but not necessarily complete treatment, was attributed as a principal factor in understanding this high proportion (R. Sullivan et al. 2015).

Within the current law on health insurance, cancer patients with insurance are reimbursed 80% of examination and treatment costs with the remaining 20% of costs paid out-of-pocket. For certain drugs, however, only 50% of costs are reimbursed. These include trastuzumab which can cost between 200million-800million VND per year for individual treatment (10,000 USD – 40,000 USD). Chemotherapy (Herceptin) is estimated to cost 500million VND per year (22,000 USD) (2013 figures) (MoH, Vietnam 2015b). Having to meet co-payments can therefore be highly restrictive (Vietnam Health Insurance Agency 2009a, 2009b).

#### 4.4 Discussion

This review revealed a lack of data related to detection, diagnostic and treatment services for breast cancer in Vietnam. Studies were localised and reported projects (for example related to screening) tended to be local or regional. Despite significant increases in breast cancer incidence in the past decade (Thuan et al. 2016), there is only a modest body of literature to inform decisions about the planning and provision of cancer services. Although a number of articles provided useful case study approaches, particularly around risk factors and breast cancer treatment, there are no system wide or large population-based studies that have mapped breast cancer services from detection to palliative care. More specifically, there is a need for research about how people access services, what barriers exist to receiving care, and on the quality of breast cancer care.

There are very few studies and trials on detection of breast cancer. Despite Lan identifying that ‘an early detection strategy for breast cancer should be developed to improve life expectancy of women with breast cancer in Vietnam’ (Nguyen H. Lan, Laohasiriwong, & Stewart, 2013), no papers identified interventions to improve detection. While initiatives for screening have been implemented by the Vietnamese government and other agencies, few screening programmes have been evaluated. There is additionally a need for studies that test which characteristics of detection programmes and services help to improve engagement with the medical care system and downstage diagnosis.

There are also knowledge gaps regarding the management of women with breast cancer related to where (and to whom) women present within the health system. Generally, there is a need to improve our understanding about how women with breast cancer seek help and interact with the health care system. Closing these knowledge gaps would contribute to research-informed planning and resource allocation.

The results of this scoping review suggest that primary care is under-utilised and that patients tend to seek cancer services at a tertiary care level (Duong 2015) and often when the cancer is at an advanced stage. Information about the availability of breast cancer services in primary and community care would allow targeted strengthening the health system overall. The review showed that there has been no review of levels of awareness among health professionals about breast cancer symptoms in

relation to whether health care professionals are able to conduct CBEs and appropriately refer women with breast cancer symptoms for diagnostic confirmation. A lack of information on human resources, capacity, and areas for strengthening, was a key finding within this review.

Breast cancer treatment and health system guidelines have been developed for LMICs (Benjamin O. Anderson et al. 2008; Gelband et al. 2015; R. Sullivan et al. 2015). In addition, Vietnam has developed guidelines for treatment options related to stage of diagnosis (Nguyen H. Lan, Laohasiriwong, and Stewart 2013). However, the nature and extent to which there is a good match between guideline recommendations, planned activities and service provision is not clear. The provision of good quality, safe, and timely surgery is the primary breast cancer treatment recommendation for countries with resource limitations (WHO 2008; R. Sullivan et al. 2015). It is noted that while increasing a country's surgical capacity to treat cancers is expensive, it is a more realistic option (because it is more easily incorporated into existing health systems) than scaling up chemotherapy or radiotherapy services (Gelband et al. 2015). Mastectomy remains the most available, effective basic surgery option in low income countries. In countries with radiotherapy capacity, breast-conserving surgery with radiotherapy is additionally recommended and is considered as effective as mastectomy (Gelband et al. 2015).

In Vietnam, surgical treatment is used in most cases of breast cancer. No data were found to indicate clearly that up-to-date surgical guidelines were in place and whether or not systematic, robust evaluations were regularly undertaken. There is a need to give consideration to the role of clinical audits in the health system given that 'national surgical audits are a potent method for improving systems of cancer surgical care' (R. Sullivan et al. 2015). More data on the numbers of women receiving chemotherapy and radiotherapy would be useful, as would data on treatment outcomes. This would allow forward planning by placing such data in the context of evaluating the capacity of the system to treat women with chemotherapy and radiotherapy. Data on treatment outcomes would be useful within an audit, and as a measure of success within any evaluation.

The ESMO (European Society for Medical Oncology) recommend that breast cancer treatment should be carried out in 'breast units' by multidisciplinary teams of

oncologists, surgeons, radiologists, pathologists, and where appropriate reconstructive surgeons, and psychologists (Senkus et al. 2015). While these conditions may not exist in LMICs, they represent a benchmark of best practice. Where it is not realistic to create specific cancer units, it is recommended that cancer treatment should be organised and incorporated into the existing health system, with an integrative approach linking up services across healthcare levels (Gelband et al. 2015). Consideration should additionally be given for the creation of teams of professionals working at lower levels of the health system primarily with the responsibility of breast cancer detection and referral. It is unclear to what extent this approach has been implemented in Vietnam.

International guidelines state that, 'Preoperative chemotherapy is the preferred primary treatment for locally advanced breast cancer because it allows an early assessment of sensitivity to treatment as well as breast conservation' (Benjamin O. Anderson et al. 2008). Given high costs, radiotherapy and chemotherapy may not be considered realistic treatment options in many LMICs. Where resources and facilities exist, it is recommended that they should be organised at the secondary level, making the service more accessible to patients (Benjamin O. Anderson et al. 2008). Radiation therapies should be available given their efficacy in treating early-stage breast cancer and as breast conservation treatment (Benjamin O. Anderson et al. 2008). In Vietnam, there currently appears to be little capacity to provide radiotherapy treatment and studies should explore whether or not this is a cost-effective option for treatment in the future.

Guidelines suggest that tamoxifen should be used in hormone therapy for low and middle income settings (Benjamin O. Anderson et al. 2008). Vietnam's current practice seems to be in line with this recommendation. For oestrogen-receptor positive cancers five years of endocrine drug therapy is recommended. This is realistic in low-resource settings using tamoxifen (generic). Although 'aromatase inhibitors produce better results than tamoxifen and are recommended for countries with enhanced and maximal resources', the lower cost of tamoxifen makes it a viable alternative (Benjamin O. Anderson et al. 2008). Trastuzumab is not generally considered a cost-effective option in low-resource settings (Gelband et al. 2015). However, this conclusion that is contrary to at least one of the articles returned in our literature search (T. T. C. Nguyen and Nguyen 2014).

The WHO (2013) recommended that cancer diagnostic and treatment plans (not just targets), should contain clear treatment pathways. These plans should include priority setting, quality and standards checks, information on the organisation of services, service integration, and linkages to palliative care, and the establishment of clinical guidelines for treatment. While Vietnam has a National Cancer Control Plan, it is not clear whether it incorporates systematic planning, reporting, and evaluation mechanisms. Vietnam does not have a full, comprehensive and operational cancer registry, which represents a limitation in terms of providing data to inform decisions. Only nine hospital-based cancer registries exist across the country (Thuan et al. 2016), out of 63 provincial hospitals. This shortage of data is not unique to Vietnam, and represents a challenge across many low and middle income settings (Demment et al. 2015).

Data are also sparse regarding perceptions of social and cultural barriers in relation to access to, and use of, services. No qualitative studies have been conducted on breast cancer in Vietnam. Research is required on the social, economic, and cultural determinants of breast cancer diagnosis, treatment, and survival in Vietnam particularly given the later detection rates among married women. It is likely that economic barriers such as the role of health insurance and the capacity to make co-payments play a role in late detection but there is a need for empirical studies to investigate this issue. The cost-analysis conducted by Lan (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013) did not account for direct non-medical costs (eg. travel, accommodation, and time) and indirect costs (lost income).

A population-wide cost analysis and estimation is required that includes both direct and indirect costs of treatment services and accessing them. In the absence of research on social and cultural barriers to accessing diagnostic and treatment services, studies conducted in expatriate communities may provide insights useful for designing services. There is an extensive literature on health behaviours of Vietnamese communities living in the United States and Canada that may provide entry points for further research in Vietnam (A. B. Nguyen, Clark, and Belgrave 2014; T. Nguyen et al. 2001). For example, research about Vietnamese women living in the United States shows that they are less likely to undergo clinical breast examination or mammography than American women (A. B. Nguyen, Clark, and Belgrave 2014). While language barriers (and other barriers not relevant in a Vietnamese context) may

partly explain these discrepancies, further information about other barriers and perceptions may prove indicative and may help inform research in Vietnam.

This scoping study also did not find any studies or grey literature that discussed palliation for breast cancer patients in depth. Systemic capacity appears to be lacking, especially given that as much as 70 percent of patients in oncology departments were estimated to be in late stages of cancer progression (MoH, Vietnam 2015b). Very little information on palliation exists at the lower levels of the health system, and levels of palliative care training for staff were reported as only 8% in one survey of 392 physicians (Tsao et al. 2019). Further study on this aspect of care and a fuller analysis into the capacity of the health system to respond to cancer are needed.

#### **4.5 Conclusion**

There has been limited research published on breast cancer services in Vietnam. This scoping review shows that in some areas Vietnam's cancer control and treatment strategies are in line with international recommendations for low and middle income countries (for example, in relation to surgery and hormone-therapies), while in others Vietnam does not meet international guidelines (for example having a detailed cancer control plan, systems of registration and evaluation, and population-wide cancer registries).

The development of a national breast cancer control and treatment programme should be a key priority for the Ministry of Health, incorporating systematic and nationwide screening activities to downstage breast cancer diagnosis. The Ministry of Health has identified long-term breast cancer control goals, including the extension of screening programmes and building systemic capacity for diagnosis and treatment (both in facilities and human resources) (MoH, Vietnam 2015b), but, as highlighted by Trieu et al, 'In Vietnam, despite increased health-care and public awareness, a breast cancer national control program as recommended by the WHO has not yet been established' (Trieu, Mello-Thoms, and Brennan 2015).

More research from the perspective of women with breast cancer is required, and clinicians and patients should be included in the planning of cancer control and treatment systems. Further work is required to support these processes, as well as further research investigating the different social and structural barriers that contribute

to late diagnosis and treatment non-completion. This review provided the basis for the studies presented in the following chapters. It also highlights the need for clinician and patient's perspectives to be captured and included in processes to strengthen the organisation and delivery of breast cancer services.

## Chapter 5

# Breast cancer messaging in Vietnam: an online media content analysis

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### Introduction

Understanding the academic, published and grey literature on breast cancer service delivery in Vietnam (Chapter 4) is important in order to identify research gaps, challenges to effective service delivery, and attitudes of women living with breast cancer. A fuller picture regarding popular understanding of diseases, however, may be obtained via the study of mass media. The purpose of this chapter is to map media content related to breast cancer in Vietnam; present findings from a content analysis (rank-ordered frequency counts) of common themes, and conduct an inductive qualitative analysis on media content and images.

Mass media is recognised as a crucial mechanism for health communication. Media often has a reach that greatly exceeds that of academic publications (Remler 2016). It may be used to promote health messages; while equally it may be used as a vehicle for the proliferation of misinformation about health. This nexus between the potential benefits that may ensue from well-targeted and delivered health messaging through the media, and the contrasting potential for the proliferation of misinformation on health, that makes media an important area of study for global and public health.

A content analysis of media has the potential to provide insights about breast cancer in Vietnam that are not likely to be accessed through scoping and systematic reviews of literature. In the international context of this study, it may provide information beyond the reach of English-speaking researchers and policy-makers. In contrast to academic publishing, mass media content is presented almost entirely in the local or national language of the country in which it is produced.

Content analysis of the mass media is also important for building an equitable research partnership. Global health research is often built on multi-county and international collaborations, and conducted in a language that is unknown by one or more members of the study team. This study of media in Vietnam has allowed the wider research team

to be involved in the implementation of these studies through providing a broader and more nuanced understanding of breast cancer in Vietnam.

Media content analysis approaches are not often frequently or comprehensively built into the tool kit of the global health researcher. Usually, global health researchers search academic literature and do not tend to conduct a media content analysis in a non-English speaking setting. This chapter aims to provide a comprehensive overview of messaging on breast health within the Vietnamese media, while also incorporating and demonstrating an underused methodology within global health research.

## **5.1 The Media and Health**

It is important to understand messaging in the media because of the opportunities and challenges it creates for improving population health. Primarily it is through the media that the majority of people receive messages on advice, ideas, and experiences about health. As noted in a recent article:

Many of our perceptions about health, illness, medicine and healthcare professionals are shaped by what we see, hear and read in the mass media. While our family members, peers, and educators also are strong social influence on our health perceptions and behaviours, what we learn from these sources interacts with the mass media to socialise us about health in very complex ways (Bradley Wright, Sparks, and O’Hair 2013).

The media may have profound effects not only on how the public conceptualises illness and health, but also on people’s health behaviours (McGannon et al. 2016). If we want to deeply understand a particular health issue, we must engage with how that topic is presented in the media.

Research conducted on health content in the media has shown that often the presentation, accuracy, and communication of health information is often problematic. In her analysis of ten years of health content in the media (via international communications journals published in English), Kimberly N. Kline writes, “research consistently has concluded that health-related content in popular media is problematic from a health promotional standpoint.. (and) that media representations are still suspect – fraught with inaccuracies, misleading and problematic themes, and images that stereotype and stigmatise” (Kline 2006). Shona Hilton builds on this position,

highlighting that “popular views on issues can draw on stereotypes and present simplified descriptions of problems which do not always reflect the current state of scientific evidence” (Hilton, Patterson, and Teyhan 2012).

The media is a constantly evolving industry with multiple stakeholder groups and interests. The media can be information-based, entertainment-orientated, or a combination of the two. It can be for-profit, or publically-owned, and is utilised by governments, commercial entities, charitable organisations, and individual stakeholders. Traditional media predominately used the mediums of television and print, but the creation of social media has created new networks, mechanisms, and platforms for information-sharing and seeking, and has been described as representing a “new era of health information seeking, consumption, and creation” (Bradley Wright, Sparks, and O’Hair 2013). Stakeholders in the media may hold particular political, social, or religious perspectives that may affect the agendas of different organisations. Although some news media strive for neutral-impartial style reporting, others present information from a particular political standpoint:

Although the news media often strive for ‘fair and balanced’ reporting of issues, the reporting of news stories is influenced by a variety of social, cultural, and economic factors within news organisations and news organisation personnel that can shape the way a particular story is presented (Remler 2016).

While the “new media landscape” may pose heightened challenges for health professionals, as seen through the examples of proliferation of anti-vaccination messaging in a number of countries (Stöckl and Smajdor 2017; Signorelli 2019; Ortiz, Smith, and Coyne-Beasley 2019; Krishnendhu and George 2019; Buggy 2018), many view social media as providing a potential vehicle to more effectively disseminate important information about population health and health promotion.

Advances in communication technology offer new and exciting opportunities to empower individuals and groups in relation to their health, to significantly enhance the quality of practice of health care and public health professionals, and to address inequalities in access to health information and services. In order to ensure these results, however, the use

of these technologies must be managed and directed appropriately, and technological tools must be made equitably available (Gully 2009).

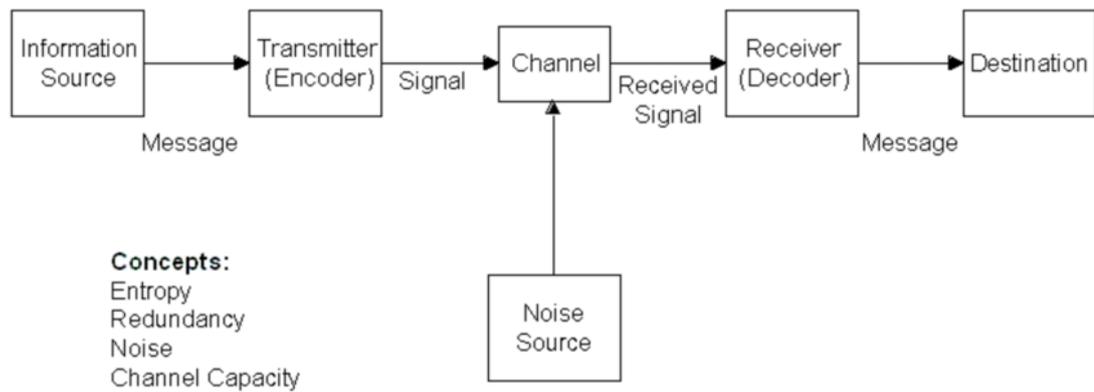
As will be discussed further in the methods section of this chapter, our study on media content related to breast cancer in Vietnam focused predominately on traditional media (newspapers), but sampled from their online platforms. Social media often links directly to these platforms, and as such the binary distinction between ‘old’ and ‘new’ media may over simplify how users move between different media platforms.

## **5.2 Theories of Media Influence**

Several theories and models have been developed and debated in relation to the dissemination, uptake and impact of information shared by the media. A broad understanding of these theories can help us better understand how to use the media to increase the uptake of health information and, in turn, promote positive health behaviour changes. To do this, a nuanced understanding of how the media operates is required. This includes information on how the media is made, interacted with, understood, and shared by consumers. This section will highlight the intersection between media and cultural studies, and introduce theories of media communication and how they manifest through real-world examples.

### ***The Transmission Model***

The Transmission or Media Communication model, as shown in Figure 5.1, was developed by Shannon and Weaver in 1948 (Fomin 2019). Telephone engineers by trade, they developed a model of communication that was linear (from information source to its destination), and influenced by five key functions and roles: the information source, the transmitter, the receiver, and the destination – all of which could be disrupted by a fifth factor of noise (external influences that influence and change the message received at the destination from that which was sent from the transmitter) (McQuail and Windahl 2013). The Transmission Model has been popular with marketing professionals and students for more than a half century because of its simplistic rationale: that the media can directly, and in isolation, influence an individual’s behaviour (for example, to buy a particular product).



*Figure 5.1: Shannon and Weaver Transmission Model, image reproduced and cited from Fomin (Fomin 2019).*

### ***Cultivation Theory***

Both the Transmission model and Cultivation Theory assume audiences are largely passive, and are malleable and impressionable to messages communicated by the media. Cultivation theory, however, argues that the media can have an impact in directly influencing how reality is constructed and presented: “in other words, cultivation theory posits that long-term repeated exposure to mass media messages shapes our understanding of the world in ways that are consistent with how reality is portrayed in the media” (Bradley Wright, Sparks, and O’Hair 2013). In relation to breast cancer; consistent, long-term media messaging (in both information/news sources, and fictionalised entertainment narratives), showing women speaking to healthcare providers about symptoms of breast cancer, may influence the long-term behaviours of women seeking early detection and diagnosis for breast cancer.

### ***Uses and Gratifications Model***

The Uses and Gratifications model posits that audiences are significantly more dynamic, variable, and active within processes of media communication than the linear passive model developed by Shannon and Weaver or the absorption effect described by the Cultivation theory. Instead of merely receiving information, people actively engage with the media to achieve certain goals: “People actively choose certain types of media and media content to gratify various psychological and social needs or to accomplish certain goals” (Bradley Wright, Sparks, and O’Hair 2013). Needs fulfilled by the media may be for information, entertainment, or for social

purposes (having knowledge of certain events or topics as boosting social capital). This model is particularly popular in the new age of media and social media in which individuals have a high degree of involvement and control over what media they consume.

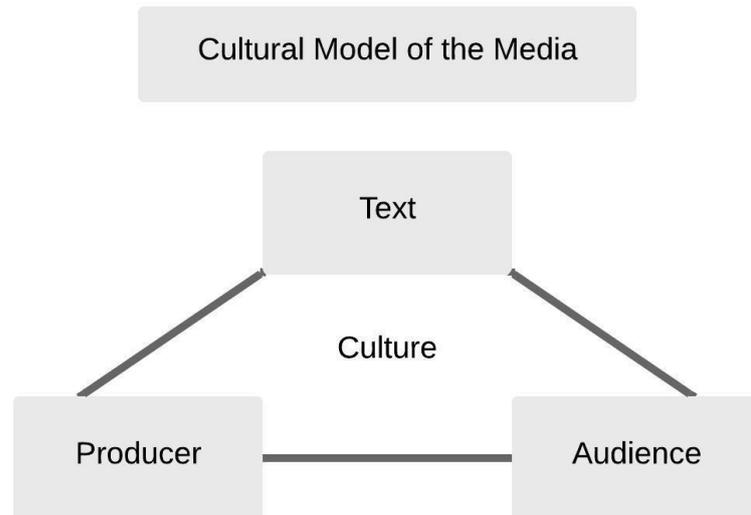
This approach to understanding the complexity and nuance of how different people engage (what uses and gratifications are they seeking to fulfil) with and use the media also helps us to appreciate variation in populations and how health communication needs to be appropriately tailored to meet the needs of different population groups. “Understanding these within-population difference allows health communicators to formulate strategies for reaching out to different segments of the population, specifically the underserved segments of the population that are less likely to have access to healthcare resources” (Dutta 2009).

### ***The Cultural Model of the Media***

Developed by Belinda and Jeff Lewis (Lewis and Lewis 2015), the Cultural model, shown in Figure 5.2, differs most significantly from the Transmission developed by Shannon and Weaver in that it is a non-linear and less deterministic model to explain the workings of media communication in informing people and shaping behaviours. Shannon and Weaver’s model is essentially a technological model, developed for the new technologies of the telephone. Whereas Shannon and Weaver contended that a communicator was in control of how information was shared and that the audience was passive in its receipt of such information, Lewis and Lewis argue for a more nuanced and complex understanding of how people interact with the media and the information they receive through it:

Cultural studies approaches to health communication acknowledge that media audiences are not passive receivers of messages, but are actively engaged in the production and adaptation of meaning. Inevitably, people generate multiple meanings from these media texts depending on their own personal experiences, significant social groups, knowledge systems, cultural practices and beliefs. They interact with media texts and their respective cultures in order to make sense of their lives and the world around them. A cultural approach explores the ways in which media-makers and audiences interact around media to actively produce meanings,

attitudes and values. Within this approach, health communication is not assumed to be a top-down, expert-led process of developing the ‘right messages’ to change the beliefs and practices of individuals. Instead, it is conceived as a process of exchange in which meanings are constantly being produced, contested and reproduced by audiences (Lewis and Lewis 2015).



*Figure 5.2: Cultural Model of the Media, Lewis & Lewis (Lewis and Lewis 2015).*

Lewis and Lewis’ model offers a nuanced theory for understanding the impact of the media, appreciating the dynamic and complex interactions that can occur between information producers, their audience and the nature of information itself. In combination with other theories, such as the Uses and Gratifications model, and the Cultivation model, we can better understand how processes within the Vietnamese media may manifest in relation to breast cancer. Lewis and Lewis’ model helps us to approach and understand health communication as more than the diffusion of information as part of a linear process. It is complex and dynamic with a high degree of variation in terms of uptake and impact.

Alongside this, we should also appreciate and be aware of the power differentials between different groups operating within the media, the audiences consuming information, and how this impacts on health. As outlined by Kimberly Kline, particularly in relation to contested information, we should consider “whose voice is privileged, why, and to what effect” (Kline 2006). Different dominant narratives and

ideologies related to socio-economic, cultural, historic, political and gendered variables influence the media in significant ways. They influence what information is prioritised within media agendas, what groups and topics within health are visible, and what health behaviours are encouraged (McGannon et al. 2016).

### **5.3 Media Content Analysis as a Methodology**

Media content analysis is a broad umbrella term for the analysis of different elements of the media in relation to a particular subject. A significant amount of work has been published on its application within health (Hilton, Patterson, and Teyhan 2012). This work focuses on systematic thematic coding of the textual content of an article based on quantitative measures of the presence or absence of a theme. For example, the thematic categories in a study on media messaging on obesity in the UK were biological factors, individual or societal drivers, and solutions (Hilton, Patterson, and Teyhan 2012).

When coding media material, headlines, stories and images can be coded with reference to their content and meanings. Much of this approach is quantitative, in that codes are tallied and analysed as frequencies related to the different objective questions and themes (e.g. how many articles mention obesity rates; diet interventions; societal inequality etc.). As highlighted by Hansen et.al. “Content analysis is by definition a quantitative method. The purpose of the method is to identify and count the occurrence of specified characteristics or dimension of texts, and through this, to be able to say something about the messages, images, and representations of such texts and their wider social significance” (Hansen et al. 1998).

However, it is worthwhile to also acknowledge the importance of qualitative analyses of text and images from media articles and items. Qualitative approaches can complement the quantitative measures employed within a media content analysis. Discourse, language, and narratives are key to understanding how a particular topic is represented, and the potential implications of that representation (Barthes 1977a). For Lupton, a “discourse analysis has the potential to reveal valuable insights into the social and political contexts in which varied discourses about health take place” (Lupton 1992). A qualitative approach, therefore, can complement and add rigour to our analysis and understanding of quantitative data.

## **5.4 Image Analysis**

“The press photograph is a message” (Barthes 1977b). Images have an incredible power and ability to communicate: “Images help us learn, images grab attention, images explain tough concepts, and inspire” (Balm 2014). Equally, image “distortion” (Hansen et al. 1998), through photo editing, cropping, inaccurate captioning, and staging has been practiced throughout history through censorship and manipulation of photographs. With the digitisation of photography and with greater availability of editing tools, the possibility for image abuse and misrepresentation is arguably greater than ever before. In other words, the “camera does lie” and often, contrary to the cliché, “a picture requires a thousand words” (Hansen et al. 1998).

The digitisation of photography, and the proliferation of stock image databases, have also created new low-cost and low-effort options for editors of media outlets and publications, in which stock images can be used to complement text content. The choices around what stock images to use can be revealing in terms of the aesthetic, social, cultural and political preferences of an editor and/or their publication. In relation to health media content, analysing these choices can provide insights into the intended meanings or messages being communicated by the media.

Visual methods for analysing the content and meaning of health media output are largely undeveloped: “Visual analysis remain relatively unused and undeveloped in comparison to the repertoire of methods and techniques deployed in relation to written and spoken languages” (Hansen et al. 1998). Since the democratisation and proliferation of digital media technology, it has become increasingly employed both as a form of data collection (through e.g. photo elicitation or autophotography) and analysis (Glaw et al. 2017). Analysis of images often follows the same thematic analysis processes used in many qualitative studies, involving structured and interpretative analysis of codes and themes (Green and Thorogood 2009).

## **5.5 A media content analysis of representations of breast cancer within the Vietnamese mainstream media**

### ***Study Objectives***

The aim of this study was to investigate and understand the content and context of messages concerning breast cancer in mainstream Vietnamese media. In particular the

study investigated what is being shared through the media (e.g. content); how was it shared (e.g. through images, testimonies, statistics etc.); was it accurate; and what could we learn about how breast cancer is understood and represented within the Vietnamese public?

### ***Methods***

Data was sourced over a twelve month period between 1 August 2017 and 31 July 2018. Online platforms of each news source were searched using the terms ‘breast cancer’ and ‘cancer’. Online news sources were chosen because they provide easily accessible and archived news content that appears both online and in print. Inclusion criteria was any media content (articles, opinion piece, pictures, advertisement), within the sample, that focused upon or included specific information on breast cancer.

Two Vietnamese researchers on the study team scored the selected articles using a data collection matrix developed collaboratively by the team. This matrix (available in the Appendix) allowed standardisation of the dataset in terms of the type of content in each article, headline, word count, and image analysis. Data were given a score of 0 (No) or 1 (Yes) on whether an article included specific thematic content (e.g. information on symptoms of breast cancer).

The data collection matrix (Appendix Item 5A) is based on previous work developed by Hilton and colleagues (Hilton, Patterson, and Teyhan 2012) to measure media content on obesity in UK newspapers. The matrix was designed to provide a quantitative overview of content concerning breast cancer in Vietnam. The research team modified this tool to include data collection boxes for key quotations, information on the ‘voice’ of people cited or referenced in each article, and to code images used in the articles. This tool enabled a comprehensive mixed-methods and hybrid approach to analysis. This approach was deemed to be the most appropriate way of both ensuring rigour and deepening our analysis, given the importance of understanding nuances in language, culture and context.

### ***Sample***

Six different news sources were selected to achieve a comprehensive overview of stories and content on breast cancer in Vietnam. These sources were chosen as they consisted of both mainstream and popular general news, and more targeted outlets for

health and women's interest and health. The sources were selected collaboratively by the research team and discussed until consensus was reached. The six sources including within our study were: Dan Tri, Vietnam Express, Vietnam Net, The People, Health and Life, and The Women.

Detailed information on readership and audience of different Vietnamese news outlets, including our chosen sources, is limited. According to a recent report from the Pew Research Centre, Vietnam has the greatest age-difference in online news users out of a survey of 38 countries. An estimated 84% of young people aged 18-29 read the news online at least once per day, compared to 51% of 30-49 year olds and 10% of those aged 50 and above (Pew Research Centre 2018). Social media use in Vietnam is high, particularly among young and wealthier people, and many people use social media as an access point for more traditional news sources. The International Telecommunications Union estimates 70.4% of the Vietnamese population uses the internet, with a high number of people having mobile phone subscriptions (147 subscriptions per 100 of the population) (ITU 2018). Nearly half (48%) of the population in Vietnam are additionally estimated to use social media to access the news at least once a day (Pew Research Centre 2018). Adult literacy rate is high in Vietnam, reported as 94% in 2009 (UNESCO Office for Statistics 2019).

### ***Data Analysis, Rigour, and Reliability of Data***

#### *Quantitative Component*

A standard operating procedure was created to ensure that data were collected in a rigorous and standardised way. Thematic checklists were created to allow frequency counting of the data across each article. Definition sheets were created collaboratively with partners in Hanoi, to improve rigour by ensuring that each theme had an agreed meaning, and that there was consensus within the study team as to what each thematic area related to. Training workshops with data collectors were conducted in which the team practiced how to input data into the matrix, highlighting any problems and confusion and allowing that to be addressed in an immediate manner. Each article was analysed as to whether the thematic area was present, with each theme being provided a score of 0 or 1 as previously described. Previously unidentified themes were captured in the 'other' section at the end of the checklist to ensure completeness of data, and recurring themes were included within the analysis.

A sample of the data collected was double coded (to check whether scores of 0 or 1 were in agreement) (32 out of 129 articles, 25%) by the two lead Vietnamese researchers on the study team. A Cohen's Kappa analysis was then conducted to assess the degree of agreement across the different codes. We followed the standard interpretation of Cohen's Kappa in which 0.01–0.20 is regarded as none to slight agreement, 0.21–0.40 as fair agreement, 0.41–0.60 as moderate agreement, 0.61–0.80 as substantial agreement, and 0.81–1.00 as almost perfect agreement (McHugh 2012).

### *Qualitative Component and Images*

Headlines and first paragraphs of each article were translated into English (See Appendix Item 5B). From this list, the research team selected a sample of articles to translate in full to use for qualitative analysis. 32 articles were selected purposively based on their relevance to the study objectives. Each article was selected through reading and scoring headlines and first paragraphs.

A coding frame was designed collaboratively by the research team, and was independently tested by each member of the team on ten randomly selected articles. The team then discussed whether the coding framework needed to be refined before being applied to the whole set of 32 fully translated articles. During these conversations, coding categories were added to the framework to provide space for data and comments on content in each article (for example, was content presented in positive or negative terms and/or tone) and any data relating to class, gender, regional or other potential biases.

The study team (2 Vietnamese researchers and 2 international researchers) independently coded the 32 translated articles, and then discussed and agreed major themes emerging from the data. The identification of key quotes by each member of the team allowed discussion on which themes were most relevant, and what should be included in the analysis. This process also allowed conversation about potential non-equivalence of translations and greater understanding for the international team on intended meanings, nuances, and context-specific meanings within translations provided. The PhD candidate collated emerging themes and led the process of data analysis. After a thorough reading of all articles and images, an image analysis framework was created (Appendix Item 5C). This included information on content of the image (medical procedure, information, diet, exercise), individuals in the image

(patient, medical professional, celebrities etc.), and whether the image was a stock image or taken for the specific purposes of the article it was included within. Specific images were selected for further analysis and to be used as examples within this chapter based on their salience and relevance to wider themes identified within the analysis.

## **5.6 Results**

A total of 129 media items were included in the analysis. Interpretation of the Kappa scores indicate relatively high levels of agreement between the two independently coded samples. With the exception of our constant scores (where one variable is constant), 12.5% of codes had no to slight agreement, 20.8% had fair agreement, 33.33% had moderate agreement, 25% had substantial agreement, and 8% had almost perfect agreement (Table 5.1.).

A frequency count of pre-specified thematic content in each article is presented in Table 5.22. The following themes were identified from both the quantitative and qualitative data: (i) prevalence of accurate and factual information; (ii) limited information concerning screening; (iii) positive coverage regarding treatment; (iv) emphasis on diet; and (v) limited personal stories or experiences. The headlines were rated as to the emotional tone of each article's headline. The majority of them (n=59, 45.7%) were rated by the team as 'neutral'; another 42 of them (32.6%) were rated as 'reassuring'; and 28 (21.7%) were rated as 'alarming'

### ***Style and Tone***

Articles tended to be largely medical and neutral in style and tone. Authoritative voices cited in the articles tended to be 'experts' (mainly medical professionals). Some of these articles referred to experts generically, for example, "as recommended by doctors, women under 50 years old with thick breast tissue forming a lump should have mammography or ultrasound to screen for cancer" (B049)<sup>1</sup>. Other articles referred to information from specific Vietnamese doctors (e.g. E025), whereas a large number of articles referred to statements made by international doctors from the US,

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<sup>1</sup> A full list of articles, translated headlines and first paragraphs are included in the Appendix. Sources are coded as: A = Dan Tri; B = Vietnam Express; C = Vietnam Net; D = The People; E = Health and Life; F = The Women.

| <b>Code</b>   | <b>Kappa Score</b> |
|---|--------------------|
| Mentions financial catastrophe related to breast cancer treatment   | 1.000              |
| Criticises the health system and healthcare providers for lack of systematic capacity to respond to breast cancer | 1.000              |
| States breast cancer rates  | 0.788              |
| Blames women for their diagnosis (for delaying speaking to a healthcare provider)                                 | 0.763              |
| Correctly identifies risk factors related to breast cancer  | 0.750              |
| Causal Factors linked to Westernisation (e.g. diet)   | 0.714              |
| Correctly identifies symptoms of breast cancer  | 0.673              |
| Mentions economic challenges for women with a breast cancer diagnosis   | 0.652              |
| Mentions social support networks for women with breast cancer   | 0.570              |
| Mentions treatment options for women with breast cancer in a reassuring tone (i.e. treatment can be curative)     | 0.563              |
| Describes what is involved in a screening procedure   | 0.540              |
| Mentions Government interventions to support women with breast cancer   | 0.529              |
| Headline Score. Alarmist. Reassuring. Neutral.  | 0.488              |
| Mentions breast cancer incidence as increasing  | 0.488              |
| Mentions traditional medicine as viable alternative to biomedical interventions                                   | 0.475              |
| Advertises pharmaceutical interventions or products for breast cancer   | 0.415              |
| Incorrectly identifies risk factors (e.g. karmic beliefs/other)   | 0.351              |
| Mentions arts-interventions to raise awareness about symptoms of breast cancer                                    | 0.351              |
| Encourages women to speak to their healthcare provider if they experience symptoms                                | 0.333              |
| Provides information on where and how to access screening services  | 0.245              |
| Mentions social challenges related to breast cancer, such as stigmatisation or experiencing discrimination        | 0.245              |
| Mentions breast cancer as a cosmetic / beauty problem   | 0.200              |
| Mentions treatment options for women with breast cancer in an alarmist tone ('deforming', hair loss)              | 0.191              |
| Mentions screening options for breast cancer  | 0.178              |
| Incorrectly identifies symptoms of breast cancer  | 0.000              |
| Blames women for their diagnosis (karmic causes)  | 0.000              |
| Mentions women with breast cancer experiencing relationship breakdown with intimate partners                      | 0.000              |
| Mentions breast cancer as a burden to the health system   | 0.000              |
| Mentions arts-interventions to reduce stigmatisation of women with breast cancer                                  | 0.000              |

\*0.000 = the constant.

*Table 5.1. Cohen Kappa Scores for doubled-coded content.*

Australia, the UK, and Singapore (e.g. C002, B049, A001). Many articles additionally included a comment or advice from the Vietnamese Ministry of Health. As discussed later in this chapter, however, the first-hand experiences of women with a breast cancer diagnosis were very rarely presented in the articles.

### ***Prevention, Risk Factors and Symptoms***

Our analysis of both the quantitative and qualitative data show a relatively high degree of coverage of factual information on breast cancer incidence rates in Vietnam (44.2% of articles); the correct identification of symptoms (33.3%); and the correct identification of risk factors for breast cancer (39.5%). In contrast, there is very little explicit misinformation circulated within our sample concerning incorrect identification of symptoms (1.6% of articles) and identifying incorrect risk factors (7.0%). Information is largely clear and accurate, as shown in the following excerpts from mass media outlets:

In order to early detect breast cancer, you must pay attention if there are any lumps on the breast, nipple deformation, fluids coming out of the nipple, redness or abnormal marks on the breast. Consult the doctor if you have any of these symptoms. (B049)

Breast cancer doesn't have any clear symptoms and requires judgement from an Oncology doctor. The symptoms may include: A lump in breast that won't disappear even after the menstruation is over; a node at the armpit may be a sign of breast cancer metastases to the nearby lymph nodes; changes in size and shape of the breast; change in breast skin and nipple colour as well as nipple excreting strange fluid. (C007)

Many of the articles used simple lists as a way of conveying information, for example "8 simple methods to prevent breast cancer" (B048) & "4 common misunderstandings about breast cancer in women" (B049). A large degree of content on prevention focused on the importance of diet, which is discussed in depth later in this chapter.

| <b>Content Code</b>   | <b>Alarming</b>    | <b>Reassuring</b> | <b>Neutral</b> |
|---|--------------------|-------------------|----------------|
| Rate Headline   | 28 (21.7%)         | 42 (32.6%)        | 59 (45.7%)     |
| <b>Content Code</b>   | <b>Coded 'Yes'</b> |                   |                |
| Mentions treatment options for women with breast cancer in a reassuring tone (ie treatment can be curative)       | 60 (46.5%)         |                   |                |
| States breast cancer rates  | 57 (44.2%)         |                   |                |
| Correctly identifies risk factors related to breast cancer  | 51 (39.5%)         |                   |                |
| Mentions screening options for breast cancer  | 49 (38.0%)         |                   |                |
| Encourages women to speak to their healthcare provider if they experience symptoms                                | 45 (34.9%)         |                   |                |
| Correctly identifies symptoms of breast cancer  | 43 (33.3%)         |                   |                |
| Advertises pharmaceutical interventions or products for breast cancer   | 42 (32.6%)         |                   |                |
| Causal Factors linked to Westernisation (eg. diet)  | 35 (27.1%)         |                   |                |
| Mentions treatment options for women with breast cancer in an alarmist tone ('deforming', hair loss)              | 29 (22.5%)         |                   |                |
| Provides information on where and how to access screening services  | 27 (20.9%)         |                   |                |
| Describes what is involved in a screening procedure   | 23 (17.8%)         |                   |                |
| Mentions social support networks for women with breast cancer   | 23 (17.8%)         |                   |                |
| Mentions breast cancer incidence as increasing  | 21 (16.3%)         |                   |                |
| Blames women for their diagnosis (for delaying speaking to a healthcare provider)                                 | 13 (10.1%)         |                   |                |
| Mentions Government interventions to support women with breast cancer   | 12 (9.3%)          |                   |                |
| Mentions social challenges related to breast cancer, such as stigmatisation or experiencing discrimination        | 11 (8.5%)          |                   |                |
| Mentions traditional medicine as viable alternative to biomedical interventions                                   | 10 (7.8%)          |                   |                |
| Incorrectly identifies risk factors (eg. karmic beliefs/other)  | 9 (7.0%)           |                   |                |
| Mentions women with breast cancer experiencing relationship breakdown with intimate partners                      | 9 (7.0%)           |                   |                |
| Mentions breast cancer as a cosmetic / beauty problem   | 8 (6.2%)           |                   |                |
| Mentions arts-interventions to raise awareness about symptoms of breast cancer                                    | 8 (6.2%)           |                   |                |
| Mentions economic challenges for women with a breast cancer diagnosis   | 7 (5.4%)           |                   |                |
| Mentions arts-interventions to reduce stigmatisation of women with breast cancer                                  | 7 (5.4%)           |                   |                |
| Mentions financial catastrophe related to breast cancer treatment   | 4 (3.1%)           |                   |                |
| Criticises the health system and healthcare providers for lack of systematic capacity to respond to breast cancer | 4 (3.1%)           |                   |                |
| Incorrectly identifies symptoms of breast cancer  | 2 (1.6%)           |                   |                |
| Mentions breast cancer as a burden to the health system   | 1 (0.8%)           |                   |                |
| Blames women for their diagnosis (karmic causes)  | 0 (0.0%)           |                   |                |

Table 5.2. Frequency counts of pre-specified content in media article (n=129).

### ***Media content on screening***

More than one third of articles (38.0%) mention screening for breast cancer, however, less than half of these articles (17.8% of the total sample) describe what is involved in a screening procedure. Only 20.9% of articles mention a location where women could access screening services. Many of the articles target their information to both younger and older women, highlighting that women of all ages can be affected by breast cancer.

In other countries, the average age of being diagnosed with breast cancer is 60-65 years old. However, according to experts, in Vietnam the average age of getting breast cancer is only 40-50 years old. In some cases, the patients are diagnosed when they are still very young. (A010)

Information on self-examination is a frequently included topic, and many articles provide very detailed instructions on how a breast self-exam should be conducted. For example:

About 80-90% of breast cancer patients have a tumour which could be found by hand when its size is above 1 cm. Many women were able to find these breast abnormalities through daily self-examination at home. Breast self-examination at home should be conducted 5-7 days after one's period is over, as the breast would be very soft, meaning it could be easily and accurately checked. The steps are quite simple, you just need to remove your bra and stand in front of a mirror with decent lighting, and observe the shape of your breasts. Lift your right hand above your head, use your left hand to check your right breast. Press and work around in circle from the nipple to the armpit to see if there's any abnormalities, then do the same with the other breast. Finally, repeat those steps in the lying down position and see if there's any fluid coming out of the nipple. (A011)

Self-screening is the most important method in breast cancer early detection. Women should make the habit of performing self-screening once every month, best after menstruation as this is the time the breasts are the softest. Continue to perform screening periodically even postmenopausal. (B043)

Information is additionally given regarding screening procedures such as mammography and ultrasound. Despite the more realistic affordability of a clinical breast examination for many women (mammography is expensive, and screening is currently not covered under the health insurance model), very little information is given on scheduling an appointment with a doctor and what is involved in a clinical breast exam.

As recommended by doctors, women under 50 years old with thick breast tissue forming a lump/tumour should have mammography or ultrasound to screen for cancer. Mammography gives quite accurate results, is simple and cheap, and may identify the tumour before you can feel it by hand. However, in order to determine if it's breast cancer or not, it may require further tests. (B049)

### ***Media content on treatment***

Media coverage concerning treatment is largely positive, with more articles discussing treatment in reassuring terms (emphasising curative aspect of treatment) (46.5%) rather than articles discussing treatment in alarmist terms (focusing on factors such as pain, hair loss, scarring etc.) (22.5%). Equally, the headlines of articles were more likely to be reassuring in their tone (32.6% of articles), rather than alarming and sensationalist (21.7%). Neutral or factual headlines were the most common (45.7%). Examples include the following:

Many breast cancer patients said they've heard scary stories regarding radiotherapy, however, several recent studies mentioned that their experiences were much better. Research on 300 women who had radiotherapy showed that half of them had heard of "scary" stories during the treatment. However, only 2% agreed that the stories were true. In fact, more than 80% of the patients said their experience with radiotherapy was "less fearful" than they expected. Researchers said studies' results showed the public still have incorrect concepts about the "modern" radiotherapy. (A014)

Instead, 84% said their side-effects – including skin issues, pain and exhaustion – were less severe than they thought. The same portion found

their treatment had little effect on their work and lives than they had feared. (A014)

Experts says that an operation to remove the tumour and preserve the breast at an early stage makes the women more confident, result in a faster recovery and fewer complications. It also doesn't require breast restructure surgery and has the same survival rate as removing the whole breast. (A011)

As with the presentation of information on other stages of the cancer journey, the articles tend to have a factual and detailed approach to describing specific processes. In relation to radiotherapy, one articles describes the process as:

There is no need for the patient to be anesthetized. A computer-control system will be connected to the tubes which are put on the chest. The system will send a small amount of radiation, or the "radioactive particles" into all tubes at the same time. The patient will be able to feel the particles moving into the tubes, but there wouldn't be any pains. The doctors will be in the next room and are able to monitor and communicate with the patient through a TV screen. The radiotherapist will remove the tubes after the final radiotherapy session. (C007)

Coverage about treatment was not universally positive, however, with articles (often focusing on the experiences of non-Vietnamese women) highlighted problems with misdiagnosis, mistreatment, and negative impacts of treatment such as pain and infertility.

Mixing up test results, the doctors removed both of (name anonymised<sup>2</sup>) (USA) breasts, while she didn't have cancer. (name anonymised) (USA) never thought she would be in such an awkward situation. Having been informed that she has genes causing cancer, the 36-year-old mother excepted to have her uterus and both her breasts removed. Only afterward that she found that she was completely healthy. (B039)

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<sup>2</sup> My edit. Names not anonymised in original Vietnamese articles

Having pregnancy-associated breast cancer, (name anonymised) must have her right breast removed, experience painful chemotherapy sessions as well risk infertility. (B051)

A similar story of a non-Vietnamese woman undergoing mastectomy after a hospital administrative error was reported in B029: “Breast removed due to doctor mistaking test result with breast cancer patient”, in relation to a 46-year old woman from the UK.

### *Lifestyle, Diet & Exercise*

As referenced in Chapter 1, and further discussed in Chapters 5 and 6, diet is centrally important in how many people in Vietnam conceptualise health, disease, prevention and treatment. This was also reflected in the media articles examined within this study. Although diet was not one of the topics to be screened for with our quantitative matrix, following our qualitative analysis we conducted a frequency count on all articles. We found that over one-quarter (27.6%) of the articles explicitly referenced lifestyle factors such as diet in relation to prevention, treatment or recovery:

In order to reduce the risk of getting breast cancer at a young age, you must recognise the importance of having a healthy diet through including green, fresh vegetables in your daily meal and avoiding substances such as liquors or cigarettes. (A010)

While the genetic, natural factors could not be changed, women can still prevent the disease through proper diet and doing daily exercises. A diet rich in vegetables, fruits, low fat should be the focus. Green pepper, sweet potatoes, garlic, tea, dark-green vegetables, wild salmon, and nuts are the food women should have daily. They are rich in anti-oxidant, and are able to eliminate abnormal cells, preventing cancer from occur. Soy bean and fermented milk are also among the foods that can prevent breast cancer. (B048)

The foods which are the kryptonite of cancer and are good for patients. The 8 meals mentioned in the following article should be remembered if you want to improve your immune system and prevent breast cancer: garlic, orange, mango, salmon, green tea, sweet potatoes, pomegranate, seaweed. (C012)

While much of the information on a balanced diet is important, reducing alcohol, maintaining exercise, and other information is often inflated or exaggerated in terms of benefit or certainty within current research. Examples include articles with the following headlines: “High-risk of breast cancer for women lacking Vitamin D” (F005) and “Eating cruciferous vegetables helps decreasing the risk of breast cancer” (E009). Other articles present information in which there is a largely undeveloped evidence-base, for example, “Stay away from bread if you have breast cancer” (C004). Toxicity of food is a common concern in Vietnam, possibly linked to food safety scandals, increased urbanisation, and potentially linked to the legacy of the Vietnam War.

Reduce contact with toxic environments: toxins exist all around us, even when we can't see them. Reduce taking toxin in your body by using clean, organic and natural food. Periodically detox yourselves by: eating vegan food, or drink juice to detox your liver, kidney, and improve your digestive system (A013).

### *Personal stories and experiences*

While there is relatively high coverage of factual information about breast cancer symptoms, screening, diagnosis and treatment options in Vietnam, there is a noticeable lack of personal stories and experiences of women with breast cancer. Very few of the articles we examined mention specific challenges faced by women undergoing breast cancer treatment in Vietnam (discussed further in Chapter 5), such as economic challenges (5.4% of articles), experience of financial catastrophe from paying for treatment (3.1%), facing social stigmatisation or discrimination (8.5%). Only 7.0% of articles mention intimate relationship breakdown, and only 6.2% mention the aesthetic impact of treatment and challenges it creates for women. Only a small portion of personal stories captured in our media content search show the importance of these themes. While these stories were fewer in frequency, they were longer and more in-depth than many of the other articles. They also tended to focus on the positives of a woman's experience and/or response to breast cancer. One article presented excerpts from an interview with a woman who gave four pieces of advice for anyone women undergoing breast cancer through treatment:

The first word is spirit. The patient must keep a high spirit, stay happy, not breaking down or feel depressed; the second is exercises; the third is medicine, abiding to the treatment the doctor provided; the fourth is diet, diverse yet balanced in order to stay healthy (F009).

Not all stories from women were as positive. As in the case of one woman who was interviewed about on her experience of breast cancer, her story was presented specifically to try and raise money to support her treatment costs. She is quoted as stating:

I just worry that should anything happens to me, who would my mother and daughter rely on? Life is harsh, and I just got tangled in it. The disease causes me pain, but thinking about the future of my family is even more painful. I don't know if I would have enough money for the coming treatment and operation? (A001)

Another, positive campaign highlighted in Dan Tri, focused on a photographic campaign by designer Li Lam, and the launch of her photographs as part of the “Always a woman to me” campaign. The article again focuses on life after breast cancer, and the maintenance of a positive and healthy attitude and self-perception. Li Lam states:

The production of the album “Always a woman to me” to honour the mothers and the women in general in hope of communicating the message: “In any situations, a woman, even without her hair or breasts, is still a mother, a wife. All women should love and be confident with their looks, and shine in their own way. From which loving themselves and lives will come naturally (F006).

This type of art and arts-based intervention are an additional mechanism through which women's stories can be shared, but their lack of coverage within the articles we examined (6.2% of articles mentioning arts-based interventions to raise awareness of symptoms, and 5.4% to reduce stigmatisation), shows another potential area for growth. Significantly, many of the articles identified by our study that did highlight personal stories focused on the experiences of Western women and Western celebrities (e.g. Angelina Jolie, Kylie Minogue, and Shannen Doherty), not Vietnamese women,

as shown in the previous section regarding misdiagnosis and medical errors for women in the USA and the UK.

### *Analysis of Images*

Only four of the 129 articles in the dataset did not include any images. A total of 237 images were analysed. Of these articles, the majority 56% (n=133) were coded as being stock images (e.g. not being taken for specific use within the article, but most likely sourced off image databases or archives), while 44% (n=104) were coded as original images taken for the specific purposes of illustrating the article.

There was a relatively high concentration of images featuring white women within the articles, with 21% of images featuring at least one white women in the context of either a patient or a women conducting a self-exam. Of these images, 7% (n=17) featured white people in non-medical photos (e.g. eating or exercising), 5% (n=12) featured white medical professionals and 10% (n=23) featured white Western celebrities. However, this number is skewed by one single article having 20 photos of Western celebrities who had a breast cancer diagnosis.

In comparison, 22% (n=51) of the images featured Vietnamese women who had a breast cancer diagnosis. However, 3 articles accounted for 25 of these images, showing the relatively sparsity and lack of visibility of Vietnamese women across our entire sample. Of these images, 5% (n=12) showed Vietnamese people in non-medical photos (e.g. eating or exercising), and 6% (n=15) featured Vietnamese medical professionals. Only 3% (n=6) featured Vietnamese celebrities with breast cancer. Differences were also shown in relation to images of white women conducting self-exams (5% of images, n=12), compared to Vietnamese women conducting self-exams (0.05%, n=1). Other findings include a relatively large number of photos (mainly stock images) showing food (12%, n=28), and images in the form of medical graphics or scans (8%, n=18).

Examples of positive imagery include pictures taken by Vietnamese photographer Li Lam as part of the previously cited mother's day campaign 'Always a woman to me' supported by the Vietnam Breast Cancer Network. The images of patients and survivors of breast cancer are empowering, using fashion and photography as a medium to tell stories about the experiences of women, and to communicate the message that women do not lose their femininity and beauty after breast cancer

treatment. A small number of articles focusing on positive experiences of Vietnamese women (e.g. F009) used positive and empowering photographs showing images of women living full and happy lives following breast cancer diagnosis and treatment.



*Left: Image from F006: Shine like a star even without one's hair and breasts*

*Right: Image from F009: The miraculous journey of a female journalist overcoming breast cancer*

Other articles use empowering images as part of breast cancer campaigns, for example, Pink Fighters (F013) showing women with breast cancer in boxing rings, in fighting poses.



*Left: Image from F016: 14 women show their naked breasts full of scars to raise awareness on breast cancer*

*Right: Image from F013: "Pink fighter" to prevent breast cancer*

Other articles cover campaigns conducted in non-Vietnamese contexts, for example an American campaign in which women who had undergone breast cancer surgery participated in a photoshoot, showing the scars from their surgeries (F016), using a positive and empowering tone throughout. With the exception of one image, all images showing a woman doing a breast examination were of white women. The photos were highly stylized, airbrushed, and non-informative in terms of how to conduct a breast self-examination. This will be discussed further in the Discussion section.



*Left: Image from A013: What do women need to do in order to prevent breast cancer?*

*Right: Image from B031: Women who get breast cancer earlier in life may have high risk of recurrence*

Images of white women in other articles (e.g. A002 highlighting the risk factor for breast cancer of being underweight), present a similarly stylised and sexualised form of white women's bodies.



*Image from A002: Risk of breast cancer due to being too thin earlier in life*

Images showing Vietnamese women in medical contexts tended to be more formal and technical than other images, for example, showing interactions between Vietnamese women and healthcare providers.



*Left: Image from B043: 8 hospital provides free breast cancer screening for patients*

*Right: Image from E022: Ha Tinh Young Doctor Association: Free breast cancer screening for 500 women*

Shocking and negative images rarely appeared within the articles analysed (similar to the tone and content of many of the articles retrieved). However, articles that did include shocking or sensationalist content often presented distressing images (e.g. A001 & F004 below)



*Left: Image from A001: The desperate situation of female breast cancer patient living with old mother*



*Right: Image from F004: 24 years old nurse had her breasts removed after 9 relatives got cancer (Image not anonymised in original, due to concern regarding consent in original image)*

## **5.7 Discussion**

This chapter presented data on newspaper stories and accompanying images that help shape popular understandings of breast cancer in Vietnam, as presented through the mass media. Findings show that information about breast cancer in Vietnam tends to be factual. There does not appear to be widespread proliferation of misinformation in the mainstream media, other than some stories that may overemphasize the power of diet and nutrition in preventing or recovering from breast cancer. As with other studies presented in this thesis, diet and nutrition are important factors associated with how health is conceptualised in Vietnam. Of more concern, perhaps, is a lack of specific information on screening, including how to do a breast self-examination, and a lack of visibility regarding the lived experience of women with breast cancer in Vietnam. Such stories may offer the potential to increase awareness and normalise discussions on breast health.

To our knowledge, very few media content analyses have been conducted in relation to breast cancer. The studies that have engaged with this topic tend to be focused on high-income contexts. These articles highlighted a number of findings and themes present in our own analysis of breast cancer media messaging and content in Vietnam. Andsager and Powers (1999), for example, refer to the difference in content related to breast cancer in U.S. news-based and women's magazines during the 1990s. Women's magazines tended to focus on personal stories and in-depth comprehensive information about challenges women may experience, whereas news-based magazines focused more on prevention, treatment, economic implications and research:

Economic interests tend to influence journalists' framing of women's health issues. The news media seldom focus on social and/or human interest angles in reporting cancer news, with less than 7 percent of newspaper coverage on cancer comprising human interest stories, such as personal survival or coping stories (Andsager and Powers 1999).

Another similarity with findings from this study in Vietnam, highlighted by McGannon and colleagues in their work on breast cancer representations in Canadian

media, was the sexualisation of women used in media campaigns to prevent breast cancer, and the metaphor of ‘war’ and women as empowered is their ‘fight’ against cancer (McGannon et al. 2016). As McGannon highlights, “Such messages are problematic because they overemphasise young women’s breast cancer risk through objectifying women’s bodies, draw upon fear appeals, and alienate women who do not align their identities with such portrayals” (McGannon et al. 2016).

The language of war and the struggle against cancer have long been critiqued as over-emphasising the role of the individual in the successful treatment of cancer, and consequently shaming individuals and families who ‘lose’ the fight by insinuating they didn’t ‘fight’ enough. Our study in Vietnam, along with other studies presented in this thesis, show the difficulty in accepting this argument when women describe such metaphors as empowering and motivating. In a cultural context in which Vietnamese women have historically played very significant roles in military campaigns (Viên 2015), perhaps these metaphors hold a particular appeal.

A question raised by this media content analysis concerns the disconnection between information shared in the media regarding breast cancer risk factors, symptoms and expectations for treatment, and reported knowledge by women in the study presented later in this thesis (Chapter 5). Despite the largely factual and accurate reporting about breast cancer in the mass media, knowledge and awareness about breast cancer is generally poor. This raises questions about the medium, focus, and delivery of content. It also perhaps highlights the limitations of mainstream media in communicating health promotional messages to at-risk populations.

A particular gap in the media content is the lack of stories focusing on the nuanced, complex circumstances and stories of Vietnamese women’s experiences of breast cancer. Our analysis of the type and style of media stories on breast cancer in Vietnam, revealed that most articles fall into the ‘Transmission model’ (Shannon and Weaver) of media communication, in that they convey a simple, factual and linear message to communicate information that can improve knowledge. However, increased knowledge in itself is not sufficient to change behaviours that reduce the impact of breast cancer, namely, better detection through self-breast examination, attending screening programmes, and early detection.

These findings suggest the value of working with newspaper editors to explain why publishing more nuanced and personal stories from Vietnamese women could be helpful. The Cultural Model developed by Lewis and Lewis (Lewis and Lewis 2015) in which meanings are produced, contested and reproduced, and in which a more robust conversation about how breast cancer is experienced and understood could be integrated into new approaches.

The simultaneous recognition of the difficult impacts of a breast cancer diagnosis on the individual, along with role modelling and the presentation of women as strong, valued, and important in spite of their diagnosis, could be further developed by the media, and may be useful in helping women overcome fears of stigmatisation and the aesthetic impacts of treatment. A relative lack of stories and content featuring Vietnamese women specifically suggests a lack of visibility for individual women and their experiences, and represents an area for potential growth and focus. Sharing more women's experiences in a positive and supportive way has untold possibilities to build a space in Vietnamese society and families that is fully inclusive of women facing the struggles of a breast cancer diagnosis and its aftermath.

Historically, cancer has been seen as a foreign disease, associated with high-income and Western countries. The extent to which the Vietnamese media perpetuates this idea is revealed in this study. Breast cancer remains something that is largely 'othered' through a high concentration of stories on Western women and Western celebrities. Such 'othering' may contribute to Vietnamese women not feeling as if the content presented in the media is directly applicable to them, and thus the behaviours of self-examination and speaking to healthcare care providers should they experience a symptoms, being not relevant.

Results of our analysis of images showed a similar relative lack of visibility of Vietnamese women, particularly images of women conducting breast self-exams. The conservative nature of Vietnamese culture may explain the preference of news organisations to use images of white women, particularly if the image reveals intimate areas of the body. As highlighted by Kline and by McGannon, gendered expectations and norms may explain the lack of images of Vietnamese women (Kline 2006; McGannon et al. 2016). 'Othering' was also expressed in the images of white women analysed, given their stylized, airbrushed, and sexualised nature.

Regarding the media content on screening, more articles focused on mammography than clinical breast examinations. Given that clinical breast examination is more accessible and affordable for many women than a mammography, research should be conducted on whether women know what to expect from a clinical breast examination, and what factors may prevent or discourage them from seeking an examination.

## **5.8 Conclusion**

This chapter and study provide valuable data and insights about the popular context of how breast cancer is presented in the Vietnamese media. Although information is largely accurate, there is a marked lack of stories about Vietnamese women's personal experiences. Such stories could help bridge the gap between what information about breast cancer is presented in the Vietnamese media, and what women in Vietnam understand about breast cancer risk factors, symptoms, screening and treatment.

This chapter has attempted to present and apply an underused public health methodology in the context of a global health issue. It is hoped this approach, and the rationale for undertaking it, are incorporated into the methodological toolkits and training of global health researchers.

## Chapter 6

# Breast Cancer Service Delivery Challenges from the Perspective of Healthcare Providers

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### 6.1 Introduction

Previous chapters have highlighted how the Vietnamese healthcare system is structured in relation to the control and prevention of NCDs, and for breast cancer specifically. No studies have thus far been conducted, however, that attempt to understand and analyse the delivery of breast cancer services from the perspective of healthcare providers, exploring questions concerning the capacity of the primary healthcare level to detect and refer, diagnose and treat. This chapter provides an overview of a mixed-methods study undertaken across all four levels of the Vietnamese healthcare system in three provinces and two metropolitan areas with the objective of identifying challenges and addressing the current lack of information on detection, diagnosis and treatment from the perspective of healthcare providers.

Following the Scoping Review of literature presented in Chapter 4, to further understand the possible challenges and research gaps concerning breast cancer services delivery in Vietnam, and to inform the development of our mixed methods study, a series of key informant interviews were conducted between December 2016 and March 2017. These interviews focused on the structure of the Vietnamese health system, specifically in relation to breast cancer services and how women with breast cancer are managed.

A framework for conducting key informant interviews in developing countries, designed by Krishna Kumar (Kumar 1989), provided the basis for the structuring of the interviews. Kumar's framework was also a useful tool in considering the process of interviewing, which she describes as equally "an art and a science". Kumar's framework emphasises the need for focused yet flexible key informant interviews that are systematically analysed, and provides a holistic overview on the importance of ordering of questions, establishing trust and rapport, conducting interviews with translators, and maintaining neutrality throughout the interview.

Key informant interviews were conducted in both English and Vietnamese depending on the preference, fluency and comfort of the informants being interviewed. Translation, if required, was conducted by members of the research team from HUPH. An interview guide (Appendix Item 6a.) was designed for flexibility and information gathering in a context in which very little information on the topic could be gathered from international literature. The study took a highly iterative approach, and key informant interviews were designed with the intention of gathering information, insights, and advice on areas where future projects and studies should focus.

Our key informants constituted a broad range of individuals from Government ministries, international organisations, NGOs, and academics. Meetings were organised with representatives from the Ministry of Health, the World Health Organisation (WHO), the National Institute for Cancer Control, clinicians at the K Hospital (Specialised Oncology Hospital) in Hanoi, representatives from the Women's Academy, and a meeting with a representative from the National Cancer Institute (U.S.) was conducted via Skype. Additional meetings were held with members of breast cancer support networks, mainly based in Ho Chi Minh City.

Notes were taken immediately after each meeting, and sent for comments and revision to researchers at HUPH. Thematic summaries of these meetings were made in and used to inform the focus of the study. The findings of these key informant interviews further indicated and informed the need for focused research on services provision across different levels of the Vietnamese healthcare system.

## **6.2 Methods and Protocol Development**

Informed by the scoping review and key informant interviews, the study presented in this chapter used a concurrent nested (embedded) mixed-methods approach (Cresswell and Plano Clark 2017). Data were collected through a self-administered survey (n=69) and in-depth interviews (n=23) with a subset of health professionals who worked at facilities across all four levels of the Vietnamese health system (national, provincial, district, commune). The study gathered data from three provinces, representing the northern, central, and southern regions of the country, and from Hanoi for a metropolitan comparative.

A mixed methods approach was considered to be the most appropriate methodology to achieve the wide-ranging and ambitious objectives of our project; in providing both

quantitative data on the quality of breast cancer services, and qualitative data to deepen understanding of different challenges that exist in providing these services.

Mixed methods studies focus on “collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies. (Their) central premise is that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone” (Cresswell and Plano Clark 2017). There are many ways of combining quantitative and qualitative approaches. An initial quantitative data collection tool (survey) was used, before organising in-depth qualitative interviews with a sample of the study population to validate and authenticate results, and to deepen our knowledge by asking for more detail on the responses provided in the interviews.

The survey was modelled on the Service Availability and Readiness Assessment (SARA) tool developed by the World Health Organisation (WHO 2015) and on previous modifications of the tool used in studies in Vietnam (Duong 2015). The modified tool (Appendix Item 6a) used the SARA template and modified it to examine services related to a single disease (breast cancer). SARA aims to provide data for policy makers to make informed, evidence-based decisions about the planning and delivery of health services and is used to gather information about service availability, readiness, and service-specific readiness. Service availability is defined as ‘the physical presence of the delivery of services and encompasses health infrastructure, core health personnel and aspects of service utilization’. Service readiness is ‘the availability of components required to provide services, such as basic amenities, basic equipment, standard precautions for infection prevention, diagnostic capacity and essential medicines’. Service-specific readiness is ‘the ability of health facilities to offer a specific service, and the capacity to provide that service measured through consideration of tracer items that include trained staff, guidelines, equipment, diagnostic capacity, and medicines and commodities’ (WHO 2015).

Following guidelines on designing surveys (Jackson and Furnham 2000), key informant interviews were conducted and the review of available literature on breast cancer services in Vietnam presented in Chapter 4 was carried out. Survey items were generated for each of the three SARA-based domains for the modified version of the survey, items were organised in the survey to reflect the six building blocks of health

systems developed by the WHO (WHO 2017). These are: leadership/governance; health care financing; health workforce; medical products and technology; information and research; and service delivery. An interview guide (Appendix Item 6B) was additionally developed for use with a subset of healthcare providers who completed the SARA survey.

### ***Pilot Testing***

The survey and interview guide were pilot tested in Bac Giang and Dong Thap provinces, interviewing representatives from the provincial hospital; representatives from two District hospitals; and representatives from two commune health stations in each province. The purpose was to receive feedback on the wording of questions, ordering, format, the content of the surveys, and to use the information provided on breast cancer services in each facility to inform the type of follow up questions asked during the interview stage of the study.

Through pilot testing, and through feedback and collaboration both within the research team and with other key informants, some of the language used in the survey was adapted to ensure that it was context-appropriate. The term ‘activities’ is used throughout the questionnaire tool instead of ‘services’. In Vietnam the word ‘services’ has the connotation of a ‘paid for’ service. Given that some of the screening programmes and awareness programmes are offered free of charge, the word ‘activities’ was chosen to avoid confusion. For example, what screening activities are offered in this area?

Other examples of changes made to the original SARA instrument related to questions about medical examinations and patient management. In Vietnam the term ‘consultation’ is generally understood to be a free service, while ‘examination’ is understood as a paid service that is covered by insurance. The term ‘management’, in relation to patient management, also has different connotations in Vietnam than in the UK. In the original data collection tools this term was used to try and understand the holistic management of patients, to include detection, diagnosis, referral, treatment and record keeping. In Vietnam the term ‘management’ is often understood only in terms of ‘treatment management’ and therefore caused confusion. During the pilot testing of the instrument, respondents from commune and district level facilities were skipping sections on management because they felt these questions only referred to

treatment. A decision was taken to replace the term with, ‘patient referral and record keeping’, to reflect the type of holistic information sought in the section.

A training session was held to ensure the research team were familiar with the data collection tools (the survey tool and interview guides). This training also allowed researchers to practice interviewing; and provide training on qualitative methodologies and researching techniques. A Standard Operating Procedure (SOP) (Appendix Item 6D) was additionally developed for use by the entire team throughout the study. The SOP was designed to give an overview of the research, to consolidate all the necessary interview guides; to provide background information and additional literature on qualitative methodologies; and to provide clear, standardised procedures and protocols for consent, data entry, and data storage.

The pilot study indicated a lack of operational capacity across the health system to provide breast cancer services, and a range of different potential barriers preventing women from accessing services. The pilot studied allowed the research team to get a better sense of what type of procedures are offered in different facilities. For example, clinical breast examination being offered sporadically at both the lower and upper levels of the health system, and ultrasound capacity being limited at the lower levels of the system.

The study tool was appropriately modified in terms of language (as already outlined), and revisions were made to the order, instructions and introductions section, and layout, at the recommendations of the participants within the pilot study.

The pilot exercise was additionally useful to familiarise the researchers with the hospital spaces that are central to this study. As described by Livingston (Livingston 2012) in her ethnographic study in an oncology ward in Botswana, the space in which healthcare services are delivered is worthy of examination. The research team learned about the complexity of patient pathways (shown in Photo 6.1), and the role of the health insurance system from the posters and information board in the hospitals. Additionally, the team were able to ask informal questions to doctors outside of the formal interviews on tours that they provided of their facilities.



Photo 6.1: An information board in a district level hospital showing the different procedures and processes for patients with health insurance (on the left) and patients without health insurance (on the right). Photo credit: Savannah Dodd. 2017.

### Sample Size and Sampling Techniques

Three relatively homogenous provinces (in terms of household income, ethnic group and population size) (Bac Giang, Hue, & Dong Thap) that are representative of the non-metropolitan provinces in northern, central and southern regions (Table 6.2) were included in the study. In addition, facilities in Hanoi were surveyed in order to capture a profile of breast cancer services in a metropolitan urban setting and to facilitate a comparison with service profiles in less densely populated settings.

|  | Bac Giang   | Hue   | Dong Thap   |
|--|---|---|---|
| <b>Area (square miles)</b>   | 382,739.93  | 506,527.92  | 337,637.03  |
| <b>Population</b>  | 1,554,131   | 1,087,420   | 1,666,467   |
| <b>Population:<br/>Urban/Rural<br/>Ratio</b>   | 145,745/1,408,386<br>(1:10)   | 391,112/696,308<br>(1:2)  | 295,959/1,370,508<br>(1:5)  |
| <b>Monthly income<br/>(unit: 1000 VND)<br/>1USD = 22,700 VND<br/>(December 2017)</b> | Total: 1103.2<br>5 quintiles<br>402.9<br>629.8<br>905.7<br>1247.1<br>2340.0 | Total: 1058.3<br>5 quintiles<br>329.7<br>638.3<br>876.1<br>1220.2<br>2235.6 | Total: 1138.0<br>5 quintiles<br>333.7<br>635.1<br>871.7<br>1199.0<br>2657.4 |

*Table 6.2. Demographic information on sample provinces (General Statistics Office of Vietnam 2014; Ministry of Health, Vietnam 2014)*

Multi-stage cluster sampling (Bryman 2008) was performed to select health facilities at national, provincial, district, and commune level. In each province, staff at the provincial hospital was surveyed and two districts were selected randomly. In turn, the district hospital and 10 commune health stations within each district were selected via random sampling. All communes were selected in districts that had fewer than 10 communes. Sample size calculation was based on pragmatic assessment of how to maximise use of resources available to facilitate the study. A purposive approach was taken in order to capture data from a range of facilities and key informants. Table 6.3. presents the number of facilities at each level in which staff were surveyed. In total, Bac Giang has 9 districts; Hue has 8 districts; and Dong Thap has 11 districts.

|                        | <b>Number of health facilities at each health system level where staff were surveyed using the modified SARA form</b> |                  |            |                  |              |
|------------------------|---|------------------|------------|------------------|--------------|
|                        | <b>Hanoi</b>  | <b>Bac Giang</b> | <b>Hue</b> | <b>Dong Thap</b> | <b>Total</b> |
| National Hospital      | 1   | 0                | 1          | 0                | <b>2</b>     |
| Provincial Hospital    | 0   | 1                | 1          | 1                | <b>3</b>     |
| District Hospital      | 0   | 2                | 2          | 2                | <b>6</b>     |
| Commune Health Station | 0   | 20               | 19         | 19               | <b>58</b>    |
| <b>TOTAL</b>           | 1   | 23               | 23         | 22               | <b>69</b>    |

*Table 6.3. Sampling Plan: Number of health facilities at each health system level.*

Interviews were conducted with a subset of staff at each of the national, provincial and district facilities that received a survey. In addition, two commune health stations per district were chosen randomly for an interview. The purpose of the interviews was to broaden and deepen the data requested in the survey, verifying information and accuracy, and providing a quality check (Cresswell and Plano Clark 2017). Examples of questions included: what do you think are the biggest challenges or barriers facing women when seeking breast cancer services; what challenges do you and other staff face in trying to meet the needs of women with possible breast cancer or a confirmed diagnosis; and what training has the staff at this facility received in the last 12 months on breast cancer diagnosis, treatment, referral etc. (who provided this training, was it

useful, and how could it be improved). A total of 23 interviews were conducted (Table 6.4.), each lasting between 45 and 90 minutes.

|                        | <b>Number of health facilities that participated in research interviews</b> |                  |            |                  |              |
|------------------------|---|------------------|------------|------------------|--------------|
|                        | <b>Hanoi</b>  | <b>Bac Giang</b> | <b>Hue</b> | <b>Dong Thap</b> | <b>Total</b> |
| National Hospital      | 1   | 0                | 1          | 0                | <b>2</b>     |
| Provincial Hospital    | 0   | 1                | 1          | 1                | <b>3</b>     |
| District Hospital      | 0   | 2                | 2          | 2                | <b>6</b>     |
| Commune Health Station | 0   | 4                | 4          | 4                | <b>12</b>    |
| <b>TOTAL</b>           | 1   | 7                | 8          | 7                | <b>23</b>    |

*Table 6.4. Sampling Plan: Number of health facilities where staff were interviewed*

### ***Participants***

Senior healthcare providers in managerial positions (director of facility, vice-director, or head of oncology department) completed the survey at each selected facility and participated in interviews at a subset of facilities. Our response rate for both our survey and interviews was 100% within our targeted sample. To protect participant anonymity demographic information was not collected on the participants in our study, although 14 of the 23 interviewed healthcare providers reported the length of time they had been working in healthcare (mean 17 years, range 3-32 years).

### ***Data Collection and Analysis***

A Standard Operating Procedure was designed for all data collection, storage and analysis. Surveys were sent to all selected health facilities and after one week a member of the research team travelled to each facility to physically collect the survey. If the survey had not been completed when the member of the research team came to collect it, the member of the research team would support the designated member of the health facility to complete the survey, and would assist in providing any clarity needed. Support provided focused on following and understanding instructions in survey. Specific training was given to each research team member on how to appropriately provide advice and support on completing the survey, and how to avoid leading respondents in how they answered the questions.

In facilities randomly selected to take part in interviews, the research team would also conduct interviews with senior healthcare providers during the same visit. Two female Vietnamese researchers conducted the interviews. All interviews were audio-recorded with participants' prior consent.

Data from the surveys were inputted into SPSS for statistical analysis. Qualitative data were thematically analysed by the research team. Transcripts were translated, back-translated, and codes to analyse the qualitative data were identified. The data were discussed, categorised and collaboratively analysed by members of the research team following standard procedures for qualitative data analysis (Green and Thorogood 2009).

### 6.3 Results

The results of this study are presented with specific attention to how they corresponded to the areas of service availability and service readiness, with reference to the WHO's six building blocks for health systems (WHO 2017). Following an overview of responses to our survey, a thematic analysis will be presented alongside a discussion of the main sub-themes emerging from both our survey results and our qualitative interviews. Responses to the survey (Table 6.5) are provided by staff working at the district and commune level facilities only. Given the small number of participants within our study working in national and provincial level facilities, to maintain anonymity their responses are only presented within the thematic discussion and review of qualitative data.

#### *Service Availability*

In relation to breast cancer the availability of breast cancer services at lower levels of the system is limited and variable. Specialised services are only available (and only authorised by the Ministry of Health) at the higher-level facilities in the Vietnamese health system (national and provincial levels).

| Service                                 | Provided | Facility Type  |                |
|---|----------|----------------|----------------|
|   |          | District (n=6) | Commune (n=58) |
| Health Promotion<br>(awareness raising) | Yes      | 5 (83.3%)      | 52 (89.7%)     |
|   | No       | 1 (16.7%)      | 6 (10.3%)      |
| Training to self-examine                | Yes      | 4 (66.7%)      | 42 (72.4%)     |
|   | No       | 2 (33.3%)      | 16 (27.6%)     |
| Clinical Breast Examination             | Yes      | 6 (100%)       | 34 (58.6%)     |

|  |                                       |                   |                    |
|--|---------------------------------------|-------------------|--------------------|
|  | No                                    | 0 (0%)            | 24 (41.4%)         |
| Opportunistic Screening  | All the time                          | 1 (16.7%)         | 8 (13.8%)          |
|  | Sometimes                             | 1 (16.7%)         | 25 (43.1%)         |
|  | Rarely                                | 1 (16.7%)         | 7 (12.1%)          |
|  | Never                                 | 3 (50%)           | 13 (22.4)          |
|  | Missing                               | 0 (0%)            | 5 (8.6%)           |
| Ultrasound   | Yes                                   | 5 (83.3%)         | 3 (5.2%)           |
|  | No                                    | 1 (16.7%)         | 55 (94.8%)         |
| Diagnosis (pathological confirmation)  | Yes                                   | 0 (0%)            | 0 (0%)             |
|  | No                                    | 6 (100%)          | 58 (100%)          |
| Treatment  | Yes                                   | 0 (0%)            | 0 (0%)             |
|  | No                                    | 6 (100%)          | 58 (100%)          |
| Palliative Services (inc. use of morphine)   | Yes                                   | 4 (66.7%)         | 13 (22.4%)         |
|  | No                                    | 2 (33.3%)         | 45 (77.6%)         |
| <b>Resources/Training</b>  |                                       |                   |                    |
| Do you have the staff, resources, and equipment to provide all breast cancer services you are authorised to provide? | Yes                                   | 3 (50%)           | 33 (56.9%)         |
|  | No                                    | 3 (50%)           | 22 (37.9%)         |
|  | Missing                               | 0 (0%)            | 3 (5.2%)           |
| Cancer and breast cancer training provided to staff at the facility  | Yes – General Cancer Training         | 3 (50%)           | 24 (41.4%)         |
|  | Yes – Breast Cancer specific training | 1 (16.7%)         | 10 (17.2%)         |
|  | No                                    | 2 (33.3%)         | 24 (41.4%)         |
| <b>Community Screening</b>   |                                       |                   |                    |
| Supports community-based screening activities  | Yes                                   | 3 (50%)           | 44 (75.9%)         |
|  | No                                    | 3 (50%)           | 11 (19.0%)         |
|  | Missing                               | 0 (0%)            | 3 (5.2%)           |
| <i>If YES, what roles are undertaken? (percentage as total percent / valid percent)</i>                              |                                       |                   |                    |
| Lead the operation   | Yes                                   | 2 (33.3% / 66.7%) | 13 (22.4% / 29.5%) |
|  | No                                    | 1 (16.7% / 33.3%) | 31 (53.4% / 70.5%) |
|  | Missing                               | 0 (0%)            | 14 (24.1%)         |
| Technical support (supporting the actual delivery of screening services, lead by a higher level health facility)     | Yes                                   | 2 (33.3% / 66.7%) | 4 (6.9% / 9.1%)    |
|  | No                                    | 1 (16.7% / 33.3%) | 40 (69.0% / 90.0%) |
|  | Missing                               | 0 (0%)            | 14 (24.1%)         |
|  | Yes                                   | 0 (0%)            | 32 (55.2% / 72.7%) |

|   |         |                   |                       |
|---|---------|-------------------|-----------------------|
| Administrative support<br>(advertising screening,<br>patient registration etc.) | No      | 3 (50% /<br>100%) | 12 (20.7% /<br>27.3%) |
|   | Missing | 0 (0%)            | 14 (24.1%)            |

*Table 6.5. Overview of results from survey*

None of the surveyed district hospitals or commune health stations offer breast cancer diagnostic or treatment services, however one participant in our interviews described that their district health facility could provide simple surgical procedures (such as lumpectomy). While all district facilities reported the ability to conduct clinical breast examination (CBE) and five reported conducting ultrasound tests (83.33%), in reality most participants within our interviews described breast cancer services and care at district and commune levels of the health system as minimal. CBE is often only provided at district facilities when requested and to those with a family history.

At the higher levels of the health system, all three provincial hospitals surveyed reported breast cancer diagnostic capacity. In relation to treatment, only two of the facilities could perform surgical interventions (mastectomy and breast conserving surgery) and chemotherapy. Radiotherapy services were only provided in one of the three provincial hospitals surveyed. Overcrowding and a lack of beds were reported at all upper levels of the health system and a number of respondents at higher levels of the health system also reported a lack of human resources capacity, with either insufficient numbers of staff, or insufficient training and knowledge of staff concerning breast cancer. One doctor at a provincial health facility summed up the challenges, stating:

In short, it's only me. I do my best to do screening and surgery. And once a week I will be available at the clinic on Tuesday mornings to examine breast cancer patients and to do screening. When I diagnose someone having cancer, the nurses are shocked and sad, as if the patients will die for sure. They do not understand. I am sad that even staff of a provincial hospital think like that.

The shortage of trained staff was communicated by respondents across the health system. At commune level there is often only one doctor per facility, meaning if that doctor is absent, ill, or on leave, then services will be reduced. At higher level facilities shortages put pressure on staff to deliver services effectively and restrict the amount

of time that can be spent interacting with patients. A respondent from a district facility highlighted this problem in relation to providing self-examination training to women, stating, “Sometimes there are too many patients. There is about 100 patients per day. If there is time we will instruct them, otherwise we wouldn’t”.

Given the potential sensitivity of breast cancer, and the invasiveness of procedures to detect, diagnose and treat, there may also be challenges concerning male doctors conducting these procedures. It was described that often a women’s preference would be for a female doctor to conduct these procedures and examinations, and yet at some facilities there were insufficient numbers of trained female staff. One district level facility reported just one female doctor with the training to conduct CBE.

The provision and availability of screening services appears to vary widely across the sample. In some areas screening activities appear to be implemented with a wide range of health care facilities involved in their delivery. Both national level facilities surveyed reported conducting and/or supporting community-based screening activities. One facility reported leading the operation, while the other reported providing administrative and technical support. One respondent from a national level facility reported that staff from the hospital would directly provide screening services (CBE only) at commune level facilities (10 per year) while also training staff at lower levels of the system to conduct examinations independently. The respondent also stated that many screening services were offered directly at the hospitals, with different organisations invited to bring their staff and members for screening.

At provincial level, two of the three surveyed facilities reported active involvement in community screening programmes, and both reported to be leading the operations. District hospitals in one province described organising three screenings per year, with an additional screening organised by a higher level facility every year (funding dependent). In another province, the provincial level facility reported supporting community-based screening four or five times every year. The senior healthcare provider from the provincial hospital reporting no involvement in screening stated, “We’ve never organised a programme coming down to the communities”, and that they were also unaware of any other organisations conducting screening programmes in the province.

This trend of facilities from higher levels of the health system leading in the implementation of screening programmes is commonly reported, with the role of the lower levels of the system to support in organisational, administrative and technical aspects of screening. This includes recruitment, advertising, and providing the venue for screening to be conducted. In total, at commune level, 75.9% of respondents stated that they had been involved in community-based screening activities. However, only 6.9% reported having a technical role in the screening process (for example, supporting examinations). A number of communes (24.1%) stated there were no screening programmes for breast cancer at all in their area.

### *Service readiness and service-specific readiness*

Although services may be available at different levels of the Vietnamese health system, resource constraints both in terms of equipment and a lack of capacity of staff to detect, diagnose, and treat breast cancer were frequently reported across all levels of the health system. Shortages in staff availability is often compounded by a lack of service-specific trained staff. In terms of equipment and physical resources, broken or old ultrasound machines, or ultrasound machines without the capacity to screen the breast, were reported at both commune and district levels. At higher levels of the health system a shortage of equipment was described particularly in relation to radiotherapy capacity. A lack of educational materials was reported particularly at commune level, which restricted the ability of staff to implement health promotional activities.

Analysing the ability of the commune level to provide screening and detection services revealed that only 58% of respondents (n=58) said that they offered clinical breast examination to women attending the clinic. For opportunistic screening, 14% reported that they ‘always’ conducted opportunistic examinations; 43% stated ‘sometimes’; 12% ‘rarely’; 22% ‘never’; and 2% ‘don’t know’. Key informants and study participants involved in our data verification process, however, felt that reporting on the frequency of both clinical examination and opportunistic screening may be exaggerated. Respondents in every interview stated that opportunistic screening does not occur. There was general consensus within the research team that the term ‘opportunistic screening’ was poorly understood throughout the interviewing process.

A lack of women presenting with breast cancer was a theme reported at commune level, and while most of the commune level staff surveyed reported providing self-examination training (72.4%), the commune health stations role within the health system in regards to breast cancer appears to be limited to occasional CBE on the request of the patient; health promotional activities; and supporting the higher levels of the health system in administrative and logistical tasks if a screening outreach programme is implemented in the area.

Consistently respondents from commune health stations stated that women with breast cancer do not present at their facilities. “We don’t see patients. We were trained by the Ministry of Health (to conduct CBE) but there were no patients who came for examination”. Another respondent stated, “It takes a very long time for someone to come for an examination. Sometimes it can be two months without doing one”. One respondent stated that in the six years they had been working at the commune level there had never been a breast cancer patient in the area. This illustrates the level of disconnection between the commune level and women with breast cancer. Our data suggests that the commune level of the health system is regularly bypassed by women with breast cancer symptoms or diagnoses, either due to its lack of capacity to provide services, or because women are aware that the services they require are located at the higher levels of the health system.

A lack of training in regards to both breast cancer broadly (at commune level) and more specifically on how to diagnose and treat breast cancer (district and provincial Levels), were evident themes in both our survey and interviews. At commune level there are particular challenges related to levels of knowledge and awareness of staff about breast cancer, including symptoms and treatment options. One respondent commented on the lack of training for staff at the facility, stating: “Years ago we did have training on breast cancer. But it was a very long time ago. I can’t remember when it was. Recently, there has been no training about breast cancer”. Another respondent said, “Our capacity and knowledge is limited. How can we help others to provide the correct information?”

Another respondent from a commune health station noted that while it was unlikely that staff would be expected to provide specialised knowledge, it was still important to have a general understanding about breast cancer symptoms and the diagnostic and

treatment pathway. Given that a women's first interaction with the health system may be at commune level, staff need to recognise breast cancer symptoms and respond appropriately. The respondent stated:

Being the jack-of-all-trades, we are not specialised in anything, but it's important to update our information regularly to always know of the basics to be able to consult the patient in the best possible way.

In relation to screening activities, challenges were reported related to transporting the necessary equipment for screening, meaning that most screening activities were only CBE. Therefore, while screening may be available, it is not being supported with appropriate or sufficient physical infrastructure. By conducting screening within commune health stations, problems were also reported relating to having enough private rooms for examinations.

### ***Geographic Variations***

As previously reported, at the provincial level there are variations in the availability of services particularly in relation to surgery, chemotherapy and radiotherapy. No specialised services (surgery, chemotherapy, radiotherapy) were reported in Dong Thap. Surgery and chemotherapy were only reported at two of the three surveyed provincial hospitals, while radiotherapy is only offered at one.

At district level, variations across many services were reported. For example no facilities in Hue reported providing palliative care services, while all facilities in both Bac Giang and Dong Thap reported have provision for palliative care. All facilities in Hue, however, reported having enough staff, resources, and equipment to provide services for breast cancer effectively in comparison to none in Bac Giang, and one of two in Dong Thap. Neither facility in Dong Thap reported involvement community-based screening activities.

Commune health stations in Hue province reported higher services availability and readiness than both Bac Giang and Dong Thap. All nineteen commune health stations in Hue reported supporting community screening activities, while in Bac Giang and Dong Thap seven communes and four communes reported taking no part in community screening activities. Communes in Hue provinces equally reported higher availability of training provided to women on self-examination (84.2%), and having

enough staff, resources and equipment to provide effective services (68.4%). All other services were reported equally across the three provinces. This variation between different regions of the health system may be interpreted as indicating that there is a need to give considered attention to the allocation of resources and, generally, to try to ensure that there is a good match between needs for care and service availability.

### ***Participant views on Priorities for Breast Cancer Service Strengthening***

Priorities for how to improve breast cancer services followed directly from the challenges reported in the survey and described in the in-depth interviews. In our survey we asked three variants on how respondents would improve breast cancer services. We asked for general recommendations; the ‘easiest to implement’ recommendation; and the ‘most important’ recommendation to improve the delivery and organisation of breast cancer services. All the questions were open (blank box) and respondents were encouraged to give multiple responses.

Increased availability of training about breast cancer detection, diagnosis and treatment was commonly prioritised across all three variants in the survey. A total of 44 (total n=69) respondents mentioned strengthening capacity and training in the general recommendations section, with 17 and 18 respondents respectively recommending human resources strengthening and training in the ‘easiest to implement’ and ‘most important’ variants of the question. ‘Training’ was described in broad terms at commune level, from training on how to conduct a CBE, to providing training on using ultrasound, to training on communication skills for health promotional activities. At district level and provincial levels the focus was on how to strengthen the facility’s capacity to conduct more specialised procedures. A number of respondents highlighted strengthening service-specific capacity at district hospitals to conduct pathological tests and more complex surgical interventions.

Other commonly reported general recommendations were to extend community-based screening and/or create an annual screening programme (n=29); to improve and increase communication on breast cancer to promote awareness of symptoms (n=25); and to focus on the provision of more specialised equipment (often ultrasound machines) to the lower levels of the health system (n=13). The need to develop community-based screening, either standalone or aligned to pre-existing programmes on cervical screening, was strongly emphasised. Discussing the need for screening

outside of formal healthcare facilities, one clinician stated that, “If we have screening in the community women will feel more comfortable. They need someone to listen to their concerns and provide proper counselling for them”. It was felt that screening programmes need to be better financially supported, and that healthcare providers organising screening events could make better use of International Women’s Day and Vietnamese Women’s Day to promote breast cancer screening activities.

#### **6.4 Discussion**

Three interconnected themes were identified within our thematic analysis of the data: a lack of breast cancer service availability and service-specific readiness across all levels of the health system; a lack of capacity and resource to provide breast cancer services; and a lack of systematic and integrated population screening services. Together these findings indicate the need for systems strengthening and integration. Comparing our results to the WHO’s building blocks for health systems (WHO 2017) (governance; financing; workforce; technologies; information and research; and service delivery) suggests there are opportunities for strengthening across all six areas.

At a governance level, holistic systems planning and piloting of interventions should be further explored in the strengthening of breast cancer services in Vietnam, as should the development of a strategic breast cancer control and treatment plan. The Ministry of Health has outlined within its strategic plans for the control and prevention of NCDs (MoH, Vietnam 2015d) the objective of reorganising systems ‘for prevention, early detection, diagnostics, treatment and management of NCD from central level to commune level nationwide’, and that ‘90% of commune health stations and equivalent health care facilities (should) have enough essential equipment and drugs for prevention, detection, treatment and management of relevant cancers’ (MoH, Vietnam 2015d).

With the proper resourcing and capacity-building it has also been recommended by the Breast Health Global Initiative that many breast cancer services can be provided outside of central high-level facilities with appropriate skills-building training to detect breast cancer being provided to the general healthcare workforce (Benjamin O. Anderson et al. 2008). In Vietnam, while some training has been provided to staff at lower levels of the health system to detect and diagnose breast cancer, there remains

a need for systematic capacity-building at commune and district levels to sufficiently support breast cancer service provision.

The current vertical and central organisation of breast cancer services in Vietnam may limit accessibility and effectiveness. Most clearly, the overcrowded nature of oncology units studied at provincial and national levels indicate the need to diversify where women with breast cancer are treated within the system. Extending of the roles and responsibilities of district and commune health stations (with the appropriate support to these facilities to provide services), and investing in rural health infrastructure (Shillabeer 2016), could have a significant impact on improving breast cancer services. As stated by Yiengprugsawan et.al. in their study on reorienting the delivery of NCD services in Malaysia, Sri Lanka, and Thailand, ‘NCD care requires integration across all levels of health care: primary care screening of risk factors; timely intervention at secondary and sometimes tertiary and rehabilitation levels, and hospital discharge referrals back for management by primary care’ (Yiengprugsawan et al. 2017).



*Photo 6.6: A waiting area in Ho Chi Minh Oncology Hospital showing levels of overcrowding. Photo credit: Carolyn Taylor, presented at Global Health Symposium Belfast 2019 and reproduced with permission.*

Enabling lower level facilities in the Vietnamese health system to conduct breast examinations and breast cancer diagnostic tests may have a positive impact both in terms of reducing indirect costs and travel for women in rural districts while also reducing overcrowding in central and provincial hospitals. Although capacity-building for NCD and cancer control has been supported by the Ministry of Health, additional work needs to be done to ensure that services provided at lower level facilities meet the requirements of women with breast cancer. This will help discourage women from bypassing these facilities in favour of seeking diagnostic and treatment services at the central and national levels of the health system.

The results of the survey and interviews indicate that there is a need to give particular attention to ways in which to develop cancer services at commune and district levels to increase their visibility, proximity and access. Ideally, detection, screening, and referral services for breast cancer at the lower level of the health system should be provided as a comprehensive and integrated package, with specialised services provided by well-resourced and multidisciplinary teams at higher levels of the health system (Senkus et al. 2015).

Results from this study point to the immediate need for training and skills development to increase capacity of the workforce to diagnose and treat breast cancer. This priority has also been recognised in previous publications from the Ministry of Health and WHO (MoH, Vietnam 2015b; WHO 2011), is highlighted within the WHO's health systems strengthening frameworks (WHO 2017), and is also supported by studies that interviewed healthcare providers at commune health stations in Hanoi (Vu Duy et al. 2018). This strengthening of human resources should happen systematically and simultaneously with other efforts to strengthen breast cancer services across all six areas of the health system. The study indicated that healthcare providers at the lower levels of the system want to be given more autonomy, responsibility, and skills to contribute to detection, diagnosis and treatment activities.

The decentralisation of health systems in low and middle income contexts has been a significant trend in health systems reorganisation for forty years. In their systematic review of literature on decentralisation, Muñoz (et.al) (Muñoz et al. 2017) state, 'Experiences suggest the decentralisation of governance, financing and service-availability, could have positive impact on the system'. While challenges were noted

in decentralising resource management and that qualitative data suggests a ‘heterogeneous picture’ concerning impact, the authors argue ‘lessons learned from the decentralisation processes in LMICs suggest that factors such as adequate mix of technical skills at the local level to perform decentralised tasks, effective decentralisation of decision-making to the periphery, and political leadership are key factors for a successful decentralisation process’ (Muñoz et al. 2017).

A more systematic and strategic approach to screening should be explored. Screening was reported as ad hoc, localised, and infrequent by many participants in our study. Dong Thap province reported an absence of screening activities, and the health inequalities this may create should be addressed. Even the most systematically organised programmes, described by a respondent from a national facility, only reach an estimated 10 communes per year. There may be problems with the funding model for screening. Most screening activities are conducted by national or provincial level hospitals, the costs of which come from their autonomous budgets. This may limit scope. There is no central fund or allocation of money to conduct screening. The quantity of screenings conducted is dependent on how much money individual hospitals are able or willing to contribute towards them. One respondent described screening programmes as ‘charity’ from the hospital. Centralised planning and funding of screening programmes should be further explored, and population-based models for breast cancer screening should be developed (Harper 2011).

The overall picture is one of disjointed, unintegrated community/population screening supported in an ad hoc fashion by the upper levels of the health system. There needs to be a more coherent, integrated and systematic approach to screening across the country. As one respondent from a commune station, when asked about the strategy for breast cancer screening, responded, “I mean, there’s no plan for breast cancer screening”.

Furthermore, there is a need for integrated and robust financing structures to support breast cancer services. Economic barriers to accessing services were described as significant by multiple participants within the study, and as previously discussed, there is a lack of central financial planning for screening services. Given the complexity with the insurance system, the Ministry of Health has initiated changes to streamline patients into the central levels of the health system. While this may make for more

efficient patient referral pathways, it may also contribute to the overburdening of the top levels of the system. In the past, in order to claim health insurance, patients had to progress through the health system in a linear sequence. Often, patients would bypass the primary levels, going directly to tertiary care. If they needed extensive treatment, they would then return to the commune level and go through formal referral. A new Government directive (MoH, Vietnam 2015a), made it possible for patients to bypass the commune level and enter at district level. While in some ways this avoids duplication of work, and provides flexibility in an otherwise rigid linear system, it may also further contribute to the underutilisation of primary level health services. This may additionally compound the lack of capacity at primary levels to provide breast cancer detection and referral services.

This study provides empirical data to help inform decisions on the future direction of breast cancer service provision in Vietnam. More comprehensive data collection, and monitoring and evaluation systems would be invaluable for breast cancer systems strengthening. As noted in previous studies and chapters, Vietnam still lacks a comprehensive and integrated national cancer registry (Harper 2011), representing a further gap in terms of health system strengthening. Health financing studies, and qualitative studies that explore the experience of women with breast cancer in accessing and using screening and treatment services would be equally useful and important. Systems strengthening for breast cancer should also consider the knock-on impacts of strengthening a specific service, and be conscious of how improvements in one area can either benefit or harm services in other parts of the health system. It is important to remain cognisant that ‘all systems are contained or nested within larger systems’ (WHO & Alliance for Health Policy and Systems Research 2009).

## **6.5 Limitations**

The survey tool, while developed with extensive testing through two pilot studies, was still unable to capture as much information as hoped. Returned surveys were received with incomplete data on certain sections. This is perhaps due to the lack of information held at each facility. Due to the lack of systematic data collection of patient records, many of the questions were answered using estimations by those completing the survey, and therefore only represent broad benchmarks for, e.g. frequency of opportunistic screening.

Due to the limited sample size it was not possible to test with confidence whether findings, particularly at the upper levels of the health system are reflective of specific geographic trends or patterns. The small sample size prevented in-depth analysis of any variations of geographic differences between the North, Central, and Southern regions.

## **6.6 Conclusion**

This study suggests that there is a need to strengthen lower levels of the Vietnamese health system in relation to the detection of breast cancer. Provision of some services such as clinical breast examination, advice on self-examination, and conducting ultrasound tests (supported with appropriate training and capacity-building of healthcare providers) at commune and district levels of the health system may reduce the overcrowding and service-delivery burden experienced in provincial and national-level hospitals. Empowering lower levels of the health system to conduct breast cancer screening, which is currently undertaken on an ad hoc basis through higher-level facilities, is likely to improve access to services for women. Strengthening and extending screening services should only take place when capacity to treat has been improved and barriers to treatment reduced.

## Chapter 7

# The Experience of Women with Breast Cancer in Vietnam

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### 7.1 Introduction

This study investigates the previously unexamined experience of women with breast cancer in Vietnam along different points of the diagnostic and treatment pathway. Previous studies have indicated increased challenges for Vietnamese women and the health system posed by non-communicable diseases, and particularly breast cancer given that it often is diagnosed in later stages (Nguyen H. Lan, Laohasiriwong, and Stewart 2013; N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013; Thuan et al. 2016; Trieu, Mello-Thoms, and Brennan 2015). Research presented in Chapter 6 using survey and interview data from healthcare providers has indicated that there is a need for breast cancer systems strengthening across all levels of the Vietnamese health system. Despite the growth in research within this field, no qualitative research has yet been published on the specific experiences, needs, and challenges of women with a breast cancer diagnosis in Vietnam.

This absence of qualitative data from the perspective of women is a significant barrier in achieving effective planning of breast cancer services. Women's experiences are poorly understood. No research has been conducted on the specific challenges women in Vietnam experience. No studies have sought to describe or interpret these experiences.

Studies from other low and middle-income countries on the needs and challenges of women with a breast cancer diagnosis has shown common themes of fatalism, avoidance, lack of knowledge, and lack of access to health services. Additional themes concerning cultural attitudes towards health, decision-making and identity all contribute (to different extents in different contexts) to late stage diagnosis, and difficulties in accessing and using treatment services (Barthakur et al. 2016; Hajian et al. 2017; Xiong et al. 2016) (Full Table in Appendix).

The objective of this study was to examine the specific factors affecting women's experience of detection, diagnosis and treatment in Vietnam, with the aim of

improving knowledge about the experiences of women with breast cancer. Results were analysed within the framework of the Model of Pathways to Treatment developed by Scott et.al (Scott et al. 2013), and data collection was informed with reference to phenomenological methodologies (Taylor 2013; McWilliam 2010). Building upon Anderson's et.al. Model of Total Patient Delay (B. L. Anderson, Cacioppo, and Roberts 1995), Scott outlines multiple non-linear 'events' that occur within the pathway to treatment, and the impact of different processes that affect the duration of different stages or intervals. These events, processes, intervals and contributing factors provided the coding framework for the study and thematic analysis.

By using Scott's framework, this study and chapter attempts to capture the full and holistic nature of a women's experience of breast cancer, from knowledge and awareness of symptoms, through to management, recovery and/or palliation. By providing such rich data on the entirety of a women's or experience, it is hoped that this chapter contributes to a better understanding of the challenges experienced by women along the treatment pathway. Following a presentation of common themes experienced along the treatment pathway, the chapter then highlights key contributing factors (accounted for within Scott's model) that impact on type of experience a women may have. These factors include economic barriers, challenges in accessing health services without full insurance coverage, and geographic challenges in accessing centralised and urbanised health services. This chapter represents the first qualitative study on the experience of women with breast cancer in Vietnam to date, and it is hoped that it contributes to the magnifying of women's voices within debates on service delivery and reform.

## **7.2 Methods**

This study is characterised as a descriptive qualitative study (Sandelowski 2010, 2000), concerned with the "comprehensive summary" and the "who, what and where" of a particular experience, and reflects the choices and combinations of sampling, data collection, and interpretative techniques used within this study. Such a descriptive methodology is useful in attempting to provide unfiltered information from women in their experiences, before an analysis of the major crosscutting themes and factors that impact upon those experiences.

The research team conducted semi-structured in-depth interviews with thirteen women with a breast cancer diagnosis in Vietnam. Two interviews were organised with each woman, with the purpose of using the second interview to validate and deepen findings from the first interview, improve rigour, and to allow for trust and relationship building. This was important given the highly sensitive content shared by the participants in this study. The research team was comprised of two Vietnamese female researchers, and the candidate, an international, English-speaking, male. The candidate's role was in leading the design of the study, including interview guides, consent documentation, identifying theoretical frameworks within which to conduct the study, and providing qualitative training to the research team. The two Vietnamese researchers, given their positionality and the sensitive nature of the content of the study, were best placed to conduct the interviews.

Following each interview the entire team would meet to discuss the content of the interview. This would be audio-recorded. The purpose of this initial analysis and debrief was to additionally allow for reflection within the research team on the content of the interview, and to afford the opportunity to ask questions and probes about the content of interview. As highlighted by McMahon and Winch, structured systematic debriefing helps strengthen collaborative global health qualitative research by enhancing quality and trustworthiness of data (McMahon and Winch 2018). The results of these discussions informed the structure and content including probes for each individually-tailored second interview guide.

Detailed notes and audio-recordings from these research team meetings were taken and used to help ensure accuracy and rigour. A rapid analysis framework was also used to structure these discussions and to aid initial data analysis (Appendix 7H) This initial analysis also served the purpose of allowing the two Vietnamese researchers leading the interviews to reflect upon and discuss interviewing style and technique; and to allow reflection and discussion amongst the research team on aspects of the interview that wouldn't be captured in the transcripts, for example, tone of conversation, implied meanings of statements, and body language. Second interviews took place approximately two to three weeks following the first interview. Given the short period of time between interviews, structured debriefing was considered the most useful way of informing the second interview guides, rather than waiting for full verbatim transcripts.

### *Data Analysis and Analytical Framework*

Data was analysed with reference to Scott's Pathways to Treatment model (Scott et al. 2013) (Figure 7.1). Events are defined by Scott as the "key time points" along the pathway and include, the detection of bodily change; development of a perceived reason to consult with a health care provider (HCP); first consultation with HCP; diagnosis; and the start of treatment. Between events are different processes and intervals. Patient appraisal and self-management, decisions around help-seeking, processes of referrals and appointment making, and the scheduling of treatment all play roles in the pathway to treatment. Contributing factors, identified by Scott et. al. as 'patient factors' (including demographics, co-morbidities, social and cultural determinants), health system factors (accessibility and service delivery), and disease factors (growth rate, site, size etc.) all additionally impact on the pathway to treatment. This holistic model is suitably broad and flexible, and provides a good framework through which to analyse the results from our study, however, it may be limited in that it doesn't account for the socio-political context or key events in patients' lives. While such themes may be included under the broad umbrella of 'contributing factors', their lack of explicit recognition is a potential limitation of the model that was considered within the analysis.

Important caveats within the Scott model, include the use of the term 'intervals', replacing the concept of 'delay' used in previous models by Anderson, stating that "not only is 'delay' value laden but it is also inaccurate as many patients seek help promptly" (Scott et al. 2013).

Thematic analysis was informed by Fereday and Muir-Cochrane (Fereday and Muir-Cochrane 2006) who devised a hybrid model combining both inductive and deductive approaches to thematic analyses. Their combination of data-driven and theory-driven coding supports the demonstration of rigor and credibility in qualitative research, enhancing the reading of the raw data by allowing for both a specific theoretical reading of the data as well as an inductive one. Applied to the study presented in this chapter, such an approach allowed themes to be deduced from the thematic categories identified within the Scott model, while also allowed themes to emerge from an inductive reading of the raw data. The benefit of this is that it allowed both a theoretical, structured approach (Scott), that can be translated and directly compared

with other studies using the same Model and framework, while also not ‘losing’ the direct voice of the women interviewed, and maintaining as unfiltered a representation and description of their experience as possible.

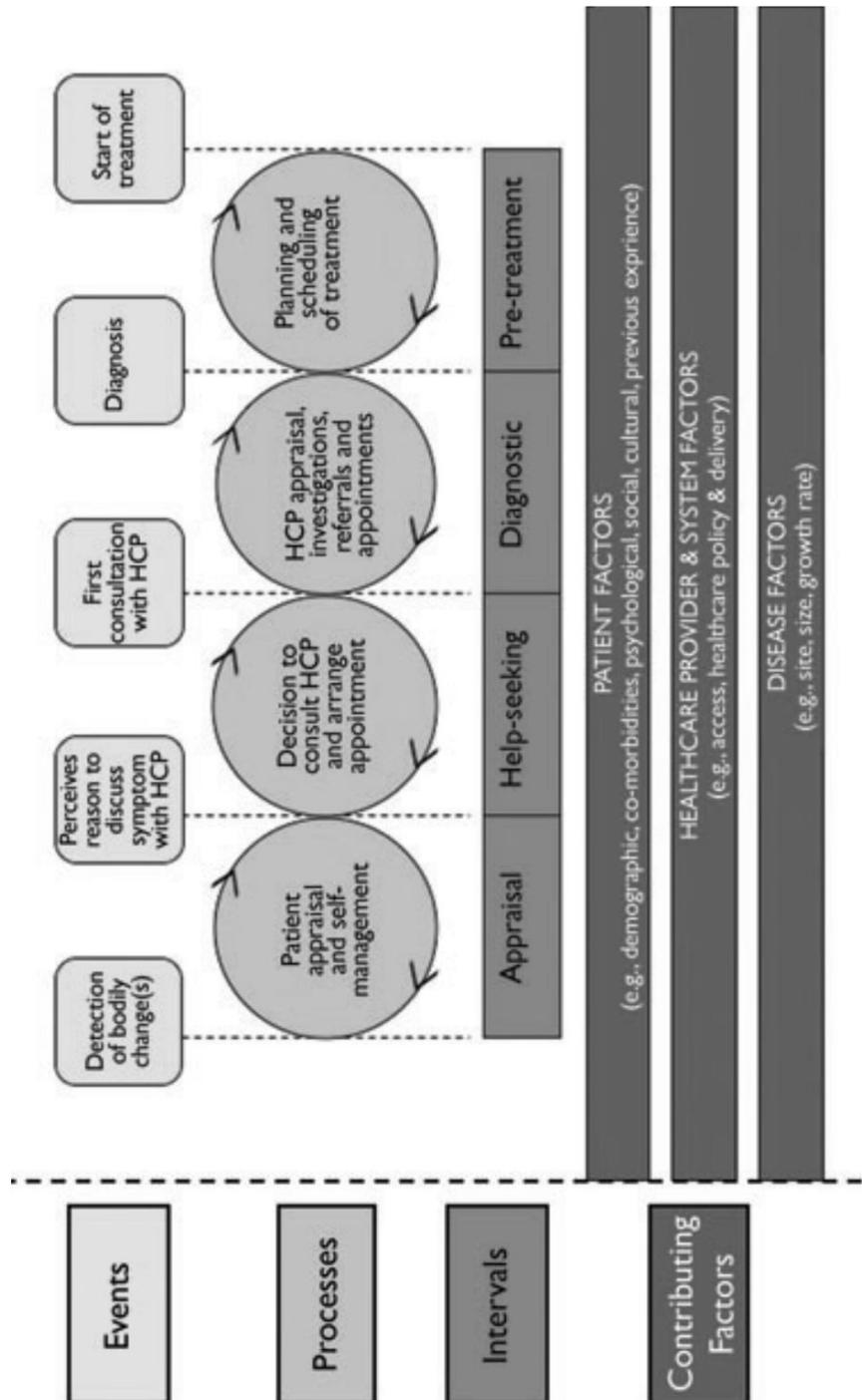


Figure 7.1: The model of pathways to treatment (Scott et al. 2013)

Investigator triangulation (the use of multiple researchers throughout the analytical process) was used to address the completeness of key themes, identify dissonance, and to improve rigour and credibility (T. Farmer et al. 2006; Carter et al. 2014). Transcripts were analysed by a multidisciplinary team of qualitative researchers, and were thematically coded in relation to the analytical framework of ‘Events, Processes and Intervals’ and ‘Contributing Factors’ as previously described. To ensure rigour, all transcripts were read multiple times, with key themes identified and discussed, and agreement reached regarding any differences within the analysis.

Transcripts were analysed both individually and inductively (to understand the full experience of a single participant) and coded to understand trends across the study participants. A codebook was developed to support this process (Appendix 7G). Themes were then identified related to each of Scott’s events, processes, intervals, and contributing factors (for example: financial challenges; comments on the hospital environment; stigmatisation etc.) using the hybrid inductive and deductive approach developed by Fereday and Muir-Cochrane (Fereday and Muir-Cochrane 2006). All data was inputted into tables and shared among the research team for further discussion. Quotations (selected examples in Appendix Item 7F) that illustrated the themes and sub-themes within the study were chosen by the lead researcher and corroborated by the wider team.

### ***Translation***

All recorded interviews were transcribed initially in Vietnamese. Two translators produced verbatim English translations of each transcript. Both translators were chosen specifically because of their additional expertise in social sciences research. Green and Thorogood highlight the importance of “fully involving” translators and interpreters into studies, ensuring that translators and interpreters are considered part of the study team, and are not used solely to outsource the translation of transcripts (Green and Thorogood 2009). Translators were included in the process of analysis to reduce the chance of translational and conceptual assumptions, improve clarity of meaning, and provide space for discussions and analysis around the nuances of how the women described their experiences. Given that, “People communicate their meanings through language, (and) words and language are the fundamental tools for creating and validating knowledge in qualitative research” (Taylor and Francis 2013),

significant time was allocated during the data analysis process to identifying nuances in language, and attempting to collaboratively understand the meaning of the data and transcripts collected.

***Participants***

The women who participated in our study were receiving or had received treatment for breast cancer in Vietnam (Table 7.1). We recruited women using a purposive sampling method through hospitals and support networks for cancer patients such as Chiến thắng ung thư (Fight Against Cancer Club) and Tinh thần - Thực phẩm - Tập luyện - Thuốc (4T Cancer Club - Mental resilience and support; diet and nutrition; exercise; and drugs and treatment). The support networks were identified through discussions with healthcare providers, key informants, and online searches. Relationships with staff at hospitals and members of both clubs were developed throughout the six months prior to data collection, which facilitated recruitment for our study. Interviews were conducted either at hospitals, the residences of women participating in our study, or convenient locations chosen by the women such as coffee shops. Of our thirteen participants, we were unable to conduct a second interview with three women due to scheduling and logistical challenges (particularly women travelling long distances from rural areas for treatment) and progression of their breast cancer. Saturation was reached when initial thematic analysis indicated comprehensive coverage of emergent themes was achieved, and in which researchers agreed that new information was unlikely to deepen the results (Saunders et al. 2018; Strauss and Corbin 1998).

| <b>Participants</b> |            |                         |                       |                           |
|---------------------|------------|-------------------------|-----------------------|---------------------------|
| <b>ID*</b>          | <b>Age</b> | <b>Residence</b>        | <b>Marital Status</b> | <b>Stage of Diagnosis</b> |
| P1                  | 29         | Ho Chi Minh City (HCMC) | Separated             | 2                         |
| P2                  | 54         | 220km from HCMC         | Widowed               | 3                         |
| P3                  | 30         | 200km from HCMC         | Married               | Not known                 |
| P4                  | 38         | 600km from HCMC         | Married               | 3                         |
| P5                  | 55         | 100km from HCMC         | Married               | 3                         |
| P6                  | -          | HCMC                    | Married               | 2                         |

|               |  |  |   |  |
|---------------|--|--|---|--|
| P7            | 40   | HCMC   | Married   | 1  |
| P8            | 65   | Hanoi (HN)   | Married   | 4  |
| P9            | 55   | 20km from HN   | Separated   | 2  |
| P10           | 37   | 16km from HN   | Married   | 2  |
| P11           | 36   | HN   | Married   | 2  |
| P12           | 33   | 30km from HN   | Separated   | 2  |
| P13           | -  | HN   | Married   | 2  |
| <b>Totals</b> |  |  |   |  |
|               | Mean:<br>25-39: 6<br>40-54: 2<br>55-69: 3<br>Missing:<br>2 | Urban: 6<br>Rural: 7<br>Rural = 15km or<br>more from city<br>limits) | Married: 9<br>Divorced/Separated: 3<br>Widowed: 1 | Stage 1: 1<br>Stage 2: 7<br>Stage 3: 3<br>Stage 4: 1<br>Missing: 1 |

*Table 7.1: Participant Information*

\*P = participant

### **7.3 Results**

#### **Events, Processes and Intervals**

##### ***Detection of Bodily Change, Patient Appraisal and Self-Management***

Women in the study described a lack of knowledge about breast cancer symptoms and treatment options prior to their diagnosis. None of the women in the study articulated an extensive knowledge of breast cancer symptoms prior to diagnosis (e.g. knowledge such as dimpling, discharge from nipples, lumps or swelling in armpits etc.). While nearly every participant in our study described the discovery of a lump as the initial moment of realisation in which there may be a problem, many did not equate this discovery to something that required immediate action.

Intervals between the detection of a bodily change (in every case this change was a lump initially, before accompaniment with other symptoms such as pain, nausea and fainting) and perceiving a need to speak to a healthcare professional were as long as five months (P12). None of the women equated the discovery of a lump to an immediate belief that it could be breast cancer. Consistently, women reported not being concerned upon the discovery of a lump specifically because the lump was not accompanied by pain. Few women within the study had exposure to in-depth public health messaging on breast cancer, and only one woman knew how to conduct a self-examination. Variation between different groups of women in their screening and health seeking behaviours are discussed later in the paper, but none of the women

diagnosed at later stages (3&4) had ever been (or in some cases heard of) breast cancer screening.

I did not have the knowledge. I thought it was only dangerous when it hurt. In the countryside, people rarely go to see the doctor. (P4)

When I need something (information), I just searched for it on the internet. I do not know which sources are reliable. (P8)

I was fine, I didn't feel any pain. So I didn't go for a health check. When I went for a health check, I had the disease and everyone was surprised. (P12)

When I found the lump, I was reluctant and waited for 1 month before going for a health check. I still went to work, I did not feel pain. Actually I didn't care about my health, because I didn't feel my health decline. (P13)

For every woman in the study, detection of bodily change involved the discovery of a lump, normally while washing. No women detected a change to their breast through an organised screening programme and only one woman reported having regular (annual) mammograms. Even women who reported attending regular private check-ups, or having company-provided check-ups (n=4), described a lack of concern and awareness around breast health prior to their diagnosis, particularly in contrast to an apparent wider level of knowledge concerning cervical cancer.

I only ever focused on the 'bottom part' of my body. Information about breast cancer is scarce. People usually do not think you can get cancer there. I only started to know about the disease after I got it. (P2)

I heard about cervical cancer more than breast cancer. I didn't have any idea about breast cancer. (P13)

***Perceived reason to seek professional assistance, help-seeking interval, and deciding to consult HCP***

A number of women (n=5) delayed seeing a medical professional for a significant amount of time (2-5 months) citing work and other family commitments as a bigger concern and priority than concerns over their health. One women described ignoring

her initial symptoms because other members of her family were ill, that she had caring responsibilities for them, and that she had to earn money for the family. As such, detection of bodily change alone did not represent a concern or priority in contrast to household responsibilities, working, and caring.

I said jokingly (to my husband) that if I feel sick too we were going to starve to death, because in the countryside you have to work every day for food you know. (P4)

Another woman (P9) waited 3 months to see a doctor after discovering a lump, even though she had a history of cancer and breast cancer in her family. Lumps were often described as being caused by blocked milk ducts and other benign problems. It was only when the lump grew or was accompanied by other symptoms (pain, dizziness, fainting) and deterioration of general health that women made the decision to consult a healthcare provider. Other factors in the Scott model, such as the failure of self-medication and the interference with the ability to work (Scott et al. 2013) were not present within the narratives of the women in our study.

For many women, having a supportive partner or family who encouraged them to seek professional healthcare advice and services, was a central factor within the help-seeking interval and the decision to seek a consultation. This theme of the importance of having a supportive partner or family was repeated throughout the narratives of women participating in our study across all events, intervals and processes along the pathway to treatment.

My husband's family and my husband are very supportive. That is my motivation to fight this disease. (P13)

In some cases the importance of a support network extended beyond the immediate family, to other family and social connections. Some women cited the importance of healthcare providers in their social circles encouraging them to seek a formal examination and diagnosis, and also with helping them to understand and acquire insurance. For many women, economic barriers (discussed at length later in this paper) may have factored into delays to organise and attend a first consultation with a healthcare provider.

### ***First Consultation with HCP, HCP Appraisal, investigations and referral***

None of the women in the study had their breast cancer detected through screening or opportunistic screening, therefore all of their initial consultations with healthcare professionals were as a result of self-referral. Where women entered the health system varied, with some initially attending their local commune health station (primary, preventative health centres), while others went directly to national and provincial oncology hospitals.

The length of time between initial examinations and detection, and formal diagnosis, for many women depended on the level of the health system which they entered. Regardless of the level in which the women entered, however, the women in our study described processes of missed diagnosis, multiple referral and confusion over their diagnosis.

The doctors did not diagnose a tumor. They said everything was OK. (P6)

In the first test they concluded that the lump was benign, but when I took the test again, it was cancer. (P9)

Seven women explicitly described receiving an incorrect diagnosis or incorrect information about their diagnosis or referral. In every case, this misdiagnosis was of something less severe than breast cancer such as fibroid breast tumours, carpal tunnel (in the arm) and benign tumours. The interval between the first consultation with a healthcare provider and a confirmed diagnosis often required multiple tests, often at different hospitals, with a lack of information or support for women to navigate the process.

A lack of information about the formal referral pathways and possible treatment routes was evident for most of the women in our study. First contact with healthcare providers tended to be short and not accompanied by support or information. This trend was replicated throughout the treatment pathway at all levels and these experiences are reflective generally of the lack of streamlined protocols in place to assist in receiving a confirmed diagnosis.

Procedures at hospitals are very complicated, so patients cannot feel at ease. I am lucky because I have my husband but most people come alone, and they have to go to this place and do things, they have to go out and make photocopies, they have to go to that place to submit and they have

to come back again. It is like they are being chased. As long as the procedures are complicated patients can never feel at ease. (P4)

The administration procedure is too complicated. The doctors are also busy, so I have to meet the doctor to take the medicine, to buy the medicine. Sometimes the doctor is not in the Department. (P13)

Often the procedural and bureaucratic complexity of moving from an initial consultation to a confirmed diagnosis cost significant time and money. One woman (P4) described having to return to her commune health station after receiving a diagnosis, in order to progress linearly through the system. This was a requirement in order to access her insurance. She estimated that the costs for all the necessary transfer letters cost her 8million VND (350 USD).

### ***Diagnosis, planning and scheduling of treatment***

The processes of confirming a final diagnosis were described as confusing, and often with little information provided by healthcare providers. One woman within our study did not know her stage of diagnosis and many described a lack of clarity on what their diagnosis meant.

If you asked too many questions they would scold you. You can't blame them though because there are too many patients at the Oncology hospital. (P3)

Additionally, some of the women described tests to confirm breast cancer as being traumatic, for example surgical biopsies being conducted without anaesthesia.

It would hurt to death. No anaesthesia. They would make an incision and then a machine would close it. (P1)

Confirmation of a breast cancer diagnosis was often described as a moment of shock, fear and panic. Many women described that many people in Vietnam equate a cancer diagnosis with death and incurability, however, probably related to the fact that all women in our study were undergoing or had completed treatment, none of the women in our study retained such fatalistic views.

When I knew that I had cancer, I still felt shock... I thought that cancer can't be cured, it is a fatal disease, so I was shocked. I was depressed. (P11)

In my hometown, when people hear cancer they think 100% you will die, there is no way you could live. Some say it costs too much and you will die anyway. You do not get any better so why do you keep doing that (traveling and paying). (P4)

The confirmation of a breast cancer diagnosis, for a number of women in the study, represented a bigger fear in terms of economic stress, than it did in relation to their health. Women describing the interval and processes between diagnosis and initiation of treatment universally talked about money and significant out-of-pocket expenditure.

When I heard about being hospitalised I started to worry. I cried then because I was afraid I could not afford it. Also that day we didn't bring a lot of money. I was not afraid of dying. (P2)

Interestingly, and perhaps because of the existence of the insurance system, none of the women in our study despite our diverse study population, significantly delayed their treatment in order to raise the money to pay for treatment. An attitude of raising the required money as they needed it seemed prevalent within the study.

### ***Treatment***

Descriptions of treatment focused on two main areas: associated economic difficulties, and discomfort in hospital. All women in our study followed biomedical treatment, some in combination with traditional medicines. No women in our study had prematurely ended their treatment, although one woman interrupted her treatment to use traditional medicine in isolation. Most women described having access to surgery, chemotherapy, and hormone therapy, and four women reported having radiotherapy.

Economic factors were discussed at length by women in the study. Our study population came from varied socio-economic backgrounds; some had their own insurance before their diagnosis; others acquired insurance during treatment; and others held certificates of the poor which allowed them to access subsidised or free health services. Every women, regardless of her context, talked about costs. For those

paying for treatment (those without certificates of the poor), overall self-reported direct costs ranged from 300million-700million VND (13,000 USD – 35,000 USD), *after* insurance. For surgery, most paid between 20million and 30million VND (out-of-pocket), while chemotherapy was often described as being anything up to 30million per session (after insurance). The lack of streamlined or standardised price points is a clear problem, with many women stating they did not understand what the economic costs were going to be before they started their treatment. Insurance coverage was reported as 80% of costs covered for surgery, and 50% for chemotherapy, however there were variations, and generally information around exact costs was opaque.

30 million per week, not to mention food costs and other medicines. Not to mention pain relievers, supplement infusion, this and that costs. That is only for the chemicals. Also the money on commuting. You have to spend millions per hour during a hospital visit. People with money think about dying because of the disease. People without money think about dying because of not having money. (P1)

A number of women described needing to sell possessions and houses in order to pay for the costs of treatment, as well as taking loans and entering into debt.

If you have a house then you can sell your house, but if you don't then what can you sell to get money for treatments. That is the problem. It is the same in every hospital in the country. (P4)

Other ladies sold their houses. They have houses in the city but they had to sell them. Like me, I do not own a house. My Mom is also sick. We have to spend money on both of us so it is very hard. (P1)

Almost all of the women focused their discussion of treatment on the conditions and overcrowding in the hospitals, and the associated lack of contact and information that healthcare providers were able to provide them with. Hospital wards were described as overcrowded with often multiple women to a bed, women lying on the floor, women receiving chemotherapy while sitting on chairs, and patients lying in corridors. One women (P3) described asking her family not to visit because of the conditions in the hospital.

It's overcrowded. Overloaded. In that room, there must be 3 or 4 people sharing a bed. They need to borrow beds and lie outside. (P9)

The difficult conditions and physician/patient ratio makes it very difficult for healthcare providers to effectively manage individual patients. These themes were also communicated by HCPs participating in the study presented in Chapter 4.

They are simply overloaded. I could not feel a lot of empathy from the nursing staff. It is just work for them. When I came to ask, they yelled at me. They kept telling me to wait, wait, wait. (P4)

I want the doctors to be more dedicated, which means they give should me more advice on the stage of my disease or which medication I need to buy or what I should do. Now, they only answer what I ask, they don't actively consult me which medicines I should and shouldn't use. They don't explain it to me in detail. (P8)

### **Contributing Factors (Patient Factors, System Factors & Disease Factors)**

So far, this chapter has presented information on the pathway to treatment and individual experiences of women in a largely descriptive format. Continuing, it is also important to examine and analyse the different factors that have impacted upon the experience of women, highlighting the different contributing factors that affect those experiences.

#### ***Patient Factors***

In terms of demographic variations, women residing in the south of the country were all members of support networks for cancer patients, while only one woman from the north was a member of a support club (which was virtual, through Facebook). Further demographic differences in experience relate to the socio-economic positions of women in the study. Given the significant economic burden associated with breast cancer treatment, women who did not receive any government support (certificates of the poor etc.) but equally did not have significant disposable income, often described the costs of treatment in the most oppressive terms. Women with certificates of the poor and near-poor had equally significant problems related to out-of-pocket expenditure.

The described belief systems of the women within our study were that cancer is curable and that biomedical approaches should be prioritised, often in conjunction with supportive/complementary traditional medicines. Some women described intervals between confirmation of diagnosis and the beginning of treatment due to a temporary sense of defeat and hopelessness felt by both the women in our study and within their wider social circles.

Many people got hopeless and did not go to the hospital to be treated. There are also people who said they did not have money and even if they were treated it's not going to work. (P7)

My husband family is poor. My relatives told me sooner or later I will die. If I do the treatment, it will waste a lot of money. So from 2015 till this October, I used traditional medicine. I did not feel hurt and I could go to work. When I went for a periodic health the result revealed that cancer cells travelled to the bone. I do not know which will be the next organ. (P10)

Only one women within the study population described traditional or alternative sources of care having curative power for cancer. Other women in the study described that beliefs in the curative power of traditional medicines were prevalent within their wider social circles and communities.

She cures people. I have seen it with my own eyes. (Talking about the ability of a psychic). (P7)

People in my countryside think that using Western medicine cause death more quickly, using traditional medicine can resist the disease. I think that only Western medicine can kill cancer cells, traditional medicine only helps slow the disease but cannot kill it. (P10)

For the most part, however, most women described a commitment and belief in biomedical approaches to treatment.

I always reinforced my thought that I will follow Western medicine. I went to the hospital for health check. My family advised me to use the herb but I determined to follow Western medicine. I know many people who used traditional medicine but could not treat their disease. Then when they went

to the hospital, the disease was in the severe stage, it could not be cured anymore. (P13)

Older women in the study felt that breast cancer would be particularly difficult for younger women with partners. Three of the women in the study were separated from their husbands, and all three indicated that their diagnosis played a role in their separation. Social stigma and relationship breakdown was discussed as being frequent among other women outside the study, with women citing both economic and aesthetic reasons for husbands leaving.

My husband left me. I have to manage myself. When I woke up, he was gone. (P12)

It would be fine if this disease only created pressure on work. However, this disease creates pressure on the family, married life, your aesthetic. The treatment takes a lot of time and money. (P11)

### ***Healthcare Provider and System Factors***

As previously illustrated, numerous healthcare provider and systemic factors created challenges for women accessing and using health services. These focused on the overcrowded nature of the hospital environment impacting on the time and capacity of healthcare providers to give the appropriate levels of communication and support to patients.

In terms of the health system and access, a number of women were particularly critical of lower levels of the health system, describing poor diagnosis and information communicated by healthcare providers. Many other women bypassed lower levels of the system if they had the capacity and resources to do so. This has been evidenced in other chapters and may represent an area for strengthening. Should appropriate capacity be built at lower levels of the system (district and provincial levels, with some detection services at commune level) this may reduce barriers in terms of distance to healthcare facilities and out-of-pocket payments.

If only lower levels hospitals were good at treating patients and could detect diseases, people would be so lucky. It would cost less, it would take less time, and it would be more effective for the patients. (P2)

The doctors (at lower levels) should have more training and study more about cancer. (P5)

Proactive healthcare providers were crucial in the stories of a couple of the women in our study, encouraging women to seek further examinations and diagnosis and providing support during the treatment process. It should be emphasised that many women recognised that often healthcare providers were doing their best to support, but that they didn't have time and the necessary training to provide the type of support and information needed by patients.

### *Disease Factors*

The women in the study did not discuss the specifics of their diagnosis in depth (site, growth, metastasis), often due to a lack of knowledge about this information. One woman did not know the stage of her diagnosis. Other women described metastasis to other parts of the body, due to presenting late at the hospital.

Due to limited amount of participants in the study, it was difficult to draw conclusive results on variation within the data. Descriptively, however, women within the group diagnosed in the earlier stages (1&2) (n=8), compared to the later group (3&4) (n=4) (one woman unknown stage of diagnosis) had greater uptake of annual health checks, normally provided for by their employers. None of the women diagnosed at later stages regularly attended health check-ups (either privately, company provided, or part of screening campaigns) prior to their diagnosis. Women from rural backgrounds and without family or residence in large cities faced particular challenges in terms of accessing centralised oncology services, especially given difficulties in scheduling appointments, long waiting times, and the length of treatment such as chemotherapy. Many women from rural background cited additional costs, such as renting accommodation near the hospitals. This will be explored more fully in the next chapter with particular reference to addition costs and challenges experienced by carers of women with a cancer diagnosis.

It was not possible to collect data on levels of income or household wealth, which are likely to be factors affecting access and uptake of services. Further quantitative research is required to understand the scale of different experiences for women diagnosed at different stages, and for women in rural and urban areas.

## 7.4 Discussion

Women across the study reported themes of lack of awareness of symptoms of breast cancer; delay in speaking to a healthcare provider; fear, shock, beliefs that cancer is incurable; and fear of treatment (in terms of pain and long term impact on the body). These themes are reflective of much of the international literature on breast health in low and middle income contexts (Review of studies using a phenomenological approach to exploring this issue available in Appendix Item 5E) (Liamputtong and Suwankhong 2015; Mehrabi et al. 2017; Xiong et al. 2016).

The association between cancer and death, and the resultant fear, is a dominant emotional reaction across multiple studies in different contexts (Obeidat et al. 2012; Shrestha 2012), with many women citing fear not just in relation to death, but in relation to pain, treatment, and physical changes. Fear (not lack of knowledge about symptoms, but a lack of knowledge that breast cancer is treatable) was directly linked by women in two studies to their decision to delay seeking medical diagnosis (Hajian et al. 2017; Demir et al. 2008). Equally some of the social challenges described by women in the study in relation to social stigma, breakdown of intimate relationships, social isolation and role weakening have all been well documented by studies in other low and middle income contexts (Hajian et al. 2017; İnan, Günüşen, and Ustün 2014; Joulaee et al. 2012; Lam and Fielding 2003; Shrestha 2012).

Interestingly, ‘fear’ and associated stresses in Vietnam, were described as extending beyond impact fear of treatment and fear of death, to also include fear of the financial implications of treatment. Cancer patients and their families experience economic stress globally. In Vietnam, however, these challenges appear particularly pronounced. Women in our study described significant out-of-pocket and significant direct costs for their treatment, and explicitly referenced their fear of costs: “I was afraid I could not afford it... I was not afraid of dying” (P3). While Vietnam has high (and steadily increasing) coverage of insurance, reported at over 87% of the population (WHO 2019b; Ministry of Health, Vietnam 2017), and equally, the poorest in society have coverage through certification of the poor, health costs are often catastrophic. Women in the study reported selling possessions, delaying treatment due to lack of finances, and the emotional and financial stress on the family unit of having to pay for treatment.

Levels of financial catastrophe (when health costs equal or exceed 40% of the household's capacity to pay), and impoverishment (when a non-poor household is impoverished by healthcare costs) (WHO 2005) from healthcare costs are high in Vietnam. A number of previous studies have indicated the severity of the problem. For example the Partnership for Action in Health Equity estimated that in 2013, 862,661 and 563,785 households across Vietnam were pushed into financial catastrophe and impoverishment respectively (Partnership for Action in Health Equity 2013). At particular risk were households that were elderly, rural and of lower economic status. An additional recent study on the financial burden for households paying for cancer treatment reported that 37.4% of the households within the study (1,141) were impoverished by the treatment costs for cancer (H. Minh et al. 2017).

Women in the study without certificates of the poor estimated costs ranging between 13,000-35,000 USD. In a study in 2010, Lan and colleagues (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013) estimated more conservative costs for 5 years of treatment, reporting an average of 975 USD per patient. Lan et. al. did not account for out-of-pocket expenditure, whereas many women in this study discussed both direct and indirect costs (bureaucratic and administrative costs, accommodation, food and travel). Even accounting for out-of-pocket expenditure, inflation, some of the women in the study paying additionally for semi-private rooms, and the improving Vietnamese economy, it is unclear why there is such high variation in reported costs between these studies. Wider costing studies should therefore be undertaken.

A number of services, such as surgery and chemotherapy are only partially covered by insurance. And other services such as screening and mammography are currently not covered under the social health insurance model. While the study accessed women who had insurance and were able to afford the out-of-pocket payments (despite the significant stress caused), and women covered by certification of the poor, it is likely that there are significant portions of Vietnamese society that are unable to afford and access treatment for cancer. There should be consideration given on how to remove these barriers while also considering increasing the levels of coverage for certain treatments like chemotherapy and radiotherapy. A full costing study would be necessary to ascertain the feasibility of this approach.

Population or targeted screening campaigns remain limited, and none of the women in our study entered the health system through a screening programme. While there have been a number of one-off screening campaigns (described in Chapter 2) and initiatives (e.g. organisations such as the Bright Future Foundation have recently funded and purchased a breast cancer screening bus) screening remains largely inaccessible for many women. Interestingly, more women seemed to be aware of screening services for cervical cancer, and this may represent a model of good practice from which to build upon.

This study suggests significant challenges remain for women in Vietnam in relation to stigmatisation of breast cancer. Interventions that seek to challenge traditional narratives of disease causation, as well as challenging narratives surrounding gender politics, the role of women, and confronting the aesthetic impacts of breast cancer treatment may be useful. Many women described directly or indirectly the theme of relationship breakdown post-diagnosis. Given the importance of a strong support network for women when navigating oncology services, campaigns that explore role-modelling showing supportive male behaviours and relationships may be beneficial.

A number of women reporting poor knowledge about breast cancer still went directly to the oncology hospital after discovering lumps, and did not enter the health system at either lower levels of the health system or general hospitals. When interrogating why a woman would go to the oncology hospital instead of the general hospital if she didn't know anything about cancer, the research team discovered a linguistic anomaly. The hospital in English is called the Hanoi Oncology Hospital. In Vietnamese, however, it is referred to as 'Bệnh viện Ung bướu Hà Nội'. The literal translation for this is Hanoi Tumour Hospital. In this sense, even if a woman knew very little about 'cancer', and its symptoms, she may go to the hospital for anything that represented a 'tumour', such as a growth or abscess. It's a slight difference, but an important one to be aware of; it highlights the distinction between understanding disease in biomedical terms (oncology), and poor health in more lay terms (growths, tumours, and lumps). It also suggests that women going directly to the oncology hospitals after discovering symptoms is not necessarily indicative of high levels of knowledge about cancer.

Mental health needs of both women and carers and families were additionally communicated throughout our study, but very little information exists on formal or

informal services available to support them. More research should be conducted on this area, with specific reference to the wider impacts of a cancer diagnosis on the entire family unit.

### **7.5 Limitations**

It was not possible to conduct second interviews with three of the women within the study. This was due to difficulties in scheduling interviews around their medical appointments and that many women only come into Hanoi or Ho Chi Minh City periodically for treatment. It was not possible to do a second interview with one of the women in the study due to her deteriorating health. Participants included in the study were also limited to those with knowledge and resources to have accessed treatment services, therefore the study is not likely reflective or representative of all women in Vietnam, particularly those women with breast cancer who are not in treatment.

Many of the economic figures provided by the women in this study regarding, for example, cost of treatment and out-of-pocket costs should be considered as broad estimations. As with any figures generated from memory recall, caution should be used when interpreting the significance of these figures.

### **7.6 Conclusion**

The study presented within this chapter has highlighted significant challenges that exist for women with breast cancer in Vietnam. Cancer control and treatment in Vietnam has improved dramatically in the last two decades, but further work is required particularly engaging with different factors that influence whether women can access services, and how these services are experienced. This chapter highlights a number of these themes, focusing particularly on the need for financial support for women with breast cancer and their families to reduce economic barriers to treatment and financial catastrophe. Other factors such as social stigma, lack of support systems, and long intervals and mistakes along the patient pathway were consistent findings that should be addressed with focused interventions and further research. This chapter represents the first attempt to produce in-depth descriptive research on the experiences of women with a breast cancer diagnosis in Vietnam. Beyond presenting new information, it is hoped that this study contributes to a shift in research in Vietnam in which a greater quantity of qualitative studies are undertaken.

## Chapter 8

### Roles and Unmet Needs of Informal Cancer Carers in Vietnam

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#### 8.1 Introduction

Applebaum and Breitbart describe informal carers as “relatives, friends, and partners who have a significant relationship with and provide assistance (i.e., physical, emotional) to a patient with a life-threatening, incurable illness” (Applebaum and Breitbart 2013). As will be discussed within this chapter, the concept of informal caring is often synonymous with family roles in Vietnam, with carers rarely being recognised as a distinct group. Whether viewed explicitly as carers or as family, their role and importance is, indisputably, significant. As Vietnam undergoes an epidemiological transition from the burden of communicable diseases (Hinh and Minh 2013a) to those of non-communicable, the nature and burden of caring is likely to change dramatically. It has been well documented that cancer creates significant challenges for caregivers. Research has increasingly shown the impact that caregiving can have on the physical, emotional and mental health of people providing care (Santin et al. 2014). Factors such as stress, loss of control, anxiety and depression are all commonly experienced by cancer caregivers (Northouse et al. 2012). Previous studies have additionally demonstrated that poor health of the carer may correlate to poorer health for patients (Segrin and Badger 2014; Kim et al. 2008), indicating the further value of supporting carers to improve the health of patients.

There are an estimated 165,000 new cancer diagnosis in Vietnam per year (GLOBOCAN 2018). Given the family-centred and collectivist nature of caregiving in Vietnam, as will be described within this chapter, this indicates significant numbers of people involved in caregiving for people with cancer. Research on the needs of carers in Vietnam is limited, particularly in relation to the specific needs of caring for someone with cancer. In addition, empirical data about the needs of informal carers who provide support for their family member or close friend when they are in hospital is sparse.

Research about informal caring in Vietnam has focused on caring for people with dementia and/or Alzheimer disease (T. A. Nguyen et al. 2018), stroke (Hayashi, Hai,

and Tai 2013), and HIV (Lundberg et al. 2016; Tran et al. 2017). Research also tends to focus on the needs of Vietnamese carers and communities living in North America (Meyer et al. 2015; Donovan and Williams 2015). A review of this literature indicates that needs for Vietnamese carers are multifaceted and complex. Carers of family members who suffered a stroke indicated that at the point of hospital discharge they lacked information about how to prevent stroke recurrence, the best food items and meals to provide, and local (non-centralised) hospital services for stroke patients. Almost half of the informal carers who were surveyed (n=93) indicated that they faced economic challenges in relation to their caring responsibilities (Hayashi, Hai, and Tai 2013). Carers of people who were living with HIV described feelings of isolation and experiences of stigmatisation and discrimination as well as a perceived pressure to keep the diagnosis of their family member a secret (Lundberg et al. 2016). HIV nondisclosure, stigma, and financial pressures among others were listed in a second study on carers adherence to supporting paediatric antiretroviral therapies (Tran et al. 2017). Duty to parents, pervasive emotional stresses such as grief and trauma, and the importance of culture in understanding the caregiving experience were key themes emerging from a study on the needs of carers for Vietnamese people living with dementia in Canada (Meyer et al. 2015).

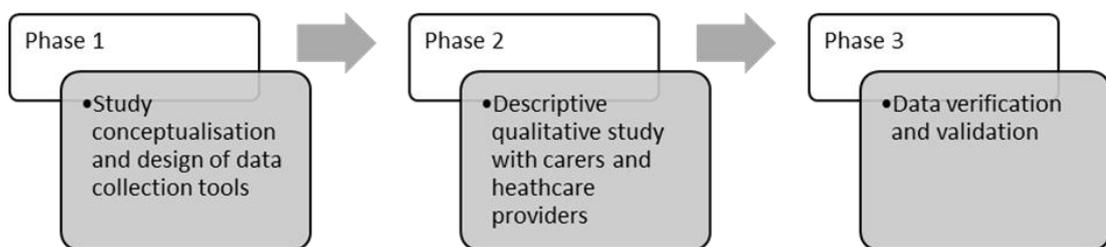
Through presenting in-depth data from interviews with carers and healthcare providers, this chapter presents the results of an analysis of the roles and needs of carers for people diagnosed with all types of cancer in Vietnam, specifically in a hospital/inpatient context. This study was conducted as part of a wider research collaboration on the needs of carers of people with all types of cancer in Vietnam, and not breast cancer specifically. However, the findings and themes emerging from this study are also likely applicable and reflective of the needs of carers of someone with a breast cancer diagnosis.

Given the importance of carers, the lack of capacity within the health system to holistically support patients and carers (as discussed in previous chapters), and the specific challenges of caring for someone with cancer, this chapter highlights an important and neglected area of study. It represents context-setting research through which to inform future interventions and service reform. Within the context of this thesis, it also adds to an understanding of how cancer is lived and experienced in Vietnam. While Chapter 6 highlighted challenges of healthcare professionals in

supporting cancer care and treatment, and Chapter 7 focused on the experiences of women with a breast cancer diagnosis, this chapter completes the circle by highlighting the perspective of carers, family and wider social networks.

## 8.2 Methods

A 3-stage approach was chosen so as to both appropriately inform the focus of the study and the development of data collection procedures, and to improve rigour and credibility through validating, verifying and triangulating data emergent from the main study (Figure 8.1).



*Figure 1: Study Design*

Key informant interviews and focus groups discussions (FDGs) with healthcare providers and carers formed phase 1 of the study. From this it was ascertained that carers and family currently receive limited support in their roles and that resources should be developed to assist them in their caring responsibilities. Our key informant and FDGs highlighted that carers experience of range of challenges and needs related to lack of information on how to care, lack of emotional support, and the financial challenges of being a carer (phase 1). These key informant interviews and FDGs helped to inform the collaborative development of an interview schedule (Appendix Items 8A & 8B) and data collection procedures for our main study (phase 2). This additionally allowed the piloting of questions and their adaption and revision.

FDGs and in-depth interviews (IDIs) were conducted with carers and healthcare providers in central, national-level oncology hospitals in Hanoi and Ho Chi Minh City (phase 2). Similar to Chapter 7, this descriptive qualitative study was informed by Sandelowski, who states: “Data collection in qualitative descriptive studies is typically directed toward discovering the who, what, and where of events or experiences, or their basic nature and shape. Data collection techniques usually include minimally to

moderately structured open-ended individual and/or focus group interviews” (Sandelowski 2000, 2010). FGDs and IDIs were led by an experienced qualitative Vietnamese researcher, conducted in Vietnamese, and lasted between 60-90 minutes.

Following these first two phases, further focus groups and in-depth interviews were facilitated in which the findings of the studies were presented to carers and healthcare providers (some of whom had previously been involved in the study, and others who had not), for the purposes of verifying, validating and deepening the analysis of the results (phase 3). Discussions were again led by a senior Vietnamese qualitative researcher and supported by the international study team.

All focus groups were part-translated simultaneously (by a second Vietnamese researcher) for wider involvement by the international research team. Simultaneous part-translation (summarising of conversations) was employed to maximise the flow of the focus groups by reducing interruption or needing time for translation, while also providing an opportunity for the international members of the research team to bring their experience, questions and probes to the interviews. All interviews and FDGs were transcribed verbatim and fully translated into English for analysis by the whole team following similar procedures as those described in Chapter 7.

### *Participants*

Carers were recruited via convenience sampling within hospital settings in Hanoi K hospital and Ho Chi Minh City Oncology hospital. Recruitment was led by administrative and medical contacts in each hospital department. Carers were approached in person, and HCPs by email. Inclusion criteria were that participants were currently caring for cancer inpatients at the hospitals and were over the age 18, or HCPs working in the either hospital.

Carers (phase 2, n=20) (Table 8.1) were predominately female (65%), with all carers with the exception of 1 being direct family members (parents, siblings, children and family by marriage). Cancer site varied, with breast, colorectal, oesophageal, stomach, and ovarian all named. HCPs represented a broad range of medical staff from departments of surgery, radiotherapy, palliation, nursing, nutrition and social work, and included staff in both senior and junior positions.

Carers gave of their time between their caring responsibilities. With the exception of two carers within the key informant interviews (phase 1) and one in the main study (phase 2), all carers were informal and not paid. Each participant was provided with a small financial compensation for his or her time in contributing to the study.

| <b>Contacts in the Study</b>   |                        |   |                                       |
|--|------------------------|---|---------------------------------------|
|  | Study Design (Phase 1) | Descriptive Qualitative Study (Phase 2) | Verification and Validation (Phase 3) |
| Carers   | 12                     | 20                                      | 10                                    |
| Doctors  | 10                     | 11                                      | 9                                     |
| Other Healthcare Professionals (Nurses, Nutritional Dep, Social Work Dep.) | 13                     | 11                                      | 14                                    |
| Non-government organisations   | 0                      | 1                                       | 0                                     |
| <b>Total</b>   | <b>35</b>              | <b>43</b>                               | <b>33</b>                             |

*Table 8.1: Contacts in the Study*

### ***Data Analysis***

The ‘voice’ of carers are prioritised within the analysis and are complemented and triangulated with data from key informants and stakeholders such as doctors, other healthcare providers and staff from non-governmental organisations. Our results focus on data generated in the main study (phase 2). These results were corroborated with data gathered through dissemination and verification interviews (phase 3). Thematic analysis (Taylor and Francis 2013) of all data collected was conducted within the main qualitative study (phase 2) (figure 8.2), creating an inductive codebook based on the themes that emerged from initial independent and collaborative readings within the research team. Once a codebook had been agreed, the research team individually analysed the dataset, highlighting key quotations (presented in Appendix Item 8D) and recurrent themes, and then discussed these results extensively in both face-to-face and online meetings. Vietnamese members of the research team travelled to the UK for ten days to contribute in-person to the analysis of the data, the creation of codebooks, and discussions on key themes. This face-to-face time between members of the multidisciplinary and international team allowed greater discussion, triangulation of results and key themes, and improved rigour within the analysis of results.

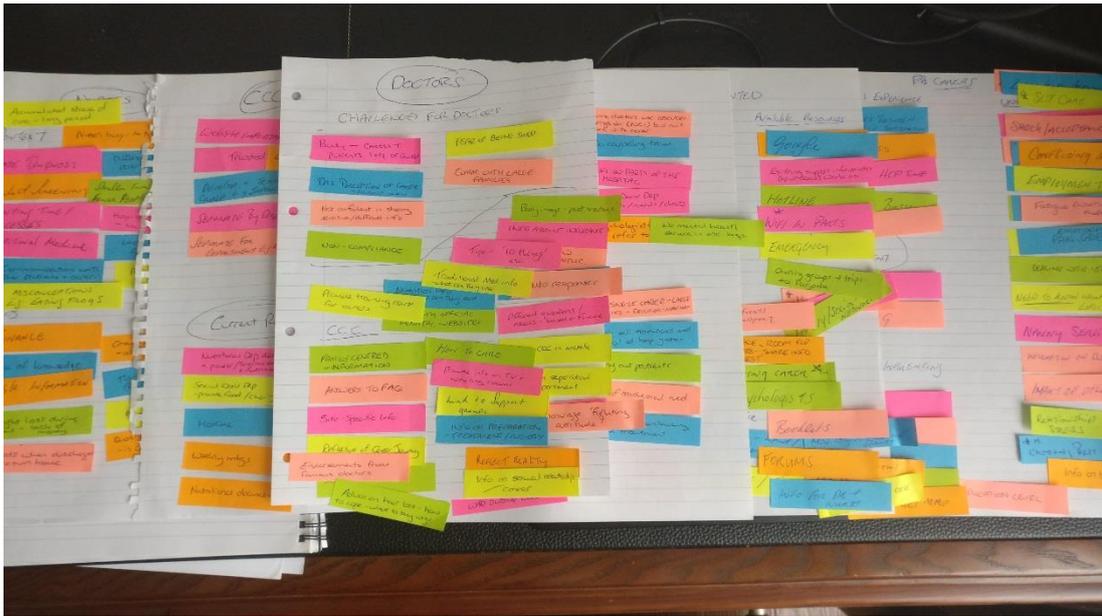


Figure 8.2: Collaborative exercise to inform the design of our codebook

### 8.3 Results

Carers<sup>3</sup> and HCPs described the specific roles carers often take in Vietnam. Four key interconnected thematic areas were additionally identified from the data on the needs of carers: material needs (accommodation & finance); informational needs; emotional and support needs; and training needs.

#### *The Role of Carers and the Context of Caring*

Carers play a vital and central role in supporting patients within Vietnamese cancer hospitals. Despite this, they often lack visibility (due to a prioritisation of patients needs and limited time and capacity of healthcare professionals), and their roles often not being recognised nor incorporated into procedures or protocols within hospitals.

In Vietnam, caring is often shared between large groups of the extended wider family, and rarely is only provided by a single carer. There isn't a commonly used word for 'carer' in Vietnamese, with people largely just referring to 'ngươi nha' (people in family) and 'ngươi than' (people with close relationship). Rarely, and only in cases in which a family has a higher level of income, a carer will be employed and referred to as 'ngươi giúp việc' (person who helps).

<sup>3</sup> Carers denoted as 'C' in selected quotations. HCP = Healthcare providers. HN = Hanoi. HCMC = Ho Chi Minh City.

Carers are often responsible for a wide-range of responsibilities within hospitals, including: feeding, washing, assisting with minor medical procedures (e.g. changing dressings), supporting the patient to move between departments for scheduled appointments and examinations; and supporting with hospital administration, including navigating payment and insurance. Carers often act as main decision-makers for medical decisions, and are responsible for communication with hospital staff.

The family member will be the person who decides on what treatment to take and what care to give. They are the ones who provide financial support, and everything. In Vietnam, families have to take care of people. The families are the ones who provide the financial support, emotional support, so they have a lot of power in terms of taking care of patients. And the patients, they think that, OK, late stage of cancer is the end of life, so they do not have strong minds or strong physical health to deal with the situation. Families are the ones who will be in charge of that on behalf of the patient. (HCP/HN)

And there are so many difficulties: eating, living conditions, and many other things. For example, family members have to wash their clothes. But the hospital staff told us not to wash our clothes in the hospital. (C/HN)

It is as important (to be a carer). A doctor can only treat the inside of the body, but the feeling and emotion is more important. It needs to be taken care of before and after treatment. So we need to care psychologically so that they don't feel sad. I think that we cannot fight with the disease if we are sad despite of having the right treatment. Generally my younger brother is very lucky, his wife was very thoughtful, she loves her husband. She cares for him on every single thing, trying to avoid infection, and trying to keep him healthy. (C/HCMC)

One carer highlighted how changing demographics have impacted on increasing the burden on carers.

A very obvious problem is that the uncles and aunties here have less children than the previous generation. Now, families with more children only have 3 or 4 children. Normally, there are only 1 or 2 children. (C/HN)

Culturally, to care is an important part of being family, and family are often expected to fulfil this role even when it clashes with hospital protocol such as asking carers to leaving during busy periods of the day. While carers are needed, and expected to be present in the hospitals, carers described a number of structural regulations which make it difficult for them to provide this role, for example being asked to leave the ward during working hours. Carers often reported resistance or resentment at being asked to leave. Carers communicated concerns, that given the overcrowded nature of the wards, that a patient would be neglected if they were not there to provide support.

We do not want to be in the hospital but our parents are sick so many times when they are weak, we are near them, we are there for them whenever they called for help, and we are ready. (C/HN)

My wife has not been able to walk after the surgery. In the days after that, I had to help her to use the toilet, feed her, and I was still asked to get out. Sometimes I got mad, I said, “now you don't have anyone to care for the patient, but you still throw us out? We do not want to lie here, but we have to. If we are not here, who's holding the toilet?” Do the doctors and nurses ever take the toilet to the patients? (C/HN)

We have not enough staff to take care of our patient all days. And their parents, their wives and husbands always want to stay beside them. (HCP/HN)

As the intermediary between HCPs and patients, carers have a significant amount of control over what information a patient receives. In the past, some HCPs described a culture of information being withheld from patients for fear of causing anxiety, or concern that a patient would ‘give up’ upon hearing their diagnosis. The extent that this practice has changed is ambiguous, but is reflective of the possible power that carers hold as gatekeepers of information.

The family always wants to hide the information. If we want to hide from the patients, we must tell their relatives. At least one of the relative must know. It's common now (to inform a patient about their diagnosis). But before, the doctors thought that doctors often hide, they didn't tell the patients about their cancer. But now, they often think that they must tell

patients, it means that the patients should know about their illness. The reason is, that is the best way to encourage them to fight. (HCP/HCMC)

Because of the education of patients in Vietnam is low, when I inform the cancer patients and when the patient gets a diagnosis of cancer, I usually tell the patient's family, not the patient. All information. That is, all the information I did not tell the patient, I told the family members. Because the inpatient in Vietnam is very worried, very anxious, very fearful about cancer. (HCP/HN)

### ***Material Needs: accommodation & finance***

Both carers and HCP discussed described the hospital/inpatient context and environment in which carers carry out their role as challenging and difficult. Carers and HCP noted the heavily overcrowded nature of the centralised oncology hospitals, resulting in patients often sharing beds. As described in the previous section, respondents described carers as contributing to this overcrowding due to the need and desire for carers to be present at patient's bedsides.

Many carers and HCP reported that carers and patients must travel long large distances to centralised oncology hospitals in Hanoi or Ho Chi Minh City. Due to this travel many carers reported problems with finding affordable and comfortable accommodation for the duration of the patients treatment. Carers described having to share motel rooms with other carers, or staying the corridors and communal areas within hospitals when they're asked to leave the wards. Often carers will sleep beside or under patient's beds when they are in the wards. Carers described fears for safety in motels, as well as concerns around theft of possessions should they stay and sleep on the wards or in corridors.

The family members are not allowed to stay in the ward. They can only come into the ward when needed. Family members have to take a mat to sleep outside in the corridor, and each time we came here for 25-30 days. I am the main caretaker. I sleep like that. I have aches and pains but I have to suffer. I am tired. (C/HCMC)

The first time I spent up to tens million for renting motel out there. The first days, I didn't know how to find the cheap motel. I came to a place up

there and it cost me 300,000 VND per day (13 USD). I was shocked. It cost me a million for three days, without counting food costs. (C/HN)

In the room there is a fan and a small bed. The roof was covered by some thick papers. I'm not mentioning about the water conditions. So, that's it, I had to leave. I moved to another place. So I came to the second place, the water there was running so weak that I could not clean the soap on my body. So I stayed there from the morning to the evening that day. I brought my suitcase to another place to rent. (C/HN)

Economic challenges related to aforementioned accommodation and travel were described as adding to the already difficult economic pressures created by cancer. These are often compounded by carers having to take time away from work to support their family member. As described in Chapter 5, cost of treatment and lack of full insurance coverage can result in financial catastrophe for many patients, and by extension, their families.

My mom gets car sick, so she could not go by bus. Each time she went to Hanoi we had to pay 4 million for taxi and 2 million for the train. (C/HN)

I think that most of the cancer patients that come here are from provinces (countrysides). We face difficulties in travelling time, and worse, is the financial problems. The majority of cancer patients are in remote provinces and live in difficult conditions. We eat charity rice. We eat charity porridge. (C/HN)

Of course, the financial problem is worse when you have to stay off work. When you go to work you will have more money than when you are at home. (C/HN)

### ***Informational Needs***

Many carers described having a number of informational needs. These are categorised in two broad categories: information carers required about and for the patient related to their diagnosis, expectations for treatment, and questions about nutrition and traditional medicine; and information they needed to both support themselves, and to provide logistical information on things like accommodation and places to stay near the hospital.

Even though we are family members, our knowledge about the field of cancer is still very limited. Now I have to take care of nutrition, psychological health, and I am telling you my experience of patient care is very limited. (C/HN)

Information needs for the patient were normally prioritised by carers within the study, and is perhaps reflective of the importance placed on the caregivers role. Carers wanted information on a wide range of factors, from the aetiology of cancer, to information on the 'best' hospitals and doctors, to information on probability of survival.

We needed to choose a place to get treatment. For cancer, there are many places but how to find the best and most suitable, that is very important, because there are also many hospitals that have the ability to treat. I have to look around so that I know that here is the hospital specialized in cancer. Before I don't know the difference between hospitals. So I think it is important to choose a treatment place. (C/HCMC)

Carers often requested simple information on, for example, the stage of the patient's diagnosis and what this meant. They reported lack of accessibility to information and also the lack of communication between healthcare providers and carers and patients (often due to healthcare professionals being stretched and lacking time to have in-depth conversations as described by HCPs in Chapter 4). Information was often self-sought by carers via online resources which were often described as conflicting. This problem is potentially exacerbated by patients relying on internet sources for information about cancer, and not knowing which sources to trust and which sources were accurate.

Basically I'm not a person in the field so I do not have the knowledge but the knowledge on the Internet is too wide, so the knowledge we learn from internet is difficult to apply for the care of our family patients. What to eat, what not to eat, milk is allowed or not. Our information is not good and you don't know what to select to hear. (C/HCMC)

Information online is not selective. Information from different sources is not correct, thus the readers have the wrong understanding. So when the patient asks questions, the doctor will explain the patient exactly. But the

patient will not accept the explanations of doctor because what doctor said is different from what they hear and read.” (HCP/HCMC)

While the shared, family-orientated nature of care may alleviate stresses by not relying on a single individual, challenges were highlighted concerning communication between HCPs and a large group of people, each of whom were at the hospital at different times. Given the time pressures on HCPs and the overcrowded nature of Vietnamese oncology hospitals, this has the potential to result in the sharing of misinformation and may contribute to carers feeling like they lack specific information on how to best support patients. HCPs referenced efforts made to create solutions to communication problems, such as the creation of regular group meetings organised by the hospital to try and answer common questions from carers.

When one person comes, they take care the patient. The next person comes, they also take care the patient. So as a doctor, we feel very upset. Doctors, nursing staff, head nursing staff and nurses... they give medicines to different person each day. Sometimes the family has 8 children. Sometimes they have low awareness. They even sometimes don't hand over the medicine which is the most important” (HCP/HN)

HCPs additionally recognised that a lack of information contributes not only to poorer patient care, but also to increased levels of anxiety and stress among carers, impacting upon their health and wellbeing.

Carers expressed a need for detailed information on nutrition. Carers described a feeling of confusion or uncertainty of what they currently should be feeding the patient and when. Carers wanted to know what food they should provide (meals are not provided by the hospital) to help maximise patients' treatment and recovery. Specific dietary information was required for different types of cancer, different stages of diagnosis, and different stages of the treatment process (e.g. food for surgery, food during chemotherapy etc.).

The doctor is not able to advise you carefully about nutrition, they only consulted about the drugs or the daily necessities. I had to search the internet. But the information from internet is not the same. (C/HN)

Food for patients is sometimes provided by charities working within the hospitals. HCPs, however, described challenges in monitoring food that was donated or purchased by the charities.

Currently we also try to advise the charity people to provide nutritional meals for patients, but only some charity people agree to do, because not all charity people are also willing to do that. For charity, people are going to buy vegetables, buy meat to cook and bring people here or they use money to pay for an organization to cook but we are not sure if the food was nutritional enough so then people afraid of that. (HCP/HN)

There have been attempts in some hospitals to provide food for patients through the hospital cafeteria, but patients and their families are still expected to pay for the meal, and often are unable to do so.

We advise that nutritional meals for patients and charity meals for family members. But to tell you the truth, I witnessed that there are cases they ask for one meal but two people shared that meal because they could not afford one each. (HCP/HN)

Information needs to support the carer focused around training (discussed later in this Chapter) and on providing practical information on how to navigate the hospital administration, how to find cheap and comfortable accommodation, and how to support their emotional and mental health. It was suggested that resources such as booklets and online information should be created and provided to carers when they arrive in the hospitals.

### ***Emotional and Support Needs***

Carers described a wide range of emotional and psychological needs, and a lack of specialised services available to help them cope with the strain and emotional impact of caring. Carers described feelings of stress, shock (at the diagnosis), fatigue, grief, sadness, and difficulties in caring for themselves.

I need more than the sick person. The patient just lies in one place, but I am suffering. (C/HN)

I went to the coffee house after that, I went to the second floor to cry hourly, because she was diagnosed at the late stage, my mother is so old, she may die on the operating table. Then with such surgery she cannot live long either. It is very miserable psychologically and the financial problem is also a common one. I determined that for my family health is the number one priority. Talking about difficulties, there are many. (C/HN)

HCPs acknowledge that, due to the volume of patients and the severity of their needs, the emotional needs of carers are often unaddressed.

Patients have so many issues that are unable to support. So we almost skip or ignore the family member. Because obviously you have to care for your patients, and it takes your time. So apart from provide counselling you can't help much (the patients' carers). (HCP/HN)

Patients are usually worried a lot and it leads to a lot of problems such as unresponsive treatment, weight loss, appetite loss, and so on. We often tell patients not to worry much about the diseases and should think that they are not sick, they don't need to worry. Family members are very important in motivating and comforting the patient so the patient relieves depression. Usually, in the late stages, the patient is afraid of being abandoned because many caregivers have been helping for a long time, they are tired, and could not afford to pay anymore and they will abandon the patients. Patients are really afraid of that. (HCP/HCMC)

Sometimes the carers become pessimistic, they found it doesn't go anywhere so will slowly leave the patient, the patient continue to fall into depression and gives up as well. So the patient gives up, the close ones do not want to continue anymore and they ask for the discharge. We don't have chance to continue to provide treatment for them. (HCP/HCMC)

Carers additionally reported stresses upon relationships between carers and the patient, and of the lack of groups and communities from which they could seek support. Spousal conflict and challenges in decision making were frequently described, including worries about carer burnout and fatigue leading to abandonment. HCPs additionally observed similar emotions and strains, and described how patients sometimes worry that their carer will abandon them due to the stresses they experience

in their role. Most support for carers to manage their roles and associated pressures comes from their peers on the wards or in motels close to the hospitals, rather than from formalised services.

Patients often feel uncomfortable. Husbands and wives also fight and argue... so we need to calm them down, pat them. Some couples in the ward fight, and swear to each other. I told the wife to forgive the husband because he has disease and is under pressure. He denied to take drugs, swears, and asks for death. So you have to say nice words, persuade him.  
(C/HCMC)

Family members are very important in motivating and comforting the patient so the patient relieves depression. Usually, in the late stages, the patient is afraid of being abandoned because many caregivers have been helping for a long time, they are tired, and could not afford to pay anymore and they will abandon the patients. Patients are really afraid of that.  
(HCP/HCMC)

### ***Training needs***

Carers indicated a need for training and preparation for being a carer, particularly around certain clinical procedures. This included information on how to care for their family member and how best to support them during their treatment and recovery, and may be linked to the expectation on carers to be decision makers during treatment. Due to the crowded nature of hospitals, carers described having to undertake roles in providing medical treatment, for example holding chemotherapy bags, holding IV fluids, and changing dressings on wounds. Carers reported needing specific training to fulfil these roles, particularly given that they would need to continue some of these roles when the patient is discharged.

By the end of the week, the doctors and nurses are busy. If I call, it takes them a very long time to get here because they are busy taking care of many people. Sometimes I have to learn how to do it myself. Sometimes I even want to learn the way to get the veins myself. They are so busy that sometimes they make mistakes. (C/HN)

I have asked the doctor very carefully, so when the doctor came, I asked him what is the best way to stop bleeding and how to treat hemorrhage. The doctor told us some methods, so now it's stable. But the thing is when I get home, I don't know how to treat. (C/HCMC)

Along with specific training, carers highlighted the need for clearer signposting to different services and sources of information. While some supportive resources and services have been developed (such as information sessions, online groups, leaflets and posters), often carers were unaware of how to access them and where they can find out information on what is available. HCPs recognized the value of having carers who were trained and prepared, and suggested that training could be provided to carers to better support them. Additionally, while paid caregiving remains uncommon in Vietnam, some HCPs suggested this was a possible area for growth.

The training of caregivers is very essential. Actually, it is necessary to have a school which organizes nursing classes or class for carers. Before, there existed places that trained for caring staff. (HCP/HN)

We need more services for the people, to take care for the patients, when the son has to work very far. It's also available but not the hospital's service. People do not know how to work. I also want to find people, from a service center, with a little training. (C/HN)

#### **8.4 Discussion**

Cancer carers in Vietnam are experiencing multiple unmet needs. These unmet needs often affect carer's health, and influence the extent to which they can adequately care for patients. Needs are material, informational, and emotional.

The nature and burden of caring in Vietnam has likely shifted dramatically within a short period. For much of history, caring would have been in response to (mainly) infectious and communicable disease. Such disease required care for short periods. Cancer, and many non-communicable diseases, change this model. The increased and increasing cancer burden in Vietnam (Pham et al. 2019; S. M. Nguyen et al. 2019), however, has not changed how caregiving is conceptualised. Carers are still expected to be present and central in the care of their family member, and are expected to sacrifice time, work, and often their own health in order to do so. Cancer, as shown

within this, and many other studies, requires time-intensive care, often for prolonged periods in specialised and centralised oncology hospitals.

Caring and family are largely synonymous and inseparable in Vietnam. One study exploring the needs of Vietnamese caregivers in Canada, described this view that caring obligations are so internalised into the role of family, stating “It’s is like eating, you just do it’ (Donovan and Williams 2015). This study found similar themes and highlighted the importance of thinking about the needs of carers both individually, and in terms of supporting the care of patients. The contextual overview at the beginning of this thesis also highlighted norms around how family is conceptualised that are relevant to the interpretation of the results from this study. For example, after marriage many women move into the homes of her new husband’s family. Many of the woman’s responsibilities (care and domestic obligations) often transfer from her biological family to her husband’s family (Malarney 2003). This norm was not discussed within our study but could be an area for further analysis.

Cancer remains poorly understood and there is low awareness concerning what to expect within both treatment and care (Thuan et al. 2016). Cancer treatments are invasive and often permanent. And cancer is expensive (H. Minh et al. 2017; N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013). All these factors make the experience of caring for someone with cancer in Vietnam (largely) new. New forms of support have yet to be developed despite this need and the changing burden of care, and as a result carers are living with a high level of sustained and unmet needs.

Patient support networks are becoming increasingly established for people diagnosed with cancer in Vietnam. Such clubs are reported by patients to have provided significant emotional support and solidarity as patients navigate difficult shared experiences. Such clubs have not yet been established for carers, and may represent a possible area for exploration. “The club is for patients. The patient’s family is busy. The patients meet together and exchange, and try to change the atmosphere. I think it is possible for patients to meet each other and they will have fun chatting” (C/HN). Support for carers remains absent. Given the importance of carers, it is important to consider integrating them into the health system, providing effective information and support, and at the same time, creating mechanisms within the health

system to support their own health and wellbeing. Carers support networks, therefore, may be one useful mechanism through which this can be achieved.

Information resources (both online and physical) along with the creation of communal rooms for carers to stay in when they have to leave the wards, should be considered. Such pragmatic, low cost interventions have the potential to greatly reduce challenges experienced by carers, and should be explored within future interventions. Training courses may support capacity-building for carers and may also provide a point of contact for face-to-face dissemination of information specific to caring. They may also support preparedness for caring outside of the hospital. Interventions testing training for dementia carers have been previously trailed with success (Sousa et al. 2016), and could be explored in relation to the specific needs of cancer carers in either Vietnam or in other LMICs.

As this study was conducted in hospital settings it is likely not reflective of specific or different needs that carers experience at home and in the community. In-depth research that also explores different needs for people caring in the community should be explored. Given difficulties in accessing oncology hospitals due to location and costs, research on needs to the community may be required to support carers with the most pronounced challenges.

## **8.5 Conclusion**

This chapter has attempted to provide a final piece of context-setting empirical data on the experience of cancer and breast cancer in Vietnam. It complements the data presented in Chapters 6 and 7, and has highlighted the importance of carers. It has described the changing context and burden around caring in Vietnam from the perspective of carers. Carers describe challenges they face in terms of lacking information, requiring emotional support, and requiring training and signposting of different services. Interventions that trial different physical and online informational and supportive resources would be an invaluable next step in supporting carers manage both the health of patients as well as supporting their own health and wellbeing. Integration and increased visibility and recognition of carers within the health care system would likely benefit both carers and the people they care for.

## Chapter 9

### **Implications for Breast Cancer Service Delivery in Vietnam**

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This thesis has presented data from diverse key stakeholders within contemporary debates concerning breast cancer service delivery in Vietnam. With studies involving relatively small and localised datasets, it wouldn't be appropriate to claim that this thesis presents a comprehensive picture of breast cancer in Vietnam. However, through using several different data collection methods, and through the inclusion and input from multiple key stakeholders (and particularly the inclusion of voices and experiences of women, carers, and healthcare providers), this thesis has been able to produce an initial contextual overview from which recommendations can be deduced and future research pathways identified.

It is additionally hoped that the findings and reflections presented within this thesis also promote learning and reflection among the global health community, provide an example of a collaborative multi-institutional research partnership, and stimulate conversation on how to improve and appropriately reform elements of practice.

#### **9.1 Connecting Research to National and Global Agendas**

The Vietnamese government and Ministry of Health have highlighted their objectives for tackling NCDs through their strategic plans for the control and management of NCDs (MoH, Vietnam 2015c). Broad objectives have been identified, such as to "organise a system for prevention, early detection, diagnostics, treatment and management of NCD from central level to commune level nationwide"; and for "strengthening the system of examination and treatment facilities to provide comprehensive, advanced and high-tech services in diagnosis and treatment of patients with NCDs, and at the same time providing technical support for lower level facilities, ensuring early detection, effective treatment and continuing long term management of NCDs" (MoH, Vietnam 2015c). Detailed plans are not yet available, although challenges such as poor quality of data, limited knowledge of healthcare providers, no comprehensive screening and limited equipment are all noted as challenges with the national strategy for cancer control (B. D. Nguyen 2011).

The Ministry of Health's vision and objectives complement the wider global health agenda. NCDs have increasingly gained recognition as an area of global focus. Goal 3 of the Sustainable Development Goals (SDGs) aims to "Ensure healthy lives and promote well-being for all at all ages" and to reduce premature mortality from non-communicable diseases through prevention and treatment by 33% by 2030 (UN 2015). The SDGs provide a comprehensive framework for global priorities that were ratified by 193 countries in the UN General Assembly in 2015. Throughout the SDGs there is a strong health equity agenda, seen most clearly through a focus on universal healthcare coverage, and explicitly referenced in Goal 10: Reduce Inequalities. The achievement of many of these goals are considered explicitly linked and interconnected (Ginsburg, Bray, et al. 2017). As discussed in Chapter 3, the political context and history in Vietnam is strongly equity and equality focused. This has likely influenced drives towards universal health coverage and extension of the social health insurance programme, and through appealing to similar values and ideas, the extension and strengthening of breast cancer services may also be achieved. Full universal health coverage has been achieved by neighbouring countries in Malaysia (100%) and Thailand (98%), suggesting it is a viable target for Vietnam (H. Minh et al. 2014).

Globally, cancer outcomes for women remain highly unequal (Ginsburg, Bray, et al. 2017). Samarasekera and Horton highlight that the disparity in outcomes and global burden of cancer is mirrored by a funding and advocacy context in which women's cancers are still largely considered a disease only experienced in high-income countries (Samarasekera and Horton 2017). They highlight that improvements for cancer care for both cervical and breast cancer are viable in LMICs, despite a lingering fatalism in which interventions are considered too expensive and in which other women's health challenges take priority. They state categorically that "cost-effective, feasible interventions and global policy options exist" (Samarasekera and Horton 2017).

## **8.2 Context & Health Systems**

Global health, non-communicable diseases, and cancer represent a complex network of intersecting national and international policy arenas, often at odds with each other and frequently disconnected. Context is

crucial to successfully drive radical transformation to close the cancer divide for women (Ginsburg, Badwe, et al. 2017).

Understanding and appreciating context, and how it impacts upon the organisation and delivery of health services, has been a central theme with this thesis. Context can be understood as the beliefs and practices regarding health, the experiences of people regarding their health, the organisation of the health system, the capacity of healthcare professionals, the historical development of services, external characteristics and factors impacting upon an intervention, the global picture including historic and contemporary power inequalities, as well as global funding streams and priorities (Craig, Di Ruggiero, and et. al. 2018; Moore et al. 2015; Pfadenhauer et al. 2017). Context can relate to individuals, families and societies. It is often specific for different geographies and population groups. It can relate to media and health messaging, and it is often intrinsically connected to political systems and government.

Given this broad and interconnected understanding of context, this thesis has attempted to collect data from key stakeholders within these different areas. This thesis presents information on the history of Vietnam, the development of the health system, and different factors impacting upon it (Chapter 3). It has presented an overview of published data on breast cancer service delivery and explained the current organisation of the health system regarding oncology services (Chapter 4). It has explored media messaging on breast cancer, given that the media is often the principal source of information for people regarding their health (Chapter 5). Chapter 6 captures reflections and data from healthcare providers at different levels of the Vietnamese health system on challenges experienced in providing services. Chapter 7 highlights the direct experience of women with a breast cancer diagnosis, while Chapter 8 describes the broader experiences of families and support networks in caring for someone with a cancer diagnosis. Viewed together, this thesis represents a broad and diverse data set with key input from multiple stakeholder groups, and provides a broad context from which future recommendations and research can be developed (Figure 9.1).

Viewing these diverse datasets as a whole is important when making recommendations that are cognisant of the whole health system, and how decisions

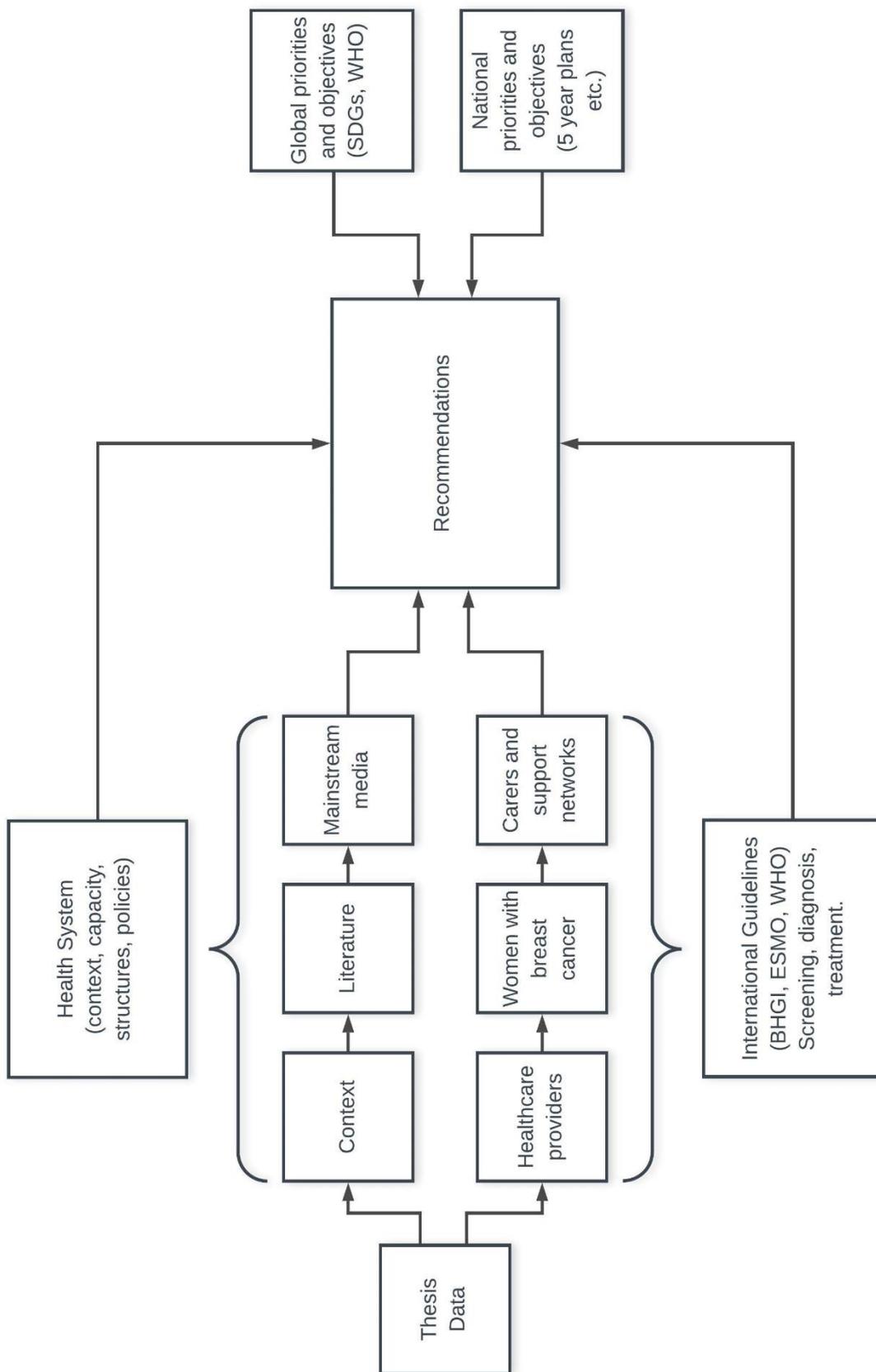


Figure 9.1: Overview of research process for informing evidence-based recommendations

made on one area have the potential to create consequences and problems in other areas. As affirmed by the WHO, in their Systems Thinking for Health Systems Strengthening report, “Every intervention, from the simplest to the most complex, has an effect on the overall system, and the overall system has an effect on every intervention” (WHO & Alliance for Health Policy and Systems Research 2009).

Health systems are complex, interconnected, and often opaque. Recommendations generated from the data in this thesis need to be relevant regarding the current capacity and structure of the health system. Equally, international guidelines have been developed for breast cancer prevention, control and treatment in low and middle income contexts. The data generated within this thesis helps us to benchmark and assess compliance with these international guidelines. This chapter will highlight the connections between these different areas and discuss the possible implications for health system reform and future research. It will then introduce discussion comparing findings with the WHO’s Health Systems framework, and the Beyond the Building Blocks framework introduced in Chapter 2.

### **9.3 Implications for breast cancer service delivery in Vietnam**

Previous data and published literature have shown that breast cancer is a growing burden in Vietnam (Thuan et al. 2016). Incidence is increasing while stage of diagnosis and mortality remain late and high (GLOBOCAN 2018; N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013; Dinh Nguyen 2011; Trieu, Mello-Thoms, and Brennan 2015).

Data from this thesis indicates that breast cancer remains poorly understood in Vietnam. Women with breast cancer and carers of cancer patients in our studies lacked knowledge about causation, prevention and treatment expectations, particularly prior to a confirmed diagnosis. Women discussed pervasive views and beliefs that cancer is incurable even when treated. Stigma associated with cancer is still common and likely a key barrier to women presenting early for diagnosis (as discussed in Chapter 7).

Information about awareness in the general population (as opposed to women already with a breast cancer diagnosis) is still required. Recall from patients on their beliefs about cancer prior to their diagnosis is helpful in highlighting possible trends, although further population-based research on this important topic is needed. Downstaging of breast cancer is more likely to be effective when a population is well informed and

knowledgeable about signs and symptoms of disease, as well as being aware of how to access the health system. The WHO states that raising population awareness of symptoms of breast cancer remains one of the key strategies within a population-based control programme (WHO 2019a).

A particularly interesting contrast exists between the large amount of factual and informative content returned within the mainstream media (online platforms of newspapers in Vietnam) analysis presented in Chapter 5, and the lack of knowledge about breast cancer described by women. It might be deduced from this contrast that information about breast cancer is available (and as presented in Chapter 5, Vietnam has a high literacy rate, therefore making such information accessible), but that the message and/or the medium through which it is communicated is ineffective for reaching its target audience(s).

This contrast is also likely reflective of the need for more nuanced media models than that of the linear Transmission Model developed by Shannon and Weaver (Fomin 2019). Media messaging, and how people interact with the media, is complex. Models such as that developed by Lewis and Lewis (Lewis and Lewis 2015) (presented in Chapter 3) that understand health messaging as more than the diffusion and dissemination of facts, should be integrated into health promotional campaigns and interventions. Active audience engagement, production and creation of content could help inform future health promotional interventions, especially given the lack of media content focusing on the individual experiences and stories of women with breast cancer. More media content describing specific experiences of Vietnamese women could be potentially used to raise knowledge and awareness of how to conduct a breast self-exam and on the importance of quickly seeking out professional support if a woman becomes aware of symptoms.

Although women in Vietnam face multiple social and cultural pressures and expectations around modesty and stoicism, and given that stigmatisation was a theme in our studies (as highlighted particularly in Chapter 7), such media content may provide the opportunity to normalise conversations around cancer and women's health, as it has done in other contexts (for example, the impact of Jade Goody's experience of cervical cancer in the UK (Lancucki et al. 2012; Bowring and Walker 2010). Should this theme be explored further in future research or interventions, it

would need to be approached with sensitivity and led by willing Vietnamese patient advocates.

While examples from international contexts may be informative, this research suggests that there is a need for culturally-specific information and its dissemination in Vietnam, particularly regarding nutrition in both prevention and treatment of breast cancer. To the best of our knowledge, no other studies on cancer have as explicitly highlighted the link between conceptions of health and nutrition in Vietnam, however, there is a more substantial body of literature in other fields such as social science and anthropology (Jamieson 1995; Shillabeer 2016).

Nutrition was discussed across all key stakeholders groups interviewed in studies within this thesis, however, women with breast cancer and carers (Chapter 7 and 8) focused most explicitly on the linkages between food and health. Food is considered to have both preventative and curative qualities (associated with the restoration of balance in the body, of *yin* and *yang*, and hot and cold foods). Carers particularly discussed food and the need for cancer-specific information on nutrition. This is possibly because they considered the provision of food to be one of their key roles in caring for someone with a cancer diagnosis, and is likely linked to structures in hospitals in which provision of food to patients is not considered the role of the hospital or hospital staff. Given the importance in how people conceptualise health and nutrition, it's inclusion (cancer-specific nutrition information on e.g. what to eat during different phases of treatment) should be considered within future messaging and information dissemination campaigns.

Such preventative measures such as increasing awareness and knowledge, as well as increasing access to early detection and screening facilities particularly at lower levels of the health system (discussed in both Chapter 6 and 7), may contribute to a downstaging of breast cancer in Vietnam. As discussed, stage of diagnosis in Vietnam is typically late, with some studies suggesting as high as 64% of women may be diagnosed at stages III and IV (Dinh Nguyen 2011). Other studies report similarly high numbers of 49.5% (Thuan et al. 2016) and 36.4% (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013) diagnosed as stages III and IV. Although Lan and colleagues (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013) estimated no significant differences in costs of treatment for groups diagnosed earlier and groups diagnosed later, they did

note that survival times were significantly longer for those women diagnosed earlier. Strengthening prevention and promoting early detection may be one method for reducing the overall burden of breast cancer on both women and the health system.

The need to increase knowledge, understanding, and early detection of breast cancer at a population-wide level, however, may also pose particular ethical challenges regarding the implications for the rest of the health system. Data presented in this thesis indicates that the Vietnamese health system is not yet sufficiently supported and equipped to provide holistic, accessible and effective breast cancer treatment services for those in need. Increasing awareness and encouraging screening therefore runs the risk of increasing unmet demand for services leaving women with a diagnosis of breast cancer but few options for treatment, and the associated financial, social, and psychological impacts that have been documented in this thesis (reported in Chapter 5).

There are currently no systematic and regular national population-based screening campaigns in Vietnam. Screening programmes that have been implemented have often not been accompanied with systematic data collection, and costing studies trialling different screening or treatment methods are localised and limited (N.H. Lan, Laohasiriwong, Stewart, Wright, et al. 2013). Screening is currently not covered by the social health insurance model and screening coverage is estimated at as low as 10% of eligible women nationwide (Harper 2011). Chapter 6 highlights the limited and unsystematic nature of community-based screening programmes in Vietnam, which are often led by hospitals at central and/or provincial levels. These programmes are often funded from the budgets of higher facilities, and as such are only implemented should there be a surplus budget. It is unclear the extent to which the absence of regular centralised screening programmes is related to lack of systemic capacity, resourcing challenges, or concerns related to upstream implications of extending screening for the health system.

The ability of healthcare providers to conduct clinical breast exams is variable, as is knowledge from women on how to conduct self-examination. No large scale surveys have provided data on exact levels of knowledge, but the study presented in Chapter 6 of this thesis suggests that only 59% of HCPs at commune level conducted CBEs at their facility. Additionally, only 16.7% and 17.2% of providers surveyed at district

and commune health stations respectively reported having received breast cancer specific training, and only 6.9% of respondents at commune level reporting having a technical role (e.g. assisting in the screening procedures) supporting the delivery of community-based screening programmes. Increased and specific training for breast cancer were identified by HCPs as priority areas across all levels of the health system. Targeted strengthening may be required in specific regions and provinces, as shown by the variation (narrative-based, not statistically significant) described by providers surveyed and interviewed in different provinces.

A review of previous studies also identified one screening campaign of 50,000 women in Vietnam which reported having challenges related to lack of diagnostic equipment, and lack of health insurance coverage (MoH, Vietnam 2015b). Challenges for accessing screening services are particularly pronounced in rural areas and lower levels of the health system, and if a women is diagnosed with breast cancer there are multiple economic, bureaucratic, and logistical barriers to accessing treatment services. Again, systems strengthening and provision of services at lower levels of the health system (accompanied with appropriate training of HCPs and resourcing) may reduce these challenges.

Should screening be extended, decisions will need to be taken on the type of screening procedure to use. Our review of existing literature identified one study that indicated a possible cost-benefit of CBE as a screening method, estimated at 994.96 USD per life-year saved (N.H. Lan, Laohasiriwong, Stewart, Wright, et al. 2013). CBE is largely supported to downstage symptomatic breast cancer where mammography is unavailable (Brennan 2016; Benjamin O. Anderson et al. 2008). Some international studies have additionally suggested benefits of CBE reporting no differences in long-term mortality rate between using CBE and mammography, with others arguing that downstaging by CBE is more effective than asymptomatic mammography screening for reducing mortality in LMICs (Miller et al. 2014; Yip 2019).

Further costing studies on breast cancer screening methods are required to offer empirical economic evidence to policy makers in Vietnam. This is particularly important because other international studies have questioned the benefits of CBE screening, citing that no randomised control trails have been conducted showing benefit to reducing mortality (Denny et al. 2017). Additionally, observational studies

on this subject have produced inconsistent findings (B.O. Anderson et al. 2015). Difficulties in synthesising data on the impact of CBE have also been described by Brennan, highlighting that “the technique of CBE is not well described in most studies, and is generally not standardised in clinical practice nor clinical trials” (Brennan 2016).

Early detection guidelines from the Breast Health Global Initiative (BHGI) indicate that CBE along with referral for mammography in positive cases, along with mammography screening in a target group, should be implemented in limited resource countries with the goal of downstaging symptomatic disease, while treatment should be focused on mastectomy breast conserving surgery (Benjamin O. Anderson et al. 2008). Denny and colleagues importantly note that “although breast cancer downstaging might be a necessary prerequisite to improving breast cancer outcomes and quality of life, alone it would be unlikely to reduce mortality since the benefits of early detection can only be realised if it is followed by prompt diagnosis and effective multimodal treatment” (Denny et al. 2017). The need for such holistic health system strengthening in Vietnam is also shown in Chapter 6 and the review of literature (Chapter 4), which indicate a lack of capacity at some hospitals to conduct pathological testing (B. D. Nguyen 2010), with trends of misdiagnosis also being reported by many women and carers within our studies (Chapters 7 and 8).

When considering cancer screening options in LMICs, Sullivan et.al additionally describe the need for infrastructure, education and advocacy, and consideration of the ethical issues regarding access to treatment (T. Sullivan, Sullivan, and Ginsburg 2015). Women participating in studies in this thesis (reported most extensively in Chapters 7 and 8) described significant economic, geographic, and social barriers to accessing treatment. Barriers included lack of insurance, partial insurance coverage of costs, and significant out-of-pocket expenses. Study participants were able to at least partially access treatment, but are likely not reflective of the experience of many women in Vietnam.

#### **9.4: Breast Cancer Services in Vietnam and the Building Blocks Framework**

The WHO’s Health Systems Framework and it’s 6 Building Blocks of (i) service delivery, (ii) health workforce, (iii) health information systems, (iv) access to essential medicines, (v) financing, and (vi) leadership/governance provide a framework to

discuss findings generated by the studies in this thesis. Combined with the additional elements of ‘household production of health’, the inclusion of multiple stakeholders in health, and ‘social determinants of health’ introduced by Sacks et. al. (Sacks et al. 2019), these concepts allow a discussion on the strengths and limitations of breast cancer service delivery in Vietnam.

Findings from this thesis suggest that improvements could be made across all 6 Building Blocks of the WHO’s framework. Breast cancer service delivery is limited, particularly at lower levels of the health system; the health workforce lacks training at lower levels of the health system; health information in the form of cancer registries lack integration and completeness; funding of NCD and cancer services remains comparatively low; and while NCD plans exist, there are no comprehensive or detailed plans for improving breast cancer outcomes. Recognising the many improvements to cancer services over a short period of time, and the scale of the challenge, all 6 areas require strengthening.

Regarding treatment specifically, research in this thesis has indicated that specialised and centralised oncology hospitals currently provide most treatment with support from provincial and district hospitals for minor procedures (MoH, Vietnam 2013b). However, there is a great deal of variation in capacity of different hospitals to provide such services. The results of the scoping review (Chapter 3) report that 10 of 63 provincial hospitals do not have access to radiotherapy equipment, and staff in 10 hospitals indicated they could not guarantee provision of surgical interventions (WHO 2011). As shown in Chapter 6, there was also a high variation reported by healthcare providers across provincial hospitals within our study, with only two of the three provincial hospitals reporting the capacity to provide surgery and chemotherapy, and only one of the three hospitals providing radiotherapy.

Beyond the 6 Building Blocks, Sacks et. al. highlight the need to consider key stakeholders, social determinants of health and the household production of health. It is clear from the findings presented in this thesis that multiple social and economic barriers exist to accessing breast cancer services, that effective interventions will need to engage with beliefs and norms about breast cancer and seek to influence health behaviours; and that women’s voices have been largely absent from current planning processes. Sacks’ model also highlights the need to develop partnerships and to

support community-based responses to both health promotion and training of community health workers. These responses appear underdeveloped for cancer in Vietnam, and may represent an area for future focus.

Economic barriers to accessing services were reported across studies in this thesis. The current insurance model often appears provide enough coverage for some women to initiate treatment. However, frequently women abandon treatment or risk impoverishment due to the large portion of costs they must pay out-of-pocket. Costs related to both significant direct medical costs as well as indirect costs associated with travel, hospital administration, and loss of income. The results of the study presented in Chapter 7 indicated that while provisions such as the certificate of the poor have likely increased access to services for the most economically marginalised, the group sometimes referred to in Vietnam as the “near-poor” (often informal workers) may be at greatest risk of being unable to cover costs of treatment. Findings from this thesis are coherent with data presented within other studies describing high rates of treatment non-completion for women (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013) and high levels of financial catastrophe for women undergoing treatment (R. Sullivan et al. 2015).

The World Bank estimates that average annual income in Vietnam is 2,400 USD (2018 figures) (World Bank 2018a). Given the costs described by women in treatment (women in our study not in receipt of certificates of the poor reported costs ranging from 13,000-35,000 USD), it is easy to see why breast cancer treatment (even with insurance) is inaccessible to large parts of the population. Even with much more modest cost estimates (Lan and colleagues (N.H. Lan, Laohasiriwong, Stewart, Tung, et al. 2013) estimated costs for 5 years of treatment at an average of 975 USD per patient in a study in 2010<sup>4</sup>), costs are likely restrictive for many women. While social health insurance coverage has increased significantly in Vietnam from 60% to 87% between 2010 and 2018 (WHO 2019b; Ministry of Health, Vietnam 2017), if Vietnam is to reach its goals of achieving universal health coverage, further interventions (for example extending payment exemptions to the poorest in society as well as reducing co-payment costs for treatment) may need considered.

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<sup>4</sup> See Chapter 7 for discussion on this disparity.

Policy changes extending insurance coverage need to be coupled with interventions to increase the capacity to provide breast cancer services, not only in national centralised hospitals but also in facilities operating at lower levels of the health system. Extending capacity to provincial hospitals is already occurring in some provinces in Vietnam, with specialised oncology hospitals opening in provinces such as Bac Giang. Further system strengthening at provincial levels could reduce out-of-pocket payments for travel and accommodation costs. This would reduce geographic and economic barriers to treatment, while also reducing the burden and overcrowding experienced at higher levels of the health system.

These recommendations are supported by literature from other LMIC contexts (Muñoz et al. 2017; Yiengprugsawan et al. 2017). In their systematic review of decentralisation of health systems in LMICs, Munoz and colleagues (Muñoz et al. 2017) report that accompanied with appropriate training, skills and good leadership, decentralisation of service delivery could have positive impacts on health outcomes. Such systems strengthening are likely to allow greater patient/physician contact time, increase capacity across the health system, improve communication and holistic care, and will likely improve experiences for carers and support networks as well as for women with breast cancer.

### **9.5: A Phased Approach to Strengthening Breast Cancer Services in Vietnam. A suggested Roadmap**

Given the screening challenges and the ethical questions related to increasing early detection, increasing access to treatment services is one important area and priority within breast cancer service strengthening. Data from this thesis would indicate further work on reducing barriers to accessing treatment (social determinants of health) and further health systems strengthening (the WHO's 6 Building Blocks) are required before the BHGI guidelines on screening and treatment could be holistically implemented across the Vietnamese health system. As barriers to treatment are reduced, screening and knowledge and awareness campaigns can be extended. A phased approach to systems strengthening (as shown in Figure 9.2) could be considered as a way to balance immediate needs with ethical considerations regarding capacity to treat. Such phasing could include both core and complimenting actions, with the goal of achieving both national targets, and ensuring compliance with

international guidelines and benchmarks. Complimenting actions (Figure 9.2), such as piloting of screening and knowledge and awareness campaigns are likely to provide useful information and learning that can be scaled-up when the health system has the capacity to meet increasing demands.

| Suggested Phasing of Health Systems Strengthening for Breast Cancer Services in Vietnam |   |  |
|---|---|--|
|   | Core Actions  | Complimentary Actions  |
| Phase 1   | <ul style="list-style-type: none"> <li>- Development of national plans for breast cancer control and treatment</li> <li>- Audits of capacity of health system to provide breast cancer services along the treatment pathway</li> <li>- Context setting research and gathering empirical evidence to inform the strengthening of services</li> </ul>   | <ul style="list-style-type: none"> <li>- Interventions with the objective of gathering data to inform how to raise population knowledge and awareness, reduce stigma around breast cancer, and encourage early detection and diagnosis</li> </ul>  |
| Phase 2   | <ul style="list-style-type: none"> <li>- Development of detailed, target orientated strategic plans for breast cancer control and treatment</li> <li>- Supporting development of integrated population-wide cancer registry and systematic data collection</li> <li>- System strengthening through supporting the training of healthcare providers and integration of some services (such as CBE, ultrasound and follow up care) into lower levels of the health system</li> <li>- Continued strengthening of higher levels of the health system to reduce variations in capacity to treat</li> <li>- Reduce barriers to treatment through continuing to expand the social health insurance programme, with objective of achieving universal health coverage</li> </ul> | <ul style="list-style-type: none"> <li>- Trialing of screening programmes and supporting targeted community-based screening initiatives in provinces with capacity to treat</li> <li>- Nationwide campaigns on increasing awareness and knowledge, normalising conversations about breast cancer, and reducing stigma</li> <li>- Formalising and strengthening support to carers and families of people affected by breast cancer</li> </ul> |
| Phase 3   | <ul style="list-style-type: none"> <li>- Development of population-based screening programme (CBE with referral) in target population group</li> <li>- Social health insurance coverage extended to include screening procedures</li> <li>- Central funding of community-based screening programmes</li> <li>- Targeted programmes to support early detection and access to treatment for women from ethnic minority groups and high risk groups</li> </ul>   | <ul style="list-style-type: none"> <li>- Engagement with patient groups, carers, healthcare providers and other key stakeholders to evaluate programmes and make recommendations on further service reform</li> </ul>  |

Figure 9.2: Suggested phasing of health systems strengthening for breast cancer services in Vietnam.

As shown in Figure 9.2, and in evidence provided within the chapters of this thesis, progress has already been made in Vietnam towards achieving goals in both phases 1 and 2. Health information systems are being developed and barriers such as incomplete insurance coverage are being addressed. These suggestions may be seen as a possible initial roadmap building on this momentum, but should be complimented with further evidence, studies, and key stakeholder input.

Given the positive initiatives already introduced by the Vietnamese government (described in Chapters 1 and 3), and increased recognition of the growing burden of NCDs, these suggestions are likely in line with the current trajectory of the Ministry of Health and Provincial Departments of Health. Objectives set by the Ministry of Health (MoH, Vietnam 2015c) need to be matched with detailed plans of service extension and system strengthening based on locally generated, high-quality quantitative and qualitative data. Such work would also contribute to health financing reform and efforts to strengthen the capacity of Vietnam's health workforce. As previously highlighted in this section, strengthening local levels of the health system is only feasible and ethical should the appropriate investment in resources and training be provided to achieve that objective. Directing patients to lower levels of the health system without this investment could be potentially damaging for their treatment and care. Choices relating to the allocation of resources will be a significant determinant on whether these phased recommendations are feasible.

## **9.6 Implications for global health research, partnership development and training**

Global health partnerships are, and are likely to remain, necessary for the production of well targeted and rigorous research. Genuine partnerships are now listed as a prerequisite in grant applications for funds from many global health agencies. This highlights the need for global health researchers to think and plan for how such partnerships should be created, managed, and implemented.

Much is written within the global health literature on the need to create equity in collaborations (Crane 2011; Eyben 2006; Chambers 1997; P. Farmer 2005). However, often practitioners in this field do not meet their own standards (Boum II et al. 2018; Gautier, Sieleunou, and Kalolo 2018). If we are to radically change and improve the direction, efficacy and possibilities within the field of global health research, inverting

power relations (rather than equalising them) should be the primary goal (McCoy et al. 2008). Researchers and research institutions from LMICs have the contextual knowledge and language skills needed to carry out rigorous research. Because they are embedded in the research settings, they are also best placed to be able to carry out longitudinal and cohort studies, which require a large degree of continuity and sustainability. The role of researchers from high-income countries should then focus upon providing training, area-specific guidance and advice, and funding.

Reframing partnerships provides not only opportunities to create environments that may be more conducive to producing good research (e.g. by empowering researchers from LMICs with extensive contextual knowledge of their own countries); but also may encourage institutional power shifts from high to middle and low income countries. The concept of ‘capacity building’ should be equally redefined. Currently, this concept is almost exclusively applied to the development of capacity and training of researchers working at institutions in LMICs, and often only as an ‘add-on’ to core research programmes. In reality, researchers from high-income countries learn just as much, if not more, from working with partners in LMICs than what they provide to partners through formal training workshops. The recognition of this dynamic would likely help us to redefine partnerships as a whole, in which benefits and learning are shared between institutions. The delivery of workshops and training from partners at both high income and LMIC institutions and the receipt of training from students across both institutions should become normal practice, and could greatly improve capacity, understanding and knowledge across entire research teams.

### **9.7 Strengths, Limitations and Next Steps for Research**

As previously stated, this thesis has been able to collate diverse data from multiple different stakeholder groups and information sources, and has provided a holistic contextual overview of how breast cancer services are organised and the context in which they are delivered. In the scoping review conducted to inform this thesis knowledge gaps were identified relating to: the lived experience of women with a breast cancer diagnosis and challenges they faced in accessing services; how the health system functions, challenges experienced in delivering services from the perspective of healthcare providers; and levels of knowledge of healthcare providers on breast cancer. This thesis has addressed each of these knowledge gaps and has additionally:

collated and analysed existing literature and evidence; compared findings in relation to both Ministry of Health targets and plans as well as international guidelines and benchmarks; and sourced additional data on breast cancer from both the mainstream media in Vietnam and from carers and support networks. The experiences of women with breast cancer, carers, and healthcare providers constitute evidence, and are important to inform health system reform and service delivery in Vietnam. This thesis has contextualised these data within a wider discussion on global health and global health research partnerships, providing critically reflective data from the entire research team who supported the production of this thesis.

The thesis has a number of limitations, which are also indicative of areas for future research. Sample sizes in the mixed methods study presented in Chapter 6 were small, and as such made statistical analysis impossible. It was never intended that these studies would provide a comprehensive overview of breast cancer in Vietnam, but rather that they provide initial data from which larger studies can be developed to check, corroborate, and scrutinise findings on a broader scale, and inform the development of interventions to test theories and recommendations suggested in the thesis.

This thesis largely identifies challenges for women who are from the majority Kinh ethnic group. Research on the specific needs and challenges of ethnic groups have not yet been conducted and were beyond the capacity of this thesis. Given that many ethnic groups live in remote and mountainous areas, speak different languages, and have different social and cultural norms, specific research related to their levels of knowledge on breast cancer (and other NCDs) as well as their engagement with the health system may be useful. Given that evidence also suggests that ethnic minority groups in Vietnam often have poorer health outcomes (UNFPA 2011), such research should be considered an area of priority. Further qualitative research on gender and relationship dynamics related to breast cancer conceptualisation would be equally important. Large costings studies both examining discrepancies in self-reported costs highlighted in this thesis, and studies costing different scenarios for breast cancer service delivery would be of immeasurable use to policymakers.

The study on the unmet needs of informal carers highlighted both the important role played by carers and the challenges they experience. This is an under-researched area

in Vietnam, particularly in the area of cancer, and it is hoped this chapter provides important data to inform future research and intervention development to better support and integrate carers into the health system. This is important for many reasons. For example, one study suggested that breast cancer is the leading cause of life years spent with disability in 119 countries, with clear implications and challenges posed for carers and families (Ginsburg, Bray, et al. 2017). This study, however, only addressed the needs of carers in hospital and in-patient settings. No data was collected on the (likely) different needs of carers in the community and at home. Given research also suggesting a lack of palliative training for healthcare providers in both hospitals and the community, with only 8% of 392 surveyed physicians responding that they had enough training on providing palliative services (Tsao et al. 2019), it is necessary to support broader in-depth research on both caring and palliation.

This thesis also presented data from an analysis of online media content from mainstream newspapers. The findings of this should be corroborated and deepened through studies exploring social media content specifically, given that our study identified high use of internet, smart phones, and social media in Vietnam, and the likelihood that information presented online may be different to that presented through mainstream media outlets (Hunter et al. 2019).

## Conclusion

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In a short period of time, Vietnam has successfully expanded access to health services, invested in improved health infrastructure and systems, and has seen significant gains across several indicators of health. However, the growing burden of NCDs in general and cancer in particular creates new challenges for the health system and requires interconnected solutions. Next steps should include supporting the systematic collection of data (both qualitative studies and randomized trials of interventions) to provide evidence to find the most effective and cost-effective ways to reduce barriers to accessing services. New qualitative studies could focus more explicitly on themes of gender roles and relationships, and how these impact on both the conceptualisation and experience of breast cancer, or on the needs of women from ethnic minority communities. Additionally, investing in training, equipment and infrastructure are all components conducive to achieving both national and global targets for reducing the burden of breast cancer.

Other work outside the health system arena, such as social engagement and efforts to destigmatize cancer, are also needed. The normalisation of discussions around breast cancer, increased visibility of women with a diagnosis, and an explicitly gendered approach to reducing social and cultural barriers to improving women's health and wellbeing should all be considered within a holistic, phased and multi-layered strategy to downstage breast cancer diagnoses. Recognition and support for carers and families who care for people with a cancer diagnosis is equally important.

This thesis has attempted to provide evidence of the need for such change through collating and analysing the existing evidence base as well as providing empirical data from key stakeholders. It has developed an evidence-based suggested roadmap of phased and interconnected health system reforms aimed at improving access to breast cancer services for women. This roadmap attempts to balance immediate needs of women with the current capacity of the health system, alongside ethical considerations regarding access to treatment services.

This work to reduce the impact of breast cancer is only one component in much wider national and global efforts to improve the lives of women and their families who are

affected by breast cancer. It is hoped that this thesis can support and encourage future Vietnamese researchers, policymakers and healthcare professionals as they continue their work in this hugely important area.

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## Appendix

**Appendix Item 4A: Data table (titles & key findings) of articles identified within the scoping review (not inclusive of grey literature, eg. Government reports/decrees/NGO reports).**

| <b>Breast Cancer in Vietnam. Articles Identified within the Scoping Review<br/>(not inclusive of grey literature, eg. Government reports/decrees/NGO reports)</b> |             |  |  |                 |
|---|-------------|--|--|-----------------|
| <b>Author</b>   | <b>Date</b> | <b>Title</b>   | <b>Findings</b>  | <b>Language</b> |
| <i>Meeting inclusion criteria (Keywords; 'Breast Cancer' &amp; 'Vietnam' (English) and 'Breast Cancer' (Vietnamese) in the title)</i>                             |             |  |  |                 |
| Trieu, P. D. <i>et al.</i>  | 2017        | Risk Factors of Female Breast Cancer in Vietnam: A Case-Control Study          | <ul style="list-style-type: none"> <li>• Significant association between breast density, menopause status, number of pregnancies, number of babies born, hormone use and levels of physical activity with breast cancer in Vietnamese women.</li> </ul>  | English         |
| Nguyen, J. <i>et al.</i>  | 2016        | A Matched Case-Control Study of Risk Factors for Breast Cancer Risk in Vietnam | <ul style="list-style-type: none"> <li>• Body Mass Index, lower parity, and later first childbirth all associated with breast cancer</li> <li>• Four or more births significantly reduced the chance of breast cancer</li> <li>• No significant difference between breast cancer and age at menarche, age at first parity, total months breastfeeding, oral contraceptive use, and menopause.</li> </ul> | English         |
| Trieu, P. D. Y. <i>et al.</i>   | 2015        | Female breast cancer in Vietnam: a comparison across Asian specific regions    | <ul style="list-style-type: none"> <li>• Breast cancer is the most common cancer for women in Vietnam. In the 1990s, the most common site-cancer was cervical/uterus</li> <li>• Breast cancer is commonly diagnosed at later stages (Stage II = 61.2%) and in women between the ages of 45-55</li> </ul>   | English         |

|                              |      |   |   |            |
|------------------------------|------|---|---|------------|
|                              |      |   | <ul style="list-style-type: none"> <li>• Geographical variations. Hanoi has almost double the incidence of Ho Chi Minh city.</li> </ul>   |            |
| Le Thanh Duc <i>et al</i>    | 2015 | The role, efficacy, feasibility of neoadjuvant AP regimen in inoperable stage III breast cancer ( <i>PhD Thesis</i> ) | <ul style="list-style-type: none"> <li>• By using AP regimen as neoadjuvant chemotherapy, the survival of the patients with inoperable stage III breast cancer was improved.</li> </ul>   | Vietnamese |
| Nguyen, T.T.C. <i>et al.</i> | 2014 | Cost-Utility Analysis of Trastuzumab in Treatment Of Metastatic Her2-Positive Breast Cancer in Vietnam                | <ul style="list-style-type: none"> <li>• The treatment of metastatic HER2-positive breast cancer with Trastuzumab is considered cost-effective in Vietnam</li> </ul>  | English    |
| Dieu Dieu                    | 2013 | Trends of breast cancer in Vietnam  | <ul style="list-style-type: none"> <li>• From 2004 to 2008, the prevalence of breast cancer increased rapidly from the age of 30-34 and peaked at 55-59 at the rate of 135.0 / 100,000 people</li> </ul>  | Vietnamese |
| Lan, N. H. <i>et al.</i>     | 2013 | Survival probability and prognostic factors for breast cancer patients in Vietnam                                     | <ul style="list-style-type: none"> <li>• Survival rates for breast cancer in Vietnam is lower than other countries of similar socioeconomic level and that have similar stages of diagnosis</li> <li>• Married women with breast cancer have a significantly lower survival rate than unmarried women, and women diagnosed at later stages had worse survival rates</li> </ul>                      | English    |
| Lan, N. H. <i>et al.</i>     | 2013 | Cost of treatment for breast cancer in central Vietnam  | <ul style="list-style-type: none"> <li>• Direct medical costs for the treatment of breast cancer in Vietnam were estimated at \$975 per patient (range: \$11.7-\$3,955)</li> <li>• Patients without health insurance had significantly lower levels of service utilisation</li> <li>• Costs do not differ for patients diagnosed early or late, but survival times differ significantly.</li> </ul> | English    |

|   |      |  |   |  |            |
|---|------|--|---|--|------------|
| Lan, N. H. <i>et al.</i>  | 2013 |  | Cost-Effectiveness Analysis of a Screening Program for Breast Cancer in Vietnam   | <ul style="list-style-type: none"> <li>• Implementation of a CBE programme for women aged 40-55 would increase life years gained.</li> <li>• CBE screening in Vietnam, by WHO criteria, is considered a cost-effective screening intervention</li> </ul>               | English    |
| Thuan Tran Van <i>et al</i>   | 2013 |  | Breast cancer and risk factors related to family history in Vietnamese women      | <ul style="list-style-type: none"> <li>• Approximately 10% of breast cancers are inherited</li> <li>• The rate of breast cancer is higher in those who smoke, drink alcohol, live in rural areas and have higher BMI but the difference was not significant</li> </ul> | Vietnamese |
| Dinh Nguyen, T.   | 2011 |  | Breast Cancer in Surgery in Vietnam   | <ul style="list-style-type: none"> <li>• Breast cancer is often diagnosed late in Vietnam</li> <li>• Most women undergo mastectomy</li> <li>• Demonstrated effectiveness in curative treatments, with low recurrence and high five-year survival</li> </ul>            | English    |
| Tu Nguyen Thi Nhu <i>et al</i>  | 2010 |  | Factors related to breast cancer knowledge of women in Binh Dinh province in 2010 | <ul style="list-style-type: none"> <li>• General knowledge and awareness of symptoms and signs of breast cancer was low</li> </ul>   | Vietnamese |
| Duc Nguyen Ba <i>et al</i>  | 2003 |  | Breast cancer   | <ul style="list-style-type: none"> <li>• Women who have mothers, sisters, and daughters with breast cancer were at higher risk than those who have no family history of breast cancer</li> </ul>   | Vietnamese |
| <i>Additional articles included within analysis (Keywords not in title)</i> |      |  |   |  |            |
| Thuan, T. V. <i>et al.</i>  | 2016 |  | Cancer Control in Vietnam. Where are we?  | <ul style="list-style-type: none"> <li>• 49.5% of women diagnosed at Stages III &amp; IV</li> </ul>  | English    |

|                            |      |   |  |            |
|----------------------------|------|---|--|------------|
|                            |      |   | <ul style="list-style-type: none"> <li>• Screening campaigns are costly, and emphasis should be put on increasing levels of awareness of symptoms and treatment options</li> <li>• High costs for patients and partial insurance coverage leads to high levels of treatment non-completion</li> </ul>  |            |
| Tiep Do Quoc               | 2015 | Knowledge of cancer prevention in Quang Binh province   | <ul style="list-style-type: none"> <li>• Knowledge about the risk of breast cancer was limited</li> <li>• Knowledge about signs or symptoms of breast cancer was also low</li> </ul>   | Vietnamese |
| Thuan Tran Van             | 2013 | Cancer Prevention   | <ul style="list-style-type: none"> <li>• Increased risk of breast cancer in women with menstruation after 18 years of age, the first births over 20 years old are statistically significant</li> </ul>   | Vietnamese |
| Dieu, B. <i>et al.</i>     | 2012 | Cancer Challenges and National Cancer Control Programs to 2020 (Vietnam)                          | <ul style="list-style-type: none"> <li>• The breast cancer incidence in Vietnam has increased steadily over the last decade from a crude rate of 13.8 per 100,000 women in 2000 to 29.9 per 100,000 women in 2010, with an estimated 12,533 breast cancer cases in the country. The estimated number of breast cancer cases in 2020 is 38.1 per 100,000</li> </ul> | Vietnamese |
| Duc Nguyen Ba <i>et al</i> | 2010 | Results of national cancer program 2008-2010  | <ul style="list-style-type: none"> <li>• 9 of 63 provincial hospitals had no functioning pathology departments and 10 cannot admit patients with cancer. Cancer patients are referred to other hospitals with oncology departments</li> </ul>  | Vietnamese |
| Vach Trinh Huu             | 2010 | Assessment of the need for cancer prevention for the community in Hanoi, Hue and Ho Chi Minh City | <ul style="list-style-type: none"> <li>• Only 16% are aware of the risk factor of non-breastfeeding. Other factors such as not having children or late first childbirth, unhealthy diet, smoking, using hormone therapies over a prolonged long time (including birth control pills) were very low</li> </ul>  | Vietnamese |

**Appendix Item 5A: Data collection matrix for media content and discourse analysis.**

**Coding Sheet: Breast Cancer in Vietnam**  
 coder initials .....

| 1 Article ID |                    |        |        |        |
|--------------|--------------------|--------|--------|--------|
|              | Letter<br>(Source) | NUMBER | NUMBER | NUMBER |

| 2 Date of Article |       |      |
|-------------------|-------|------|
| Day               | Month | Year |
|                   |       |      |

| 3 Headline (full) |
|-------------------|
|                   |
|                   |
|                   |

| 4 Link (if online) |
|--------------------|
|                    |

| 6 Location of article (if in paper) |   |
|-------------------------------------|---|
| Front Page                          | 1 |
| Not Front Page                      | 2 |

| 6 Focus of Article          |   |
|-----------------------------|---|
| Cancer (inc. breast cancer) | 1 |
| Breast cancer specifically  | 2 |

| 7 Word Count |        |        |        |
|--------------|--------|--------|--------|
|              |        |        |        |
| NUMBER       | NUMBER | NUMBER | NUMBER |

| 5 Rate headline   |   |
|---|---|
| Alarmist (likely to increase reader anxiety, emotive language)    | 1 |
| Reassuring (likely to reduce reader anxiety)                      | 2 |
| Neither /Nor (tends to be factual, a statement or bland language) | 3 |

| 8 Lead Paragraph |
|------------------|
|                  |
|                  |
|                  |

| Are any of the following expressed in the text?  | YES | NO |
|--|-----|----|
| States breast cancer rates   | 1   | 2  |
| Mentions breast cancer incidence as increasing   | 1   | 2  |
| Correctly mentions risk factors related to breast cancer   | 1   | 2  |
| Incorrectly identifies risk factors (eg. karmic beliefs/other)   | 1   | 2  |
| Casual Factors linked to Westernisation (of/ eg. diet)   | 1   | 2  |
| Correctly identifies symptoms of breast cancer   | 1   | 2  |
| Incorrectly identifies symptoms of breast cancer   | 1   | 2  |
| Encourages women to speak to their healthcare provider if they experience symptoms                                 | 1   | 2  |
| Mentions treatment options for women with breast cancer in a <b>reassuring</b> tone (ie treatment can be curative) | 1   | 2  |
| Mentions treatment options for women with breast cancer in an <b>alarmist</b> tone ('deforming', hair loss)        | 1   | 2  |
| Mentions economic challenges for women with a breast cancer diagnosis  | 1   | 2  |
| Mentions financial catastrophe related to breast cancer treatment  | 1   | 2  |
| Mentions breast cancer as a burden to the health system  | 1   | 2  |
| Mentions social challenges related to breast cancer, such as stigmatisation or experiencing discrimination         | 1   | 2  |
| Mentions breast cancer as a cosmetic / beauty problem  | 1   | 2  |
| Mentions women with breast cancer experiencing relationship breakdown with intimate partners                       | 1   | 2  |
| Mentions Government interventions to support women with breast cancer  | 1   | 2  |
| Mentions social support networks for women with breast cancer  | 1   | 2  |
| Mentions arts-interventions to raise awareness about symptoms of breast cancer                                     | 1   | 2  |
| Mentions arts-interventions to reduce stigmatisation of women with breast cancer                                   | 1   | 2  |
| Mentions traditional medicine as viable alternative to biomedical interventions                                    | 1   | 2  |
| Mentions screening options for breast cancer   | 1   | 2  |
| Describes what is involved in a screening procedure  | 1   | 2  |
| Provides information on where and how to access screening services   | 1   | 2  |
| Blames women for their diagnosis (karmic causes)   | 1   | 2  |
| Blames women for their diagnosis (for delaying speaking to a healthcare provider)                                  | 1   | 2  |
| Criticises the health system and healthcare providers for lack of systematic capacity to respond to breast cancer  | 1   | 2  |

|   |   |   |
|---|---|---|
| Advertises pharmaceutical interventions or products for breast cancer | 1 | 2 |
| Other   | 1 | 2 |
| Other   | 1 | 2 |
| Other   | 1 | 2 |
| Other   | 1 | 2 |

|   |            |
|---|------------|
| 10 <b>Qualitative Analysis (1)</b><br>(Content and quotations included within the article)  |            |
| Stakeholder Position 'VOICE' (journalist, patient, survivor, healthcare provider, government official etc., and information on organisation stakeholder represents if applicable) | Key Quotes |
|   |            |
|   |            |
|   |            |
|   |            |
|   |            |

|                                   |
|-----------------------------------|
| 11 <b>Researchers Reflections</b> |
|                                   |

## IMAGE or VIDEO Information

1. Image/Video description (duration, context):
2. Position of Image (top of article, included within article, end of article)
3. Position size: Full page, half page, quarter page, smaller than a quarter page
4. Include copy of image if possible:

**Appendix Item 5B: Titles and lead paragraphs of each item included within the media content and discourse analysis.**

| Code | Title  | Lead Paragraph  |
|------|--|---|
| A001 | The desperate situation of women with breast cancer                                      | Not only poor, now she also got breast cancer, which makes things even more difficult. Even though suffering from the disease, she still has to take care of her mother whose legs were amputated due to diabetes complications and her daughter who is going to go to university |
| A002 | Risk of breast cancer due to being too thin earlier in life                              | A recent research found that being underweight when young will increase the risk of breast cancer when premenopausal  |
| A003 | Is it possible to “seal” the protein in order to prevent breast cancer?                  | Scientists have found that by preventing some proteins from reacting with h progesterone (sexual hormone to maintain pregnancy), it is possible to prevent breast cancer among people carrying the high-risk genes  |
| A004 | Breakthrough: An injection may “disintegrate” the tumor of terminal cancer               | A woman who was predicted to has only few months left to live by doctors, after all breast cancer treatments had failed, was cured completely after a breakthrough injection  |
| A005 | Almost 95 million goes to Ms. Hue who has breast cancer                                  | With her husband passed away long time ago, Ms. Hue has to struggle on her own to raise two children. Unfortunately, recently she was also diagnosed with metastasis breast cancer, hence was hospitalized for treatments with many difficulties still lie ahead                  |
| A006 | Is it necessary for female breast cancer patients at early stage to receive chemotherapy | Most women with breast cancer at earlier stage don’t need chemotherapy post-surgery. This result was published on 3/6/2018 by the breast cancer treatment piloting program funded by the US Government in USA and 5 different countries   |
| A007 | Is the increase of CA 15-3 the sign of breast cancer                                     | Many women are worry that they have breast cancer due to their blood test show high CA 15 – 3 score. So, what is CA 15-3 and is its increase the sign of breast cancer?   |
| A008 | Breast cancer patient: Cancer cells develop faster in the case of hard tissue            | According to a recent published research on Biomaterials, women with thicker and harder breast tissue will have higher risk of breast cancer, due to thick breast tissue provide the condition for cancer cells to attack normal cells  |
| A009 | How can fish help prevent breast cancer?   | Breast cancer emerges when the cells in breast start developing uncontrollably. Some of the symptoms of breast cancer include having lumps in breast, nipple fluids and changes of shape or structure of the nipple or breast.  |
| A010 | Breast cancer among young people: Do you know how to protect yourselves?                 | In all countries, the average age of getting breast cancer is 60 – 65 years old. However, according to experts, in Viet Nam, the average age of getting breast cancer is only 40 – 50 years old. In some case, the patients were diagnosed when they are still very young.        |
| A011 | Early detection of breast cancer through self-check at home                              | Thanks to periodically breast checking at home by touching, Mrs. T.T.N (63 years old, Ha Noi) was able to find a breast tumor at phase I – the early stage of breast cancer. After having an operation to remove the tumor, preserve the breast combine with medicine, her        |

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|      |   | condition is now stable, and no cancer cell is found anymore.   |
| A012 | Breast cancer detection:<br>Experiment cancer test using urine sample                     | A Japanese company is ready to implement the first experiment on cancer diagnosis using urine sample, allowing better screening of this fatal disease   |
| A013 | What do women need to do in order to prevent breast cancer?                               | Breast cancer is the most common kind of cancer among women, which takes away thousands of lives annually. According to the doctors, prevention is always better than treatment, and at each age, women need to take specific prevention methods  |
| A014 | Breast cancer treatment using radiotherapy: More beneficial than harmful                  | Many breast cancer patients said they've heard scary stories regarding radiotherapy, however, in fact their experiences were much better, several recent researches mentioned.  |
| A015 | 6 simple ways to reduce the risk of breast cancer   | According to the US Cancer Association, 1 in every 8 women has the risk of getting breast cancer in life. However, by implementing the following positive activities, the risk of getting breast cancer will be reduced significantly   |
| A016 | What are good exercises for breast cancer patients?                                       | Research has found how practicing aerobic and bodyweight exercises may prolong the life expectancy of people who were successfully cured.   |
| A017 | First medicine for women who acquired breast cancer from genetic mutation                 | FDA had licensed the first medicine for late stage breast cancer due to genetic reason similar to the actress Angelina Jolie  |
| A018 | 90% of men are surprised to have breast cancer  | Almost 90% of the men who were diagnosed with breast cancer by doctors were quite surprised to get this disease   |
| A019 | Birth control pills increase the risk of breast cancer by 20%                             | According to a new research from Sweden, the uses of hormone-based contraceptives such as birth control pills may increase the risk of breast cancer by 20%   |
| A020 | 02 more medicines for metastatic breast cancer treatment are implemented in Viet Nam      | 02 new medicines targeting HER2-positive metastasis breast cancer: pertuzumab and trastuzumab emtansine (T-DM1) are officially used in Viet Nam   |
| A021 | Breast cancer may return after 20 years   | According to researchers, breast cancer may "lay low" and recur after 20 years unless the patients maintain the use of medicine to prevent it.  |
| A022 | Treatment for advanced stage breast cancer: There are cases survive for more than 4 years | According to Dr. Le Thanh Duc, Director of the 5th Internal Medicine Department (National Cancer Hospital), the life expectancy of breast cancer patients has improved in the last 10 years   |
| A023 | Would breast cancer become a burden of Viet Nam   | According to Dr. Tran Nguyen Ha, Director of 4th Internal Medicine Department, Hochiminh City Cancer Hospital, breast cancer is in the top 5 most common cancer among Vietnamese women and is predicted to soon take the lead position, as comparing to other countries, the current prevalence is low, but have the trend to rise quickly. |
| A024 | 20 stars who "battled" breast cancer  | From the prevention campaign by Lesley Murphy to Rita Wilson's call for other women from her own  |

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|      |  | experiences, listen to the stars sharing their stories of overcoming the disease.   |
| B003 | Chance for breast cancer screening, consultation by professor from Singapore       | Only one time on 24/7, Prof. Dr Mikael Hartman will come to the Singapore - Viet Nam Cancer Clinic to provide counselling and screening and treatment.                              |
| B004 | The Singaporean Professor, Doctor who treated hundreds of breast cancer patients   | Dr. Mikael Hartman used to drive 25.000km by motorbike from Singapore to Sweden to raise a fund and awareness on breast cancer in Asia.   |
| B006 | Female nurse has her breasts removed after 9 family members got cancer             | 24-year-old Esther Taylor is among the youngest British women to have surgery to remove her breast in order to prevent breast cancer  |
| B010 | Treating breast cancer without chemotherapy  | A research on more than 10.000 breast cancer patients in the U.S has pointed out that sometimes chemotherapy is unnecessary, expensive, all the while causing serious side-effects. |
| B014 | Breast cancer patient becomes photo fashion model                                  | Designer Li Lam invited many women to wear her dresses in order to inspire people to live positively  |
| B015 | 10 years having regular health screening, yet didn't know having got breast cancer | Obsessed and worried of old-age diseases, Mrs. Mai in District 7, Ho Chi Minh City regularly had periodical health check. Yet breast cancer still caught up to her unexpectedly     |
| B017 | TVB star's grief over inability to have children due to breast cancer              | Dreaming of bearing children for her husband, still Lam Thuc Man had to give her dream up to get treatment  |
| B026 | Signs of breast cancer on body that men should pay attention                       | The symptoms of breast cancer in men are similar to women: finding a lump, inverted nipple, fluid, abnormal breast development...   |
| B029 | Breast removed due to doctor mistook test result with breast cancer patient's      | 46 years old Maryam Yazdany (Britain) are suffering from pain and stress after having one of her breast removed as the hospital mistakenly diagnosed her with breast cancer         |
| B030 | Contraceptives increase the risk of getting breast cancer                          | Hormone-based contraceptives such as daily pill and implant may increase the risk of getting breast cancer among women by 38%.  |
| B031 | Women who get breast cancer earlier in life may have high risk of recurrence       | Young women who get breast cancer usually carry the mutated BRCA1/2 gene, and will have higher risk of getting breast cancer on the other breast than others.                       |
| B032 | Breast cancer may recur after 15 years   | Scientists have found that breast cancer may recur and spread after 15-20 years since its declination.  |
| B033 | 3-year-old child help aunt discover cancer by chance                               | Had Freddy not unexpectedly hit his aunt's chest, 46-year-old Michelle Brown (England) wouldn't have found the breast tumor and gotten treatment in time.                           |
| B034 | New medicine helps lengthen the life of breast cancer patients in Viet Nam         | The Ministry of Health has just licensed 02 new medicines to treat HER2-positive metastasis breast cancer, in turn helps increasing patients' lives by 5 years.                     |
| B036 | Peelings on skin may be signs of rare breast cancer                                | Starting with a peeling with the size of a rice on nipple, the wound took long time to heal and started to spread, Mrs. Ninh was diagnosed with breast paget.                       |
| B037 | Discover 72 new mutations leading to breast cancer                                 | Scientists have just discovered 72 more mutations related to breast cancer, increasing the number of high-risk mutations to almost 180.   |

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| B039 | Wrong breast cancer diagnosis made woman lose both breasts         | Elisha Cooke-Moore (USA) never thought she would be in such an awkward situation. Having been informed that she has genes causing cancer, the 36-year-old mother expected to have her uterus and both her breast removed. Only afterward that she found that she was completely healthy. |
| B040 | 500 women participated Singapore-standard breast cancer screening  | Almost 500 women participated in the campaign "Adore your bust, choose early screening" organized by Singapore-Viet Nam Cancer Clinic in Ho Chi Minh City  |
| B042 | Charmed actress cried receiving chemotherapy for breast cancer     | "I was so sick, I felt like losing myself ", actress Shannen Doherty spoke of the first time receiving breast cancer chemotherapy.   |
| B043 | 8 hospital provides free breast cancer screening for patients      | About 10.000 women from 40 years old were provided screening, breast ultrasound and mammography if suspected of cancer.  |
| B044 | Hair dyes are suspected to cause breast cancer                     | A research in England has found that regular hair dyeing would increase the risk of getting breast cancer among women.   |
| B045 | Angelina Jolie's doctor shared 10 tips on breast cancer prevention | Dr. Kristi Funk advises women to eat more cruciferous vegetables, fruits with high oxidants, drink soy milk... in order to prevent breast cancer.  |
| B047 | From a wart on breast, a woman discovered her breast cancer        | Mrs. Tien found a small wart on her left breast when performed self-examination. When she came to hospital for biopsy and was diagnosed with breast cancer.  |
| B048 | 8 simple methods to prevent breast cancer                          | Breast feeding, maintain weight, proper diet, have genetic examination if there are relatives with breast cancer ... will help women to reduce the risk of getting the disease.  |
| B049 | 4 common misunderstandings about breast cancer in women            | Many people wrongfully assume that the larger the breast the easier to get cancer, or breast tension before menstruation is the sign of breast cancer.   |
| B050 | Man breast swollen to weight 4kg due to breast cancer              | Having an ulcer on the left breast, Mr. Quyen thought that was caused by insect, was diagnosed with breast cancer after having it checked.   |
| B051 | Breast cancer battle diary of a mother                             | 32-year-old Melissa Thompson (USA) shares her story in order to inspire people with the same situation.  |
| B052 | Breast cancer may spread to other body parts                       | Cancer cells may spread to bone, liver, lung, brain through blood veins and pea-shaped lymph nodes   |
| B054 | Workaholic woman overcame breast cancer twice in 16 years          | Having her right breast removed at 33, 16 years later, cancer cells spread to her left breast, however, not once that Mrs. Hoang Anh had the intention to give up.   |
| B055 | 5 ways to keep positive after breast cancer treatment              | Practice exercises at least 30 minutes a day; have a good diet; stay positive... are the best remedies for health.   |
| B056 | Girls with precocious puberty have higher risk of breast cancer    | If the girl starts her period when she is 8, parents better take their daughter for a health screening   |
| B057 | Breast dents warn risk of breast cancer                            | The tumor is an accurate factor for breast cancer diagnosis, some changes of the body such as dents on breast may also be the warning sign of the disease.   |
| C001 | Miraculous fruit that eliminates breast cancer cells               | Researchers from Texas, USA have found that the extracts from peaches can kill cancer cells, ever in the case of the most "problematic" ones.  |

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| C002 | Good habits effectively prevent breast cancer any women can do regularly          | Breast cancer is a dangerous disease among women. However, there are daily activities that may help reducing the risk of getting its.   |
| C003 | Women who dye hair regularly have higher risk of getting breast cancer            | Medical Professor Kefah Mokbel from Princess Grace Hospital, London recently has performed a study and concluded that women who dye hair regularly have high risk of getting breast cancer.   |
| C004 | Stay away from bread if you have breast cancer                                    | A substance found in bread may obstruct or reverse the effect of breast cancer medicine.  |
| C005 | Marvela responded to breast cancer prevention campaign                            | Recently, the cooking oil products Marvela A & D3 (under Marvela Viet Nam) at all supermarkets had put on pink ribbons. It is announced that this is a community activity through the cooperation between Marvela and Breast Cancer Network Vietnam in response to the call for breast cancer prevention in Viet Nam. |
| C006 | New treatment choice for female breast cancer patients                            | Exemestane is a new medicine to treat breast cancer, which is more effective than the now common medicine to treat metastasis cancer -Tamoxifen in preventing metastasis breast cancer among young women, as well as the ones who had surgery to inhibit ovarian function.  |
| C007 | Treating breast cancer with CBB therapy   | CBB therapy allows therapists to accurately target the position of the removed tumor, in order to prevent the radioactive rays to affect the remaining normal breast cells.   |
| C008 | Wife accepts to wear diaper over breast to maintain husband life                  | Even though having metastasis breast cancer, but as her husband had a stroke, Mrs. Hien accepted to wear diaper over her chest to save the little money left to sustain her husband's life.   |
| C009 | What food breast cancer patients must avoid                                       | Non-Communicable Diseases (NCDs) are resulted from unhealthy habits people may have. Breast cancer is among the most typical NCDs.  |
| C010 | Women who regularly do these activities have higher risk of getting breast cancer | A recent research has found that women who dye hair regularly have higher chance of getting breast cancer than others   |
| C011 | 350 free breast cancer screening chances at The Garden                            | On 9/10/2017, The Garden Mall shall cooperate with Hong Ngoc General Hospital to give away 350 chances of free breast screening and ultrasound for women above 30 years old from 12 - 20/10/2017.   |
| C012 | The foods which are cancer's "bane" and good for patients                         | 8 meals mentioned in the following article should be remembered if you want to improve your immune system and prevent breast cancer.  |
| C013 | What should be known about breast cancer?   | Breast cancer occurs mostly among women, but men may also get the disease. Breast cancer is the most common type of cancer as well as the leading cause of death among women in industrial countries  |
| C014 | Inexpensive traditional remedies for breast cancer                                | Breast cancer is a dangerous and common disease among women, which may threaten the lives of the patients as well as their survivability. Eastern Medicine and traditional medicine has several remedies for breast cancer treatment from available ingredients   |

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| C015 | What cause leading to breast cancer?                                     | Breast cancer is the type of cancer developed from milk duct epithelium or the lobes at the other end of the breast, after which they will multiply and spread directly to other tissues or parts of the body.  |
| C016 | Blue ganoderma cures breast cancer                                       | Blue garnoderma is a valuable herb to cancer patients: breast cancer, stomach cancer, liver cancer, the rare substances found in garnoderma help eliminating cancer cells and protect healthy cells.  |
| C017 | Completely cured of breast cancer thanks to Crinum Latifolium            | Depend on the stage of disease, the patient's health, other related factors, the doctor shall prescribe the most suitable treatment for breast cancer patients.   |
| C018 | What should you refrain from when having breast cancer?                  | Diet also plays an important role in parallel to the treatment in treating breast cancer. Hence, it is worth concerned what breast cancer patients should refrain from eating.  |
| C019 | "Naïve" mistakes about breast cancer                                     | Many people still think that breast cancer is mostly due to genetic, or young women wouldn't get this disease, or getting breast cancer means having a tumor... All of these are wrongful thoughts of such a dangerous disease.   |
| D002 | Screen for breast cancer when turning 40                                 | It is the message emphasized at the launching of the Action month for breast cancer prevention by the Ministry of Health, Cancer patients support fund – Bright future and other partners on October 14 on Hanoi Opera House Square   |
| E001 | 15 recommendations to prevent breast cancer                              | Breast cancer is the most common and the leading cause of mortality among women in industrial countries. This is a complicated disease, which over the years there are many studies regarding its causes and treatment. However, it is needed to detect breast cancer early through the screening of normal women. In France, for every 10 women, one will have breast cancer, but luckily, there are methods to help preventing the disease such as good diet, exercises... Following is 15 advices for breast cancer prevention |
| E002 | Signs of breast cancer   | I am 45 years old. Recently I found in my right breast, near my arm pit, a small hard stable tumor, it hurts when pressed.  |
| E003 | Eating cruciferous vegetables helps decreasing the risk of breast cancer | Cruciferous vegetables mentioned here include green cauliflower, white cauliflower, kale, cabbages. In recent years, the world is focusing on these vegetables, mainly for their surprising health benefits.  |
| E004 | Ha Tinh: provide free breast cancer screening for almost 600 women       | On morning 23/6/2018, Ha Tinh Provincial General Hospital in cooperation with the Young Doctor Association and Pharmaceutical Association, Center for Nuclear Medicine and Oncology of Bach Mai Hospital provides free breast cancer screening, counselling.  |
| E005 | Helpful meals – remedies for breast cancer treatment                     | In Eastern Medicine, breast cancer is called "Nhu Nham". In the medical documents from Yuan Dynasty, they described diseases "Đồ nhũ", "Hạch bì tương thân" with typical symptoms similar to breast cancer.   |
| E006 | Notes regarding the diet of breast cancer patients                       | There is no universal solution regarding the diet for all breast cancer patients, said Megan Morrison, Nutrition Specialist at Princess Margaret Cancer Center, Toronto   |

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| E007 | Warning signs of breast cancer in men   | Breast cancer is a common type of cancer among women. However, men should also be wary of this type of cancer, even though the chance of getting breast cancer among men is extremely lower (about 1%)  |
| E008 | How does cabbage help prevent breast cancer?  | Breast cancer is among the most dangerous diseases. Early detection and proper treatment is crucial in treating this disease  |
| E009 | Breast cancer symptoms on mammogram may increase risk of getting breast cancer      | A recent study shows that women who have abnormal symptoms in breast during periodical screening have higher chance of developing breast cancer before the next screening   |
| E010 | Breast dimples: Be wary of breast cancer  | An Australian woman, Kylie Amstrong took a photo of her breast and uploaded it to Facebook speaking about a strange symptom that was happening to her: a dim breast dimple  |
| E011 | Breast cancer, cervical cancer spares no ones, men or women                         | According to Dr. Doan Huu Nghi – Formal Director of National E Hospital, Formal Deputy Director of Vietnam National Cancer Hospital: Annually, there would be 10-20 people among 100.000 under-30 women diagnosed with cervical cancer. Whether men or women, it is still possible to get gynaecological infections, breast cancer, cervical cancer. However, these diseases can be prevented and treated by early diagnosis and timely treatment |
| E012 | Soy bean for breast cancer patients: Good or bad                                    | Rumours said that eating soy beans will increase the risk of getting certain types of cancer, especially breast cancer as estrogen is related to the development of estrogen-sensitive cancer such as breast cancer   |
| E013 | Dangerous warning symptoms of breast cancers people need to know                    | Breast cancer can be prevented if detected early. Follow are the dangerous symptoms of breast cancer that you need to know  |
| E014 | Foods that help prevent breast cancer   | Breast cancer is a complicated disease which relates to various factors. Some cannot be controlled such as gender, age, genetic   |
| E015 | 80% of breast cancer cases directly related to living conditions                    | Currently, the direct causes of breast cancer are still not found, however, a tight connection between external, internal factors and breast cancer's hormones has been discovered  |
| E016 | Acupuncture may help relieving the pains from breast cancer treatment               | Several medicines used in breast cancer treatment may cause arthritis, however a recent study found that acupuncture may help reduce this side effect   |
| E017 | New medicine for breast cancer may be beneficial for women                          | A recent clinical trial had found a new medicine for the standard regimen which slows the development of breast cancer among younger women  |
| E018 | Viet Nam receives 02 more medicine targeting HER2-positive metastasis breast cancer | At the conference “New leap in treating HER2-positive metastasis breast cancer”, leading experts from all over the country had discussed, updated information related to pertuzumab and trastuzumab emtansine (T-DM1) – 2 new medicines in the targeting treatment for metastasis breast cancer endorsed by the Ministry of Health  |
| E019 | Can breast cancer be treated without surgery?                                       | There are many treatments for breast cancer such as, surgery, chemotherapy, radiotherapy, hormonal therapy and targeting therapy  |

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| E020 | Quang Ninh: A woman with rare breast cancer is saved                                     | Doctors at Vietnam Switzerland Hospital in Uong Bi, Quang Ninh had discovered and successfully treated a rare case of breast cancer in 1 patients – which only take 1-4% among all types of breast cancer. Currently, the patients is stable, can eat, drink, walk normally  |
| E021 | Yakult supports free breast cancer screening for 10,000 women                            | This program is among the chain of activities to support breast cancer screening among women and mothers at the hospitals in Ho Chi Minh city, Hanoi and Da Nang. The main activities started on 14/10/2017  |
| E022 | Ha Tinh Young Doctor Association: Free breast cancer screening for 500 women             | Ha Tinh Young Doctor Association had cooperated with the National Cancer Hospital and Provincial General Hospital to organize a session for screening, counselling for women at the city, or from Ha Tinh and areas near there   |
| E023 | Free ultrasound, mammography for breast cancer early detection                           | In response to the campaign “We care for her – For women and the future” by the Ministry of Health and Fund to support cancer patients – Bright future. The Center for Nuclear medical and Cancer, Bach Mai hospital will accompany this program in order to implement the program “Screen for Breast cancer when turning 40”  |
| E024 | Have yourselves screened for breast cancer right away if you find a lump                 | Appearance of a lump or tumour in the breast is common among women at reproductive age. This symptom may relate to normal breast disease such as breast hyperplasia,... However, it could also be the most common symptom of breast cancer   |
| E025 | Great leaps in breast cancer treatment in Viet Nam                                       | The rate of getting breast cancer in our country is increasing as the age of patients is getting younger. However, disease prevention has achieved significant achievement over the last 10 years  |
| E026 | After turning 40, early screening for breast cancer may allow up to 80% of being treated | On October 15, within the World Breast Cancer Prevention Month, Ministry of Health, Fund to support breast cancer patient – Bright future will launch the campaign: “Breast cancer screening after turning 40” at Hochiminh City Medical and Pharmaceutical Hospital. The launching of the project is also honoured to have the present of Assoc.Prof. Dr. Nguyen Thi Kim Tien, Minister of health |
| E027 | Screen for breast cancer after turning 40  | It is the message emphasized at the launching of the Breast Cancer Screening campaign in the frame of Action month for breast cancer prevention by the Ministry of Health, Cancer patients support fund – Bright future and other partners on October 14 on Hanoi Opera House Square   |
| E028 | 8 signs of recurrence breast cancer  | At the early stage of breast cancer, surgery and chemotherapy, radiotherapy will be applied in the treatment   |
| E029 | Using leaves for breast cancer treatment: Cost money for more diseases                   | Swollen breast, ulcers, increased tumor, metastasis due to using leaves  |
| E030 | Breast feeding reduces the risk of breast cancer for both the mother and child           | Not only reducing the risk of breast cancer for the mother, breast feeding also help to reduce the risk of breast cancer in the future of her children. (According to the report of Cancer Institute).   |
| E031 | FDA endorsed the new medicine to treat recurrence breast cancer                          | The US Food and Drug Administration had just endorse Verzenio to be used to treat HER2-negative and HR-positive metastasis breast cancer patients  |

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| E032 | New promising medicine for breast cancer treatment                                | A clinical trial had found that Z-endoxifen safely and effectively shrink the tumor among women who has ER-positive metastasis breast cancer   |
| E033 | 6 simple methods to prevent breast cancer   | Breast cancer is the most common cancer among women with a high death rate. In Vietnam, for every 10 women, 01 will have a chance of developing breast cancer, which is rather high. Luckily, scientists also found simple methods which may help girls to effectively prevent breast cancer   |
| E034 | New medicine brings hope for breast cancer patients                               | Scientists have identified a molecule which may help treating breast cancer, bringing hope to patients who have already gain resistance over common treatment therapy  |
| E035 | Using antiperspirants is safe during breast cancer treatment                      | In contrary to the worry of many doctors, a recent research found that it is possible to use antiperspirant among breast cancer patients who are receiving radiotherapy  |
| E036 | Eating vegetables reduces the risk of breast cancer                               | Millions of women in the world are using HRT in combination with estrogen and progesterin in order to reduce the discomfort during menopause   |
| F001 | Shuttlecock belle Huyen Trang passed away from cancer                             | After a long struggle with cancer, shuttlecock belle Nguyen Thi Huyen Trang just could not overcome her fate   |
| F002 | 7 best methods to prevent breast cancer   | There are simple advices yet help you reduce the risk of getting breast cancer. The disease occurs when the cell in breast started to develop uncontrollable.  |
| F003 | Riding motorbikes for breast cancer prevention                                    | Nnenna Samuila and Jeminat Olumegbon started the D'Angels group in 2009, after being refused from participation by male motorbike groups in Lagos. In 2010, the 2 friends took a 617-km journey on their bike from Lagos to the Southern city, Port Harcourt. This is the moment that would change men's perception on their ability |
| F004 | 24 years old nurse had her breasts removed after 9 relatives got cancer           | Esther Taylor, a 24-year-old pediatrics nurse from Preston, Lancashire county, England has become one of the youngest women in UK to have surgical to remove breasts, even though she doesn't have the BRCA gene which cause the deadly cancer.  |
| F005 | High-risk of breast cancer for lacking vitamin D                                  | People who lack vitamin D have higher chance of getting breast cancer, colon cancer, prostate cancer, cardiovascular diseases than others. Several studies in Vietnam found that, the lack of Vitamin D is more common among women than men  |
| F006 | Shine like a star even without one's hair and breasts                             | Vietnam Breast Cancer Network cooperated with LiLam Designer to launch an album in honor of breast cancer women with the name "Always a woman to me" on Mother's day 13/5  |
| F007 | A medicine which makes the tumors glow allowing easier diagnosis of breast cancer | Scientists from Michigan University (USA) had discovered a pill which makes the tumor glow under infrared light and let doctors detect, diagnosis breast cancer earlier, easier, with higher accuracy and lower risk for patients  |
| F008 | Artificial mole helps early detection of breast cancer                            | Scientists announced that artificial mole with the ability to diagnosis early 4 types of cancer including prostate cancer, breast cancer, lung cancer and colon cancer, may become real in the next 10 years   |

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| F009 | The miraculous journey of a female journalist overcoming breast cancer                 | To Ms. Cam Bao, even after having to give up her hair, breasts, yet never did she give up her faith to live, never stop spreading her optimism to other patients  |
| F010 | Wearing pink ribbons in response to breast cancer prevention campaign                  | In Vietnam, breast cancer had surpassed cervical cancer to become the most common and the most fatal. It is estimate that annually, there is an average of 11.000 cases of breast cancer in Viet Nam  |
| F011 | Breast cancer takes 21% of the cancer cases among women                                | This information was provided at the Conference “A new leap in treating HER2-positive metastasis breast cancer”, organized by National Cancer Hospital in cooperation with the Representative Office of Hoffmann La Roche on November 11 in Hanoi |
| F012 | Identify 72 genetic mutations which may increase the risk of breast cancer among women | According to a recent study on the journal Natural and Genetic issue on October 23, scientists had discovered 72 genetic mutations which increase the risk of getting breast cancer among women   |
| F013 | “Pink fighter” to prevent breast cancer  | They are the people who eventhough have been fighting the disease, but still optimistic. Cancer actually becomes a trial to make them stronger, more beautiful and allow them to live a more meaningful life                                      |
| F014 | 11 groups with highest risk of getting breast cancer                                   | Women who have family members with breast cancer, taking many contraceptive pills, early puberty or late menopause, have higher risk of developing breast cancer than others  |
| F015 | Have breast cancer screening after turning 40  | This campaign is launched by the Fund to support cancer patients – Bright future (MOH) from 14/10 to 11/11 in large specialized hospitals in 3 cities – Hanoi, Hue and Ho Chi Minh City   |
| F016 | 14 women show their naked breasts full of scars to raise awareness on breast cancer    | 14 women volunteered to become models for photographer Ami Barwell in an album as part of the “Stand Up To Cancer” campaign during the month for raising awareness about breast cancer  |
| F017 | Breast cancer and cervical cancer screening for women above 35                         | Ho Chi Minh City Medical and Pharmaceutical University cooperated with Fund To Support Cancer Patients – Bright future (MOH) to organize the “Early screening and diagnosis of Cancer” program on 13.00 of 23/9, 30/9 and 7/10                    |
| F018 | Leading cancer among women: Breast cancer  | On average, everyday our country has 40 new cases of breast cancer, and 16 pass away from the disease. This is the most common type of cancer among women   |

**Appendix Item 5C: Image Analysis: Frequency Count Sheet**

|                                   |                            |  |
|-----------------------------------|----------------------------|--|
| No. of Images                     |                            |  |
| No. of articles with no images    |                            |  |
| <b>Image Features</b>             |                            |  |
| White Women                       | As Patients                |  |
|                                   | Non-medical                |  |
|                                   | As Medical Prof.           |  |
|                                   | A Celebrity                |  |
| Vietnamese Women                  | As Patients                |  |
|                                   | Non-medical                |  |
|                                   | As Medical Prof.           |  |
|                                   | A Celebrity                |  |
| <b>Image Features</b>             |                            |  |
| Food                              |                            |  |
| Exercise                          |                            |  |
| <b>Image is:</b>                  |                            |  |
| A medical graphic                 |                            |  |
| A food/lifestyle or other graphic |                            |  |
| <b>Image includes:</b>            |                            |  |
| A self exam                       | By white women             |  |
|                                   | By Vietnamese women        |  |
| A Medical procedure               | Involving white women      |  |
|                                   | Involving Vietnamese women |  |
| <b>Image is:</b>                  |                            |  |
| A stock image                     |                            |  |
| Not a stock image                 |                            |  |

**Appendix Item 6A: Survey tool for study on challenges experienced by healthcare professionals in delivering breast cancer services.**

QUESTIONNAIRE ABOUT BREAST CANCER SERVICES  
(NATIONAL/PROVINCIAL/DISTRICT LEVEL) (REDUCED FORM FOR COMMUNE LEVEL)

Hanoi University of Public Health

Queen's University Belfast (UK)

May-July 2017

**THIS INFORMATION IS TO HELP OUR RESEARCH TEAM COORDINATE OUR ACTIVITIES AND TO ALLOW US TO ASK FOR FURTHER INFORMATION IF NECESSARY.**

**THIS INFORMATION WILL **NOT** BE USED IN ANY REPORTS. ALL YOUR ANSWERS WILL BE TREATED WITH STRICT CONFIDENTIALITY.**

Name of health facility \_\_\_\_\_

District \_\_\_\_\_

Province \_\_\_\_\_

Name \_\_\_\_\_

Telephone number/email \_\_\_\_\_

Position of respondent \_\_\_\_\_

**If more than one respondent is consulted when completing the questionnaire:**

Name \_\_\_\_\_

Telephone number/email \_\_\_\_\_

Name \_\_\_\_\_

Telephone number/email \_\_\_\_\_

**INFORMATION AND CONSENT**

We would like your help in completing this questionnaire for our study on breast cancer services in Vietnam. The research is conducted by the Hanoi University of Public Health, Queen’s University Belfast (UK) and focuses on the accessibility and readiness of breast cancer services in Vietnam. This project has been authorised by the Ministry of Health (MOH), and our findings will help to inform the future delivery of breast cancer services in the country.

The first task of the project is to survey cancer care facilities and services using this questionnaire. Your facility was selected to participate in the completion of the questionnaire. The questionnaire is designed to identify gaps in service provision, aid the planning of service improvements, and identify the need for further studies.

The answers you provide in this questionnaire will be kept completely confidential. We ensure that your personal information will not appear in any report or presentation. Your answers will be given an anonymised identification and unique ID code. Your name will not appear in any records. Please note that you can refuse to answer questions that you feel uncomfortable to answer.

We hope that the results from the research project will contribute usefully to improving breast cancer services within the Vietnamese health system.

If you have any questions or would like to discuss anything about the study, please contact Tran Ngan at 04.62662299 or [ttn2@huph.edu.vn](mailto:ttn2@huph.edu.vn)

Are you willing to participate in the study?

Yes:

No:

Name:

---

Signed:

---

Date:

---

### ***INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE***

- Select the appropriate response to each question by **circling** the corresponding **number** next your response.
- Some of the questions may require more than one response or number to be circled.
- Please give as much relevant information as possible especially with the 'fill-in-the-blank' questions
- Follow the instructions in the right column, next to the option you choose.
- A '\*' symbol indicates additional information is included at the end of the responses options. Please read this information carefully before completing your response.
- Please take time to read the questionnaire carefully, and answer the questions with as much accuracy as possible.

### ***EXAMPLE OF HOW TO COMPLETE THE QUESTIONNAIRE***

|     |  |          |           |                              |
|-----|--|----------|-----------|------------------------------|
| B1. | Are any breast cancer screening services provided at this health facility? | Yes..... | <b>01</b> | If the answer is 02 go to B3 |
|     |  | No.....  | 02        |                              |

Answer each question using a circle, as indicated in the example above, or if the box is blank please write your answer clearly.

In this example, 'No' is indicated by circling 02. Then follow the instructions in the right hand column and move to Question B3 and skip Question B2. A 'Yes' answer is indicated by circling 01, and then answering the next question in the survey. The letter, eg. B3, relates to the section of the survey, eg. Section B.

## Section A – Overview of the facility

| Facility Identification |                          |                            |    |
|-------------------------|--------------------------|----------------------------|----|
| <b>A1.</b>              | Level of health facility | National .....             | 01 |
|                         |                          | Provincial .....           | 02 |
|                         |                          | District .....             | 03 |
|                         |                          | Commune.....               | 04 |
| <b>A2.</b>              | Grade of Facility        | Special class .....        | 01 |
|                         |                          | 1 <sup>st</sup> Class..... | 02 |
|                         |                          | 2 <sup>nd</sup> Class..... | 03 |
|                         |                          | 3 <sup>rd</sup> Class..... | 04 |
|                         |                          | 4 <sup>th</sup> Class..... | 05 |

|   |  |   |    |                              |
|---|--|---|----|------------------------------|
| <b>A3.</b>  | What activities and services relating to breast cancer are provided at this facility? (select all appropriate answers) | No services   | 01 | If the answer is 01 go to C1 |
|   |  | Health promotional activities*                            | 02 |                              |
|   |  | Training on self breast examination                       | 03 |                              |
|   |  | Community-based screening*                                | 04 |                              |
|   |  | Clinical breast examination                               | 05 |                              |
|   |  | Diagnosis (pathological confirmation)                     | 06 |                              |
|   |  | Treatment   | 07 |                              |
|   |  | Palliative Care (including Morphine injection)            | 08 |                              |
|   |  | Other (specify)   | 09 |                              |
|   |  | .....   |    |                              |
| .....   |  |   |    |                              |
| .....   |  |   |    |                              |
| .....   |  |   |    |                              |
| .....   |  |   |    |                              |
| .....   |  |   |    |                              |
| * Include breast cancer services and activities provided in conjunction with other programmes eg. cervical and breast screening |  |   |    |                              |
| <b>A4.</b>  | Do you have the staff, resources, and equipment to provide all the services you are authorised to provide?             | Yes   | 01 |                              |
|   |  | No  | 02 |                              |
|   |  | If 'No', please outline what services you cannot provide: |    |                              |
|   |  | .....   |    |                              |
|   |  | .....   |    |                              |
|   |  | .....   |    |                              |

## Section B: Services available for breast cancer

*Definition: Community-based education and screening: Activities that take place 'in the community' (outside of this health facility) and are focused on raising awareness about breast cancer or providing screening services.*

| Community-based screening and detection |  |   |                      |                              |
|---|--|---|----------------------|------------------------------|
| <b>B1.</b>                              | Does this health facility conduct or support any community-based breast cancer screening activities in the area? (both screening activities for only breast cancer or screening within wider programmes) | Yes.....<br>No.....   | 01<br>02             | If the answer is 02 go to B6 |
| <b>B2.</b>                              | What is the role of this health facility in these screening activities (select as many as apply)?  | Technical support<br>Administrative support<br>Lead the operation<br>Other (specify)<br>.....<br>.....<br>..... | 01<br>02<br>03<br>04 |                              |

| <b>B3. What activities were included in the last community-based education, awareness raising, and/or screening event?</b> |  |
|--|--|
| Services   | Provided:  |
| Training for women on breast self-examination  | 1=Yes (by staff from this facility)<br>2= Yes (by another organisation/Department)<br>3=No |
| Holding education and awareness workshops on breast cancer   | 1=Yes (by staff from this facility)<br>2= Yes (by another organisation/Department)<br>3=No |
| Conducting clinical breast examinations  | 1=Yes (by staff from this facility)<br>2= Yes (by another organisation/Department)<br>3=No |
| Conducting ultrasound tests  | 1=Yes (by staff from this facility)<br>2= Yes (by another organisation/Department)<br>3=No |
| Other (specify)  | 1=Yes (by staff from this facility)<br>2= Yes (by another organisation/Department)<br>3=No |
| Other (specify)  | 1=Yes (by staff from this facility)<br>2= Yes (by another organisation/Department)<br>3=No |
| Other (specify)  | 1=Yes (by staff from this facility)<br>2= Yes (by another organisation/Department)         |



**Definition.** Facility-based clinical breast examination: Clinical breast examination that takes place within the formal healthcare system, at the facility you work in or manage, and provided as a part of screening and detection practices.

| <b>Clinical breast examination, non-definitive diagnosis and facility-based screening activities</b>                                |                                       |  |  |
|---|---------------------------------------|--|--|
| <b>B7. Which of the following activities are provided at this health facility?</b>  |                                       |  |  |
| <b><u>(FILL IN THE NUMBER CORRESPONDING WITH THE ANSWER IN THE BLANK SPACES PROVIDED. PLEASE GIVE ANSWERS FOR EVERY COLUMN)</u></b> |                                       |  |  |
| <b>Services</b>   | <b>Provided:</b><br><br>1=Yes<br>2=No | <b>If Yes: How often are the services provided?</b><br><br>1=Every day<br>2=Twice per week or more<br>3=Weekly (less than 2 times per week)<br>4=Monthly<br>5=Quarterly<br><br>6=Less than quarterly | <b>If Yes: When was it last provided?</b><br><br>1=Today<br>2=This week<br>3=This month<br>4=In the past 3 months<br>5=In the past 6 months<br><br>6=Longer than the past 6 months |
| Advice on conducting a breast self-examination  |                                       |  |  |
| Clinical Breast Examination   |                                       |  |  |
| Ultrasound  |                                       |  |  |
| Other (specify)   |                                       |  |  |
| Other (specify)   |                                       |  |  |
| Other (specify)   |                                       |  |  |

|            |  |  |    |  |
|------------|--|--|----|--|
| <b>B8.</b> | Is opportunistic screening offered at this facility (clinical breast examination when women come to this facility for other un-related health services)? | All the time ....  | 01 |  |
|            |  | Sometimes ....   | 02 |  |
|            |  | Rarely .....   | 03 |  |
|            |  | Never.....   | 04 |  |
|            |  | Don't know ....  | 05 |  |
|            |  | If rarely or never, why?<br>.....<br>.....<br>.....<br>..... |    |  |

|            |   |       |
|------------|---|-------|
| <b>B9.</b> | Please describe in detail what happens if a women presents at this facility, or is identified during community screening, complaining of a breast lump, pain, swelling, discharge from her nipple, or other symptoms associated with breast cancer? | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
|            |   | ..... |
| .....      |   |       |

**Definition.** Definitive diagnosis: diagnosis confirmed by pathological testing and/or mammography.

|             | <b>Definitive Diagnosis</b>   |                  |                             |
|-------------|---|------------------|-----------------------------|
| <b>B10.</b> | Are diagnostic pathology confirmation services conducted at this health facility?                           | Yes.....         | 01                          |
|             |   | No.....          | 02                          |
|             |   |                  | If you answer 02 go to B17. |
| <b>B11.</b> | What diagnostic confirmation services are available at this health facility?<br><br>(Select all that apply) | Mammography..... | 01                          |
|             |   | .....            | 02                          |
|             |   | Fine Needle      | 03                          |
|             |   | Aspiration.....  | 04                          |
|             |   | Trucut           | 05                          |
|             |   | biopsy.....      | 06                          |

|             |  |   |                                  |               |
|-------------|--|---|----------------------------------|---------------|
|             |  | Excision<br>biopsy.....<br>Large volume vacuum assisted<br>biopsy.....<br>Stereotactic (mammography<br>guided)<br>biopsy.....<br>.....<br>Sentinel Lymph Node<br>biopsy.....<br>MRI<br>.....<br>....<br>Others<br>(specify).....<br>.....<br>.....<br>..... | 07<br>08<br>09                   |               |
| <b>B12.</b> | Are biopsies conducted under ultrasound guidance when appropriate?                   | Yes.....<br>.....<br>No.....<br>.....   | 01<br>02                         |               |
| <b>B13.</b> | What is routinely reported on core biopsy reports?                                   | Tumour<br>type.....<br>Tumour<br>Staging.....<br>ER (Estrogen Receptor)<br>status.....<br>PR (Progesterone Receptor)<br>status.....<br>Her2<br>Status.....<br>...<br>Others (specify<br>.....<br>.....<br>.....<br>.....                                    | 01<br>02<br>03<br>04<br>05<br>06 |               |
| <b>B14.</b> | How many patients were diagnosed with breast cancer at this health facility in 2016? | (If no figures available: please specify in the blank)  |                                  |               |
| <b>B15.</b> | Is breast cancer staging done at this facility?                                      | Yes.....<br>.....   | 01<br>02                         | If you answer |

|             |   |  |                      |                            |
|-------------|---|--|----------------------|----------------------------|
|             |   | No.....<br>.....   |                      | 02 go<br>to B17.           |
| <b>B16.</b> | What percentage of patients are diagnosed with breast cancer at each stage? (Use most recent data and state year of data) | Unknown<br><br>Stage 0<br><br>Stage I<br><br>Stage II<br><br>Stage III<br><br>Stage IV<br><br><br>100%   |                      | TOTAL                      |
|             | <b>Treatment</b>  |  |                      |                            |
| <b>B17.</b> | Does this health facility treat breast cancer?  | Yes.....<br>.....<br>No.....<br>.....  | 01<br>02             | If you answer 02 go to B33 |
| <b>B18.</b> | Does this health facility have guidelines for breast cancer treatment?  | Yes.....<br>.....<br>No.....<br>.....  | 01<br>02             | If you answer 02 go to B21 |
| <b>B19.</b> | What guidelines do you use? (Select all that apply)   | National guidelines.....<br>BHGI guidelines.....<br>...<br>ESMO guidelines.....<br>.<br>Other (specify).....<br>.....<br>.....<br>.....<br>..... | 01<br>02<br>03<br>04 |                            |
| <b>B20.</b> | In what form are the guidelines being used? (select all that apply)   | Binder/book.....<br>.....<br>Posters.....<br>.....<br>Online.....<br>.....   | 01<br>02<br>03<br>04 |                            |

|             |  |   |                            |  |
|-------------|--|---|----------------------------|--|
|             |  | Others<br>.....   |                            |  |
| <b>B21.</b> | What breast cancer treatment services are provided at this health facility?<br>(select all that apply)                   | Surgical interventions.....<br>Radiotherapy.....<br>.....<br>Chemotherapy.....<br>.....<br>Hormone therapy.....<br>Other (please specify).....<br>.....<br>.....<br>..... | 01<br>02<br>03<br>04<br>05 |  |
| <b>B22.</b> | What is the standard chemotherapy regimen used for breast cancer at this facility?                                       | Chemotherapy not provided<br>.....<br><br>Regime (write answer)<br>.....<br>.....<br>.....  | 01                         |  |
| <b>B23.</b> | Does this health facility offer adjuvant therapy (chemotherapy or hormone therapy before surgery to reduce tumour size)? | Yes.....<br>No.....   | 01<br>02                   |  |
| <b>B24.</b> | What surgical interventions are provided at this health facility?  | Surgical interventions are not provided<br>Mastectomy.....<br>.....<br>Breast-conserving surgery.....<br>Axillary surgery.....<br>Other (specify)                         | 01<br>02<br>03<br>04<br>05 |  |
| <b>B25.</b> | Is breast reconstruction surgery provided at this health facility?   | Yes (immediately).....<br>.....<br>Yes (delayed).....<br>.....<br>No.....<br>.....  | 01<br>02<br>03             |  |

|             |  |   |  |  |
|-------------|--|---|--|--|
| <b>B26.</b> | What anti-Estrogen therapies are provided at this health facility?<br>Select all that apply. | None..... 01<br>..... 02<br>Tamoxifen..... 03<br>..... 04<br>Aromatase Inhibitors.....<br>Other (specify)   |  |  |
| <b>B27.</b> | What HER2 drugs are provided at this health facility?  | None ..... 01<br>..... 02<br>. ..... 03<br>Pertuzumab ..... 04<br>.....<br>Lapatinib ..... 05<br>.....<br>Trastuzumab.....<br>.....<br>Other (specify).....<br>.....<br>..... |  |  |

|             |   |  |          |
|-------------|---|--|----------|
| <b>B28.</b> | What treatments are offered for patients diagnosed at different breast cancer stages?   | Stage I:<br><br>Stage II:<br><br>Stage III:<br><br>Stage IV: |          |
| <b>B29.</b> | How many beds are there in the treatment ward of this health facility (whole facility)? | .....  |          |
| <b>B30.</b> | Does this health facility have a specific ward for cancer patients?                     | Does not have specific ward<br>Has specific ward             | 01<br>02 |

|             |  |   |  |  |
|-------------|--|---|--|--|
|             | If yes, how many beds are in it? (state N/A if not applicable)   | Number of beds in specific ward<br>.....<br>..... |  |  |
| <b>B31.</b> | How many breast cancer patients are currently being treated at this health facility? (at the time you fill in this form) | Inpatients:<br><br>Outpatients:                   |  |  |
| <b>B32.</b> | How many breast cancer patients were treated at this health facility in 2016?  | Inpatients:<br><br>Outpatients:                   |  |  |

**Definition.** *Palliative Care: Medical care that relieves pain, symptoms and stress caused by serious illnesses, improving patients' quality of life.*

|             |  |                               |          |                           |
|-------------|--|-------------------------------|----------|---------------------------|
|             | <b>Palliative Care (including morphine injection)</b>  |                               |          |                           |
| <b>B33.</b> | Are there any palliative care activities or services provided at this health facility (including morphine injections)? | Yes.....<br>No.....           | 01<br>02 | If you answer 02 go to C1 |
| <b>B34.</b> | How many beds are there in this facility for palliative care (whole facility)?   | .....<br>.....                |          |                           |
| <b>B35.</b> | How many breast cancer patients are currently receiving palliative care from this health facility?                     | Inpatient:<br><br>Outpatient: |          |                           |
| <b>B36.</b> | How many breast cancer patients received palliative care from this facility in 2016.                                   | Inpatient:<br><br>Outpatient: |          |                           |

### Section C: Patient Referral and Record Keeping

|            |   |  |  |                           |
|------------|---|--|--|---------------------------|
| <b>C1.</b> | Are medical records created and kept for breast cancer patients?  | Yes.....<br>No.....  | 01<br>02                                     | If you answer 02 go to C5 |
| <b>C2.</b> | What information is included in the medical record for breast cancer patients? (select all that apply)  | Medical history.....<br>Observation of symptoms.....<br>Definitive diagnostic confirmation.....<br>Stage of breast cancer.....<br>Treatment provided.....<br>.....<br>Outcome of treatment.....<br>Post-discharge plan.....<br>Other (Please specify)<br>.....<br>.....<br>.....<br>.....<br>..... | 01<br>02<br>03<br>04<br>05<br>06<br>07<br>08 |                           |
| <b>C3.</b> | How is information stored? (select all that apply)  | Book.....<br>.....<br>Electronic.....<br>.....<br>Patient retained copy.....   | 01<br>02<br>03                               |                           |
| <b>C4.</b> | Is the patient's medical record electronically connected with records from any other health facilities? | Yes.....<br>No.....  | 01<br>02                                     |                           |
| <b>C5.</b> | Are patients referred to other health facilities when needed (for further diagnosis or treatment)?      | Yes.....<br>No.....<br>If not, why?  | 01<br>02                                     | If you answer             |

|             |   | .....<br>.....<br>.....<br>.....<br>.....   |                | 02<br>go<br>to<br>C12 |    |        |   |  |  |  |   |  |  |  |   |  |  |  |  |  |
|-------------|---|---|----------------|-----------------------|----|--------|---|--|--|--|---|--|--|--|---|--|--|--|--|--|
| <b>C6.</b>  | Where are the three most common facilities that patients are referred to? (including the estimated distance and reasons for referral, for example: for diagnostic confirmation, for specialised treatment etc.) | <table border="1"> <thead> <tr> <th></th> <th>Place of referral</th> <th>km</th> <th>Reason</th> </tr> </thead> <tbody> <tr> <td>1</td> <td></td> <td></td> <td></td> </tr> <tr> <td>2</td> <td></td> <td></td> <td></td> </tr> <tr> <td>3</td> <td></td> <td></td> <td></td> </tr> </tbody> </table> |                | Place of referral     | km | Reason | 1 |  |  |  | 2 |  |  |  | 3 |  |  |  |  |  |
|             | Place of referral   | km  | Reason         |                       |    |        |   |  |  |  |   |  |  |  |   |  |  |  |  |  |
| 1           |   |   |                |                       |    |        |   |  |  |  |   |  |  |  |   |  |  |  |  |  |
| 2           |   |   |                |                       |    |        |   |  |  |  |   |  |  |  |   |  |  |  |  |  |
| 3           |   |   |                |                       |    |        |   |  |  |  |   |  |  |  |   |  |  |  |  |  |
| <b>C7.</b>  | Does this health facility make an appointment for patients being referred?  | Yes.....<br>.....<br>No.....<br>.....   | 01<br>02       |                       |    |        |   |  |  |  |   |  |  |  |   |  |  |  |  |  |
| <b>C8.</b>  | Are the patient's referral notes sent to the referral facility?   | Electronically.....<br>.....<br>With the Patient (physical record).....<br>No.....<br>.....   | 01<br>02<br>03 |                       |    |        |   |  |  |  |   |  |  |  |   |  |  |  |  |  |
| <b>C9.</b>  | Do patients return to this health facility for post-treatment checkup/monitoring?   | Yes.....<br>.....<br>No.....<br>.....<br><br>If not, why?<br>.....<br>.....<br>.....<br>.....   | 01<br>02       |                       |    |        |   |  |  |  |   |  |  |  |   |  |  |  |  |  |
| <b>C10.</b> | Where do patients often go for post-treatment checkup/monitoring?   | .....<br>.....<br>.....   |                |                       |    |        |   |  |  |  |   |  |  |  |   |  |  |  |  |  |

|             |   |                                       |          |  |
|-------------|---|---------------------------------------|----------|--|
|             |   | .....<br>.....                        |          |  |
| <b>C11.</b> | Are patients provided with appointments to return for post-treatment checkup by this facility?  | Yes.....<br>.....<br>No.....<br>..... | 01<br>02 |  |
| <b>C12.</b> | In your opinion what is the percentage of breast cancer patients who discontinue treatment due to not being able to afford the costs? (At this facility. State if accurate data is available) | .....<br>.....<br>.....<br>.....      |          |  |

**Section D: Human Resources**

|            |   |  |                |               |
|------------|---|--|----------------|---------------|
| <b>D1.</b> | Number of full time and part time* staff at this health facility<br><br>* Part time: Those who have also work at other facilities | <b>Full time</b><br><b>Part time</b>   |                |               |
|            |   |  | Ft             | Pt            |
| <b>D2.</b> | Full time and part time staff classified according to qualifications  | General doctors .....<br>Specialist doctors .....<br>Non-Physicians .....<br>Nurses .....<br>Midwives .....<br>Pharmacists .....<br>Laboratory technicians .....<br>Village health workers .....<br>Administrative, finance staff .....<br>Others (Please specify) ..... |                |               |
| <b>D3.</b> | Is there any cancer training provided to staff at this facility?  | Yes, General Cancer Training.....  | 01<br>02<br>03 | If you answer |

|  |  |              |
|--|--|--------------|
|  | Yes, Breast Cancer Specific Training.....<br>No<br>..... | 03 go to D5. |
|--|--|--------------|

**D4.** What is the content of breast cancer training activities different members of staff receive and how frequently? (Fill in for staff employed at this facility and select all that apply)

| Staff           | Activities   | How many training sessions were provided last year (2016)? | When was the last training held? |
|-----------------|--|--|----------------------------------|
| Nurses          | Facilitating awareness and education workshops on breast cancer in the community.....01<br><br>Training on self-examination for breast cancer..... 02<br><br>Other (specify) ..... 04              |  |                                  |
| General doctors | Conducting clinical breast examinations ..... 01<br><br>Surgery ..... 02<br><br>Radiotherapy ..... 03<br><br>Chemotherapy ..... 04<br><br>Hormone therapy ..... 05<br><br>Other (specify) ..... 06 |  |                                  |

|                    |  |  |  |
|--------------------|--|--|--|
|                    |  |  |  |
| Specialist doctors | Conducting clinical breast examinations<br>..... 01<br><br>Surgery<br>..... 02<br><br>Radiotherapy<br>..... 03<br><br>Chemotherapy<br>..... 04<br><br>Hormone therapy<br>..... 05<br><br>Other (specify)<br>..... 06 |  |  |

|            |   |   |  |  |
|------------|---|---|--|--|
| <b>D5.</b> | Please list the different organisations who have provided breast cancer training at this facility, if applicable. | .....<br>.....<br>.....<br>.....  |  |  |
| <b>D6.</b> | How often is this health facility inspected/assessed?   | Never..... 01<br>Every 3 months..... 02<br>Every 6 months..... 03<br>Once a year..... 04<br>Less than once a year..... 05                                 |  |  |
| <b>D7.</b> | Who conducts these assessments? (Select all that apply)   | Self-evaluation/internal assessment.. 01<br>Ministry of Health..... 02<br>Independent third-party ..... 03<br>Other (please specify) ..... 04<br>..... 05 |  |  |

|            |                                 |          |    |  |
|------------|---------------------------------|----------|----|--|
|            |                                 |          |    |  |
| <b>D8.</b> | Is an evaluation report public? | Yes..... | 01 |  |
|            |                                 | No.....  | 02 |  |

**Section E. Recommendations**

|  |
|--|
| <p><b>E1.</b> What recommendations would you suggest for strengthening services related to breast cancer in your health facility and local area?</p> <p>Number your recommendations.</p> |
|  |
| <p><b>E2.</b> Among those recommendations, which ones do you think are easiest to apply that would improve services related to breast cancer for women?</p>                              |
|  |
| <p><b>E3.</b> Among those recommendations, which one should be the main priority for strengthening breast cancer services?</p> <p>Choose only ONE most important recommendation</p>      |
|  |

|  |
|--|
|  |
|--|

Total time needed to fill in the form (in minutes):

\_\_\_\_\_

Thank you very much for your time and participation!

If you have any questions or concern, please contact:

Tran Thu Ngan, MIH

Researcher

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Hanoi University of Public Health

1A Duc Thang Road, Duc Thang Ward, North Tu Liem District, Hanoi, Vietnam

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Phone: 04.62662299

**Appendix Tem 6B: Interview guide for in-depth interviews conducted as part of study on challenges experienced by healthcare professionals in delivering breast cancer services.**

**INTERVIEW GUIDE FOR HEALTH FACILITY MANAGERS AND CLINICIANS**

**SURVEY + INTERVIEW**

*An evidence-based approach to the evaluation and planning  
of breast cancer services in Viet Nam*

***NOTE TO RESEARCHER: THIS GUIDE SHOULD BE USED IN CONJUNCTION WITH THE GUIDANCE NOTES PROVIDED WITHIN THE STANDARD OPERATING PROCEDURE.***

**BACKGROUND**

1. What is your role in this facility?  
    **PROBE:** If clinician: What is your specialty area?
2. How long have you worked here?
3. How long in total have you worked in healthcare sector?

**“Even though you’ve completed the questionnaire, I’d like to ask you a bit more detailed information about this facility had ways it tries to meet the needs of women with breast cancer. This will supplement information on the questionnaire.”**

4. What are the three biggest health concerns in the communities you serve?  
    This is overall, for adults and/or children. Please be specific. (**PROBE:** Why is ‘x’, ‘y’, and ‘z’ so important here?)
5. Public Health Education and Health Promotion
  - 5a. What activities or services are provided (At the facility and in the community)?
  - 5b. Which staff members are directly responsible for this?
  - 5c. What barriers exist to providing these activities/services?
  - 5d. What do you recommend could be done to improve these activities/services?
  - 5e. Would you like to tell us anything else about this activity/service?

6. Screening in the Community
  - 6a. What activities or services are provided?
  - 6b. Which staff members are directly responsible for this?
  - 6c. What barriers exist to providing these activities/services?
  - 6d. What do you recommend could be done to improve these activities/services?
  - 6e. Would you like to tell us anything else about this activity/service?
  
7. Clinical Breast Examination
  - 7a. What activities or services are provided?
  - 7b. Which staff members are directly responsible for this?
  - 7c. What barriers exist to providing these activities/services?
  - 7d. What do you recommend could be done to improve these activities/services?
  - 7e. Would you like to tell us anything else about this activity/service?
  
8. Diagnostic Confirmation
  - 8a. What activities or services are provided?
  - 8b. Which staff members are directly responsible for this?
  - 8c. What barriers exist to providing these activities/services?
  - 8d. What do you recommend could be done to improve these activities/services?
  - 8e. Would you like to tell us anything else about this activity/service?
  
9. What do you think are the most common reasons (signs, symptoms) why women come here for a diagnosis of possible breast cancer?
  - PROBE:** Which of these signs are they most worried/upset about?
  - PROBE:** Which of these signs cause women to promptly seek referral or treatment?
  
10. For what reasons (do you think) women tend to delay coming for a diagnosis, **PROBE:** Ask about transportation, costs, not believing diagnosis.

11. What other places or people provide advice or services related to diagnosis, treatment and care of women with breast cancer? **PROBE:** ask not only about biomedical options, like pharmacies, but also other options, like herbalists, prayers, and so forth.
  
12. After a diagnosis of probable or confirmed breast cancer is made, what information is shared with the woman? with her family? [ask about each separately]:
  - PROBE:** disease progression and likely symptoms
  - PROBE:** reasons for referral
  - PROBE:** treatment options and side effects
  
13. Patient Referral
  - 13a. If a woman is diagnosed with breast cancer is she referred to another facility?
  - 13b. What challenges exist around referral?
  - 13c. Do women ever refuse to be referred and for what reason?
  - 13d. Would you like to tell us anything else about the process of referring patients?
  
14. Treatment Services (for breast cancer)
  - 14a. What activities or services are provided?
  - 14b. Which staff members are directly responsible for this?
  - 14c. What barriers exist to providing these activities/services?
  - 14d. What do you recommend could be done to improve these activities/services?
  - 14e. Would you like to tell us anything else about this activity/service?
  
15. Do women with a breast cancer diagnosis ever not comply with treatment? For what reasons may a woman not comply with treatment suggested?
  
16. Palliative Care Activities/Services
  - 16a. What activities or services are provided?
  - 16b. Which staff members are directly responsible for this?
  - 16c. What barriers exist to providing these activities/services?
  - 16d. What do you recommend could be done to improve these activities/services?

16e. Would you like to tell us anything else about this activity/service?

17. What do you think are the biggest challenges or barriers facing the women themselves when seeking [ask about each of the following separately]:

- a) Information or awareness
- b) A diagnosis
- c) A referral
- d) Treatment
- e) Follow-up care, including palliative care

**PROBE:** ask about costs, distance and transportation, quality of care (wait times, interactions with providers, training levels), the knowledge or beliefs of other family or household members (decision-makers or influential persons for the woman)

18. We'd like to ask you more about challenges you face providing services at this facility. What (other) challenges do you and other staff here face in trying to meet the needs of women with possible breast cancer or a confirmed diagnosis?

- a) What would help you and the staff here do a better job?

**PROBE** [ask separately about]:

- a) supervision and monitoring
- b) information updates
- c) training [on what topics; how delivered and by whom]
- d) regular delivery of supplies/drugs
- e) anything else

19. What training has the staff here received in the last 12 months on ...

**PROBE:** Ask about each of the following aspects of care separately. Ask who was trained, who provided the training, how useful it was, and how it could be improved.

- a) Public education about breast cancer
- b) Diagnosing breast cancer
- c) Treating breast cancer
- d) Follow-up care after treatment
- e) Record-keeping
- f) Referrals
- g) Support for women with breast cancer
- h) Palliative care

**WRAP-UP. NOTE TO RESEARCHER: THESE ARE IMPORTANT QUESTIONS AND NEED TO BE GIVEN SUFFICIENT TIME FOR COMPLETION**

- 20. We are nearly done now. We've talked about many things today. Thinking back over everything we discussed ...
  - a) what do you think we should have discussed but left out of the conversation?
  - b) what should we have discussed in more detail?
  - c) what is your key message that I can bring back to the rest of the research team, without mentioning your name?
  
- 21. We would like to ask you about some of your strongest memories while working in this facility. In your time at this facility can you think of an example when a patient's case was particularly positive (eg, successful detection or treatment)? And can you think of a time when a patient's case was negative? What factors contributed to these different experiences?
  
- 22. Is there anything else you'd like to tell us today?
  
- 23. Do you have any questions for us?
  
- 24. We need to gather information about all our participants so we can describe who we have talked to. We will describe people as a group; for instance, "In our pilot study we spoke with 8 people 6 women and 4 men, between the ages of 25 and 50 years old." All the information we gather will be private because you will not be named.
  - a) Sex [male] [female]
  - b) How old are you? ..... years
  - c) Where were you born?  
.....
  - d) Where do you live now?  
.....  
NOTE: If c) and d) are different, ask: When did you move to [place]?  
.....
  - e) What is your highest level of education?  
.....
  - f) Where was that training?  
.....

Thank you. If you have any questions or want more information about the questionnaire or this interview, contact [NAME & CONTACT INFORMATION]. We will send you and other participants a summary report of our findings. What is the best way to send the report to you? [email address, post address, other] Thank you!

**Appendix Item 6C: Consent Forms (English version) for study on challenges experienced by healthcare professionals in delivering breast cancer services.**

**INFORMATION & CONSENT FORM – HEALTH FACILITY MANAGERS AND CLINICIANS**

Thank you for your time. I am a researcher at the Hanoi University of Public Health. Today, I would like to discuss services related to cancer and breast cancer that are being provided by your health facility. Our project is in collaboration with Queen’s University Belfast (UK) and the Hanoi Medical University. The project focuses on the accessibility and readiness of breast cancer services in Vietnam. This project has been authorised by the Ministry of Health (MOH), and our findings will help to inform future delivery of breast cancer services in the country.

The interview is expected to last for approximately 1 hour. I would like to audio record the interview because I do not want to miss important information that you provide. To make it easier to create a transcript please speak loudly and clearly so that we can record your opinions at high quality.

Your answers will be kept completely confidential. We ensure that your personal information will not appear in any report or presentation. Your answers will be given an anonymised identification. Your name will not appear in any records. Please note that you can refuse to answer questions that you feel uncomfortable to answer or you may stop the interview at any time you want.

We hope that the results from the research project will contribute usefully to improving the breast cancer services within the Vietnamese health system.

If you have any questions or would like to discuss anything about the study, please contact Tran Ngan at 04.62662299 or ttn2@huph.edu.vn

Are you willing to participate in the study?

Yes:

No:

Name:

---

Signed:

---

Date:

---

**Appendix Item 6D: Standard Operating Procedure used during study on challenges experienced by healthcare professionals in delivering breast cancer services.**

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# STANDARD OPERATING PROCEDURE

## UNDERSTANDING AND STRENGTHENING BREAST CANCER SERVICES IN VIETNAM

### DATA COLLECTION AND ANALYSIS

**MAY-JULY 2017**

#### OVERVIEW

The objective of the project ‘A mixed methods approach to understanding and strengthening breast cancer services in Vietnam’ is to provide a base of data concerning the different breast cancer services offered at different levels of the Vietnamese health system. Through using a mixed methods approach (quantitative surveys, with qualitative in-depth interviews), the study aims to provide insights into the capacity of the health system to respond robustly to a breast cancer diagnosis, and to provide information on barriers to women using services.

#### OBJECTIVE OF THE STANDARD OPERATING PROCEDURE

The objective of this Standard Operating Procedure (SOP) is to provide a guideline for the data collection aspects of the mixed methods study to better understand and strengthen breast cancer services in Vietnam. The SOP is designed to standardise data collection processes, to improve the rigour and quality of data collection, to ensure appropriate storage and anonymization of data collected, and to provide a framework for analysis of the data. It is intended to be a useful tool and point of reference for researchers involved in the project, and to help guide their work and ensure quality.

#### CONTENTS

1. Data Collection Guides
  - 1.1. Self-administered questionnaire
  - 1.2. In-depth interviews
2. Data Entry

3. Data Storage
4. Analysis
5. Appendix
  - 5.1. Self-administered questionnaire for National, Provincial and District Facilities
  - 5.2. Self-administered questionnaire for Commune Facilities
  - 5.3. In-depth Interview Guide for National, Provincial and District Facilities
  - 5.4. In-depth Interview Guide for Commune Facilities
  - 5.5. Consent Form (for interviews)
  - 5.6. Ethical Approval
  - 5.7. Data Collection Log
  - 5.8. Code Book
  - 5.9. Notes on conducting in-depth interviews

## DATA COLLECTION

### SELF-ADMINISTERED QUESTIONNAIRES

- Project Information letters and Questionnaires will be sent out by post to identified facilities. Different versions of the questionnaire will be sent to different levels of facility. (National/Province, District (Appendix 5.1), and Commune (Appendix 5.2).
- A date (2 weeks in advance) will be communicated to the facility for when a member of the research team will physically come to collect the questionnaire.
- After 2 weeks a member of the research team will physically collect the questionnaires and return to the lead HUPH researcher.
- If the questionnaire has not been filled out by the participant by agreed time of collection the member of the research team will ask the participants to fill the questionnaire out and assist them appropriately during this process.
  - Training will be given on the amount of assistance the research member can give to participants during this process.
  - The member of the research team **should** encourage answers to each question, clarify any queries on type of information the question is requesting, and if there are specific reasons why the respondent cannot answer a question, that reason should be noted next to the question.
  - The member of the research team **should not** steer answers to any questions, nor make suggestions on how to answer the questions in terms of content.

### IN-DEPTH INTERVIEWS

- Questionnaires will be sent out by post to identified facilities.
- A date will be communicated to the facility (minimum of 2 weeks in advance) for when a member of the research team will physically come to collect the questionnaire and to conduct an in-depth interview on breast cancer services provided by the facility.
- A member of the research team will travel to the facility and conduct the in-depth interview using a **writable** Interview guide (Appendix 5.3 & Appendix 5.4).
- **Informed consent** will be secured before the interview commences. This involves both describing the project, and how data will be used. Interview participants should sign the consent form if they wish to continue with the study. If they do not consent to the interview the researcher will end the session. Consent form (Appendix 5.5).
- Interviews will be recorded with the consent of the interview participant. Recorders should be placed on the table, as close as possible to the interview participant. Background noise should be minimised if possible.
- If the questionnaire has not been filled out by the participant in advance of the agreed interview time, the participant will fill out the questionnaire before the interview begins. Training will be given on the amount of assistance the research member can give to participants during this process.

- On completion of steps on consent and questionnaire completion, the researcher will begin recording and use the In-depth interview guide to structure the discussion.
- There are different in-depth interview guides to be used based on the type of facility (National, Province, District (Appendix 5.3), and Commune (Appendix 5.4).

## ETHICS

This project will have secured ethical approval from HUPH. All researchers should be aware of the ethical implications of our work, and familiarise themselves with the ethical requirements for the project (Appendix 5.5).

## DATA ENTRY

### QUESTIONNAIRES

- The returned questionnaire forms will be **separated** into two documents. The first **four pages** of the questionnaire containing identifying information and consent documentation, will be removed. A new Code sheet will be attached to the remaining of the questionnaire, and a unique ID Code will be generated using the Code Book (Appendix 5.8).
- All questionnaires will be logged by researchers on their receipt into the Data Collection Log
  - (Appendix 5.7)
- The lead HUPH researcher will enter the questionnaire data into Epi Data on receipt of the questionnaires.
- Any long-form narrative answers will be translated by the research team and collected in a separate document.

### INTERVIEWS

- In-depth interviews will be logged (Appendix 5.7), transcribed into both Vietnamese and English and given a Unique ID using the Code Book (Appendix 5.8). **This code will be the same code corresponding to the questionnaire returned from their health facility.**
- Audio files from the interviews will be allocated the same unique code.
- Transcription will be conducted by a team at HUPH, and will be checked by the lead Vietnamese researchers.
- Notes taken during the interviews on the writable interview guides should be consulted by the staff transcribing the interviews, and any additional notes taken by the researcher conducting the interview should be included in the transcript in a section at the end, 'Additional Notes'.

### QUALITY CONTROL

- Lead Researchers from HUPH and QUB to check every tenth entry into the logs for quality control. Records of this activity (date of quality control checks, and findings) will be recorded in separate document.

## DATA STORAGE

- The questionnaire will have previously been separated into two parts. These two parts should be stored separately, in different locked filing cabinets.
- Identifying information contained in the log-book will be stored on a password-protected USB drive
- Hard copies of questionnaires will be kept in a locked filing cabinet in HUPH. Only members of the research team will have access to the data
- Audio files will be stored on a password-protected computer
- Electronic files (transcripts, any scanned copies of questionnaires) will be stored, anonymised, on a password protected computer.

## ANALYSIS

Analysis will be conducted by both the lead researchers at HUPH and QUB. All data will be transferred to the lead researcher at QUB who will conduct a preliminary analysis of the data, which will include

interpreting data from Epi Data, and conducting a thematic analysis of qualitative data returned through the in-depth interviews.

## NOTES ON CONDUCTING IN-DEPTH INTERVIEWS

The interview guide is designed as semi-structured. It is meant to guide conversation and act as an aid to the researcher, and is not meant to constrain the conversation. The interviewer should attempt to make the interview as conversational as possible. If topics of interest arise in the interview, not covered by the interview guide, please allow these conversations to develop.

The initial sections of the interview are designed to verify data from the questionnaire tool. Please consult the questionnaire tool as you conduct the interview to ensure that information matches accurately.

The final questions and the Wrap-Up section are very important, and appropriate time should be allocated to them. If the interview starts to over-run the designated time, focus on these questions regarding challenges, reflections and recommendations.

Follow the PROBE functions in the interview guide. Ask questions for clarification and further information as frequently as necessary.

Think about body language, question delivery, and how to construct probing and follow-up questions. A good resource for interviewers without experience is:

## **Appendix Item 7A: Interview Guide (Phase #1) for study on experiences of women using breast cancer services in Vietnam.**

### **Interview Guide #1**

Thank you very much for your time. I am a researcher at the Hanoi University of Public Health. As you know from the information you were given from (insert name of relevant support group), I would like to have a conversation with you about your breast cancer diagnosis. I would like to talk about your reflections on your experiences with seeking a diagnosis and then treatment for your breast cancer.

It's important to say we just want to learn about your experience. There are no right or wrong answers, and we appreciate your honesty in discussing this difficult subject. In terms of the format of this discussion, I will ask some open questions, but really we just want to hear a lot from you. We want to hear your story, so please take the discussion in whatever direction you feel is appropriate.

I would like to record the interview so that I have an accurate record of the information you provide. As you know from the ethics document you were provided with, if you wish to stop the interview at any time that is ok. If you wish to stop the recorder at any time that is also ok. You also know that we have some support in place if you require it, either during the interview, or afterwards.

We really appreciate your help in our study, and hope that this project will be useful in the future planning of breast cancer services in Vietnam. Do you have any questions before we begin?

- I'd like to start by asking about your life generally. Where are you from and do you have any family?
  - Probe: What was life like before you had breast cancer? What did you do?
  
- I'd like to ask when you first started to notice, or became aware of, changes in your body.
  - Probe (IF CHANGES DETECTED THROUGH SCREENING PROGRAMME): If detection through screening programme – ask what the screening programme was, who was it organised by, what was the women's experience and reflections on the screening process.
  - Probe: Had you noticed any changes before your screening? If yes, what did you think those changes could be.
  
  - Probe (IF PARTICIPANT DESCRIBES NOTICING CHANGES HERSELF): what was the first thing you noticed?
  - Probe: ask about what woman thought the changes could be (story)
  - Probe: ask about where woman received information (factual or otherwise) about breast health / breast cancer
  - Probe: What were you feeling when you noticed the changes?

- When did you decide your symptoms were serious, and when did you decide to go to see a doctor?
  - Probe: What was your main motive for wanting to speak to a doctor?
  - Were there any reasons that you may have stopped you from going to a doctor after you became aware of your symptoms?
  - Probe: Did you go to any other person or place before or after seeing your doctor?
  - Probe: Can you recount the ‘moment’ you decided to go to see a doctor?

Over the past few minutes I noted that you’ve mentioned X, Y, Z about changes you noted, when you became aware of changes in your body, and when you first went to see a doctor. Have I understood you correctly? (wait for corrections). Is there anything I’ve left out or that you’d like to add to our discussion about this? (wait for additions or indication that participant is ready to move on to next topic.)

- What happened when you went to see the doctor?
  - Probe: Were you provided with an examination?
    - Probe: By whom?
  - Probe: Were you referred to another facility?
  - Probe: Were there any challenges in getting to the facility?
  - Probe: Were you given a diagnosis?
    - Probe: What stage were you diagnosed at?
  - Probe: What was the doctor’s communication like (at all levels and points of contact)?
  - Probe: What sort of support were you given when you learned about your diagnosis?

Over the past few minutes I noted that you’ve mentioned X, Y, Z about when you first saw a doctor and the process of getting a diagnosis. Have I understood you correctly? (wait for corrections). Is there anything I’ve left out or that you’d like to add to our discussion about this? (wait for additions or indication that participant is ready to move on to next topic.)

- Can you tell me about happened after you were diagnosed?
  - Probe: Did you receive treatment?
  - Probe: Did you have to wait for treatment?
  - Probe: What was the communication like and did you have any worries?
  - Probe: What sort of support did you receive?
  - How did you feel after you received treatment?

Over the past few minutes I noted that you’ve mentioned X, Y, Z about receiving treatment. Have I understood you correctly? (wait for corrections). Is there anything I’ve left out or that you’d like to add to our discussion about this? (wait for additions or indication that participant is ready to move on to next topic.)

- Were there any things that made it difficult for you to firstly come for diagnosis, and then secondly to pursue treatment?
  - Probe: Costs. Distance to facilities. Fear. Fear of doctors. Social pressures.
- IF NOT ALREADY ADDRESSED. Were you aware of any screening programmes in your area? Did you participate? What reasons influenced your decision to participate or not?

Over the past few minutes I noted that you've mentioned X, Y, Z about different challenges you experienced in accessing services. Have I understood you correctly? (wait for corrections). Is there anything I've left out or that you'd like to add to our discussion about this? (wait for additions or indication that participant is ready to move on to next topic.)

- Thinking back over everything we've discussed today, is there anything you think we left out or should discuss in more detail?
- Is there anything else you'd like me to know about your experience of breast cancer and using breast cancer services?

Thank you very much for your time today. I know it isn't easy discussing this subject, and thank you for your honesty. I hope this project will help with the planning of services for women with breast cancer, so this has been very useful.

I would like to talk to you again in a couple weeks' time, to make sure I have understood everything correctly, and to talk about some other aspects of your experience.

**Appendix Item 7B: Interview Guide (Phase #2) for study on experiences of women using breast cancer services in Vietnam.**

**Interview Guide #2**

Thank you for meeting me again. Today I'd like to talk a little bit more about some of the things we discussed last week. And I'd also like to hear your recommendations and ideas for what would have made your experience easier.

As with the previous discussion, I would like to record the interview so that I have an accurate record of the information you provide. As you know from the ethics document you were provided with, if you wish to stop the interview at any time that is ok. Again, we really appreciate your help with this study. Do you have any questions before we begin?

- How do you feel about our discussion last week?
  - Probe: How did you feel after you left our meeting?
  - Probe: Was there anything else you would have wanted to say or talk about?

Read extracts/themes from the transcript from interview #1 identified by the research team. Talk through each theme individually.

- For each theme: Is there anything we didn't understand correctly in our first interview? Would you like to tell us anything more about this part of your experience?
- Ask Probes from analysis of the first interview (allow women to reflect on previous interview before directly asking these probes. Only ask if necessary).
- Thinking back over your whole experience, is there anything else you would like to tell us?
- Have you any recommendations you would make for how to improve breast cancer services? Is there anything that could be done differently that would have made your experience easier?
  - Probe: Ways to tackle barriers or challenges to accessing services?
  - Probe: Communication and support from formal healthcare system?
  - Probe: Wider in society, what could be done to help women with breast cancer?

Thank you again for all your time and help in this project. We really appreciate it. We will be writing our reports over the next few months and will happily share the results with you. If you need or want to speak to any of our research team in the next few weeks, please get in contact without hesitation. Our contact numbers are in the permissions form we provided you with at the start of our discussion.

## **Appendix Item 7C: Interviewer Briefing Document for study on experiences of women using breast cancer services in Vietnam.**

The purpose of our study is to better understand the experiences of women with breast cancer in Vietnam. To date, our research has focused on the formal healthcare system, collecting data from healthcare providers, policy makers and academics. But to understand how breast cancer services operate and function in reality, we need to understand the experience of women who have breast cancer. We want to learn about their story. We want to learn about the different pathways to treatment they took, what factors impacted on their journey, and what different barriers and challenges they experienced. Only by better understanding these experiences will be able to make informed recommendations on how to strengthen breast cancer services in the country.

### Study Overview

- 12 Participants (variation in where they are from, their income level, and stage of diagnosis)
- 6 Participants interviewed in Hanoi and 6 interviewed in HCMC
- 2 Interviews per participant, separated by 2/3 week period. The logic of doing two interviews is to validate and check data, allow for team analysis in between interviews, to build relationships and trust with the women we interview, and to allow women to reflect on the interviews themselves. This may encourage them to share more information during the second interview.

### Research Team Roles

- Ngan – Lead interviewer
- Ngoc – Observer, note taker, and (if required) second interviewer
- Chris – Data analysis and project support

### Interviewing Style

From the interview guide, you can see that the ‘questions’ are very open. In fact – we want to move away from looking at this guide as a list of ‘questions’. What we *don’t* want to do is create an ‘interview’ that represents a question and answer process.

Instead, what we want to achieve is to create a space for women to tell their stories, on their own terms, and in their own time. Therefore, the interview guide should be seen as a loose set of themes to frame the discussion and to direct at the interviewer’s discretion if required. The ‘Probes’ should be seen as aids to the interviewer should information not be forthcoming from the women we are talking to. Space should be provided for women to discuss the themes and probes without encouragement or direction from the interviewer. The main idea, is to try and encourage ‘story telling’, and therefore minimise the role of the interviewer as much as possible.

Silence is an incredibly useful skill to master. Don’t use the probes too quickly – give the women a chance to process their information as they talk and let them set the pace of the discussion.

At the end of each ‘section’ – if appropriate – take the time to feed back what you’ve heard to the woman you are interviewing. Not only does this allow for information

checking, and create the space for women to clarify or expand upon the information they have provided, but it also shows that you are actively listening, which is respectful, and will help to build relationships and trust.

As with all qualitative interviewing, try as best as possible to make the interviewee feel comfortable. There are no right and wrong answers. Women should never feel judgement from the researcher. Reiterate the ethics at the beginning of each interview. Think about the interview space, body language, tone of voice etc. You all have ample experience in this, but just a friendly reminder!

#### Post Interview Debrief

After each interview in the initial round of interviews, the three researchers will sit together and go through Ngoc's notes using them as a reference to frame our discussions. Ngan and Ngoc will reflect on the themes of the meeting and Chris will take notes in English, asking questions for clarification. Patterns and themes will be discussed, as well as what information could be clarified or deepened in the second interview. This process should take place as soon as possible after the interview, so ideally interviews should be organised a few hours apart. This exercise is also meant to reduce potential for bias, as it broadens the analysis process to multiple people.

#### Journaling

Each member of the research team will be asked to journal throughout the process. This exercise will constitute a formal part of our methodology and is designed to help critical thought regarding the project.

The logic behind journaling is described by Turner (2003) in relation to her own topic:

“First, as part of my methodology, and prior to meeting my participants, I dwelt extensively on the topic and wrote a journal of my own ideas, attitudes and understandings about (the topic). This enabled me to develop a clear (yet evolving) understanding of what I knew about (the topic) at any particular point in time. This movement towards identifying my own initial understanding of (the topic) was crucial, as I could not know if I was moving towards an understanding of my participant's experiences of (the topic) unless I understood my own prior assumptions, beliefs, and attitudes about it”.

This approach is informed by Gadamer's belief that we are all influenced by our biases and can never be entirely objective, but, by being aware of our biases more clearly we can attain a greater understanding of our topic. “In his principal work *Truth and Method* (Gadamer 1989), he points to the essential prejudice character of all understanding. Because we are influenced by prejudices our openness to the world is biased and we can never, even through reflection, entirely keep a critical distance and objectify” (Davidson, 2013).

Each member will be asked to journal **before** the study commences on their **attitudes, assumptions, and beliefs about the experience of breast cancer for women in Vietnam**. The study team will then share their notes with each other and reflect on the other member's pieces. (1/2 pages hand or typed).

**Appendix Item 7D: Consent forms (English version) for study on experiences of women using breast cancer services in Vietnam.**

Thank you very much for your time. We would like to talk about your reflections on your experience of interacting with the health system for both diagnosis and treatment of breast cancer.

Our project focuses on the accessibility and readiness of breast cancer services in Vietnam. This project has been authorised by the Ministry of Health in Vietnam, and our findings will help to inform future delivery of breast cancer services in the country.

The interview is expected to last for between one and two hours. We can take a break at any time. We would like to do a second interview with you in two weeks time, to ensure we have understood everything properly and to give you a chance to tell us any further information.

We would like to audio record the interview because we do not want to miss important information that you provide. To make it easier to create a transcript please speak loudly and clearly so that we can record your opinions at high quality. If you want the recorder to be turned off at any time, please let us know. After our discussion, we will create a written transcript, anonymising your information. We will then delete the audio files of our discussion.

We appreciate your help in this study, and understand that recounting your experiences may be difficult. Please take any breaks you want, don't answer any questions that you don't want to, and you can end the conversation at any time. If you need any further support, we have a counsellor partnered with the project, and we can put you in contact.

It's important to reemphasise your information will be kept completely confidential. We ensure that your personal information will not appear in any report or presentation. Your answers will be given an anonymised identification. Your name will not appear in any records.

We hope that the results from the research project will contribute usefully to improving breast cancer services within the Vietnamese health system, and we wanted to thank you very much for helping us with your project.

Do you have any questions about the interview or the project?

Are you willing to participate in the study?

Yes (signed): \_\_\_\_\_ No:  
\_\_\_\_\_

If you have any questions or would like to discuss anything about the study, please contact Tran Ngan at 04.62662299 or ttn2@huph.edu.vn

**Appendix Item 7E: Data table (Literature search of phenomenological studies conducted on experiences of breast cancer in low and middle income countries).**

PHENOMENOLOGICAL (AND RELATED) STUDIES ON BREAST CANCER IN LOW AND MIDDLE INCOME CONTEXTS

| <b>AUTHOR</b>        | <b>YEAR</b> | <b>COUNTRY</b> | <b>METHOD/<br/>FRAMEWORK</b>                                      | <b>SUMMARY FINDINGS</b>   |
|----------------------|-------------|----------------|---|---|
| Barthakur, M. et.al. | 2017        | India          | Husserl<br>& mixed method<br><br>(Palliative Care journal)        | <ul style="list-style-type: none"> <li>• Title: Body Image and Sexuality in Women Survivors of Breast Cancer in India: Qualitative Findings</li> <li>• Losing breasts, and other physical impacts (eg. hair loss) a challenge to female identity.</li> <li>• Sexual communication with partners difficult – topic avoidance.</li> <li>• Taboo related to discussing sex – impact of cancer on sexual activity etc</li> </ul>  |
| Barthakur, M. et.al. | 2017        | India          | Husserl<br><br>(Palliative Care journal)                          | <ul style="list-style-type: none"> <li>• Title: Posttraumatic Growth in Women Survivors of Breast Cancer</li> <li>• Increased awareness of life, reprioritisation, appreciation<br/>Increased empathy and generosity towards others</li> <li>• “The phenomenon of PTG was evident in varying degrees in each survivor in each of the domains: Life, self, spirituality, and relationships.”</li> </ul>  |
| Gürsoy, A. et. al.   | 2017        | Turkey         | Interpretative Phenomenological Analysis<br><br>(Nursing Journal) | <ul style="list-style-type: none"> <li>• Title: Nothing is more important than my partner's health: Turkish men's perspectives on partner's appearance after mastectomy and alopecia</li> <li>• “Most of the men stated that they felt sorry for their wives when they first saw the surgical wound of the removed breast. They also stated that they felt scared, frightened, pained, and they had a weird feeling which they could not describe. Upon seeing their wives for the first time after surgery, most of the men felt she looked incomplete.</li> </ul> |

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|                     |      |      |  | <ul style="list-style-type: none"> <li>• “Having two breasts is certainly far different than having only one. I wished I could have turned the clock back, and I also wished this had never happened. It is a real deficiency.” (4th Participant)</li> <li>• Most men also thought removal of a breast for purposes of health was important, and that the breast was not necessarily a vital organ in their views of femininity, maternity etc</li> <li>• Health more important than loss of hair</li> <li>• Men describing wanting to help, but not knowing what to do and feeling helpless</li> </ul>   |
| Hajian, S. et.al,   | 2017 | Iran | Van Manen<br>(Cancer Prevention Journal) | <ul style="list-style-type: none"> <li>• Title: Coping Strategies and Experiences in Women with a Primary Breast Cancer Diagnosis</li> <li>• Women diagnosed with breast cancer sometimes feared finding out more information about their disease, resulting in isolation</li> <li>• Fatalism (linked to passivity) strongly reported – cancer as directed by God</li> <li>• Role weakening and increased dependency</li> <li>• Some women blamed themselves for delayed diagnosis – cited fears as dominant barrier. Other women cited lack of knowledge</li> <li>• Avoidance, role retention, and cognitive acceptance cited as some coping mechanisms</li> </ul> |
| Mehrabi, E. et. al. | 2017 | Iran | Van Manen<br>(General medical journal)   | <ul style="list-style-type: none"> <li>• Title: Post-traumatic growth: a qualitative analysis of experiences regarding positive psychological changes among Iranian women with breast cancer</li> <li>• Attitude improvement, re-evaluation of the meaning of life, heightening tolerance and resistance, appreciation, seeking spiritual help, and increased empathy – all cited</li> <li>• Positive as well a negative changes associated with illness</li> </ul>   |

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|                    |      |        |   | <ul style="list-style-type: none"> <li>• “Health care professionals should apply the results of present study in intervention programs which concentrate on improving psychological wellbeing, adjustment to disease diagnosis, and, ultimately, quality of life of women with BC”</li> </ul>  |
| Barthakur, M.      | 2016 | India  | Husserl<br><br>(Journal Surgical Oncology)    | <ul style="list-style-type: none"> <li>• Title: Experiences of Breast Cancer Survivors with Oncology Settings in Urban India: Qualitative Findings</li> <li>• Generally doctors took the lead in decision-making – at the request of patients. Doctor-centred/disease-centred approach</li> <li>• Financial challenges during and post-treatment</li> <li>• Few patients reported having access to counselling</li> <li>• ‘Dismissive’ or ‘casual’ attitudes of health care staff sometimes reported – dehumanisation of the woman. Reasons such as heavy workloads and long waiting lists provided</li> <li>• Cultural norms – discomfort with examinations conducted by male doctors</li> </ul>  |
| Inan, F.S. et. al. | 2016 | Turkey | Qualitative Thematic<br><br>(Nursing Journal) | <ul style="list-style-type: none"> <li>• Title: Experiences of Newly Diagnosed Breast Cancer Patients in Turkey</li> <li>• “Nurses should be aware of psychosocial difficulties suffered during the diagnostic phase and provide care for patients. It is important that nurses provide information about the diagnostic phase to women with breast cancer and encourage them to ask questions and express their feelings.”</li> <li>• Avoidance – Emotional and behavioural</li> <li>• “Disclosure of diagnosis emerged as an important factor affecting the women’s compliance with the process. In Turkey, how to disclose a cancer diagnosis to a patient is an important ethical issue” – Doctors known for at times withholding information concerning diagnosis, or diagnosis given to family who then do not pass it on to the woman</li> <li>• Changing social relations for women in society – household obligations – wider context is important</li> </ul> |

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| Liamputtong, P. & Suwankhong, D. | 2016 | Thailand | Meaning-making (Plattner and Meiring, 2006); Feminist framework; Drawing (Guillemin, 2004)<br><br>(Oncology Journal) | <ul style="list-style-type: none"> <li>• Title: Living with breast cancer: the experiences and meaning-making among women in Southern Thailand</li> <li>• Breast cancer means death. Conceptualised as a dangerous and life threatening disease. Traumatic experience</li> <li>• Women confused at why they had cancer. Why had it happened to them? Reasons quoted included diet (salty, fatty, and burnt food – chemicals in food). Karma and/or ‘fate’ perceived as natural cause. Some suggested that abortion had causal effect, related to karama.</li> <li>• Dealing with cancer: Living for children and accepting fate/karma – meaning making. Religion used as support. “It is only through meaning making that individuals are equipped to cope with stressful, life-changing events”</li> </ul> |
| Mehrabi, E. et al.               | 2016 | Iran     | Van Manen<br><br>(Social care journal)   | <ul style="list-style-type: none"> <li>• Title: The Lived Experience of Iranian Women Confronting Breast Cancer Diagnosis</li> <li>• Limited knowledge about symptoms or severity of symptoms prior to diagnosis. Uncertainty also cited post diagnosis about treatment options, prognosis for survival etc</li> <li>• Referral to urban centres created difficult separation of families, and separated women from their children and from their support networks</li> <li>• Non-disclosure of diagnosis – feared stigma or pity</li> <li>• Fear of death, recurrence, treatment procedures</li> <li>• Belief that only God can cure definitively – their diagnosis often seen as a spiritual test</li> </ul>  |
| Xiong, M. et al.                 | 2016 | China    | Colaizzi<br><br>(Nursing journal)  | <ul style="list-style-type: none"> <li>• Title: Women’s experience of making decisions about their breast cancer: A phenomenological study</li> <li>• Context: China has traditionally paternalistic physician-patient relations</li> <li>• Four emergent themes: Authority and Expertise; Lack of Knowledge; Family support; Cultural and Social influences</li> </ul>   |

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|                     |      |        |  | <ul style="list-style-type: none"> <li>• Authority: Deference to medical authority, abdication of role in decision-making. Women chose hospitals based on their prestige.</li> <li>• Lack of knowledge: Little disease-related knowledge, poor communication with doctors</li> <li>• Family support: Families main source of comfort and role in decision-making. ‘We are one’. Often act as bridge between patient and doctors</li> <li>• Cultural and social: Male authority in decision making. High economic barriers. When expenses were high decisions were made on basis of cost, not health</li> <li>• Women wanted a greater role in decision making about their treatment, but also did not want to usurp the role of the doctor</li> </ul> |
| Günüşen, P. et.al.  | 2013 | Turkey | Qualitative Thematic<br><br>(Oncology Journal) | <ul style="list-style-type: none"> <li>• Title: Experiences of Turkish Women with Breast Cancer During the Treatment Process and Facilitating Coping Factors</li> <li>• Description of challenging impact of physical and psychological impact of diagnosis and treatment</li> <li>• Impact of treatment eg. on skin – impacting social relations, causing isolation</li> <li>• Difficulties in accessing services – psycho-social counselling not available</li> <li>• Changes in a woman’s health can impact on the whole family. Societal/familial responsibilities take priority over health</li> <li>• Belief that cancer comes from God</li> <li>• Social support indicated as most important coping factor</li> </ul>                          |
| Obeidat, R. et. al. | 2013 | Jordan | Heidegger<br><br>(Nursing Journal)             | <ul style="list-style-type: none"> <li>• Title: Controlling Fear. Jordanian Women’s Perceptions of the Diagnosis and Surgical Treatment of Early-Stage Breast Cancer</li> <li>• “For several women, the preexisting fear of breast cancer stopped them from reporting the mass the first time they found it.”</li> </ul>  |

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|                    |      |         |  | <ul style="list-style-type: none"> <li>• Fear of recurrence reported by all women to different degrees</li> <li>• Trust in God – some women thanked God for the perspective that disease and poor health brought them – anticipated rewards for their strength in suffering</li> <li>• High level of trust/deference to healthcare professionals – very few women asked questions of doctors or surgeons –some women voiced regret of this approach</li> <li>• Reliance on social network</li> <li>• “Especially for younger women, not only did mastectomy cause disfigurement and loss of physical attractiveness, but it was also an assault to their femininity.”</li> </ul> |
| Joualee, A. et.al. | 2012 | Iran    | Van Manen<br><br>(Quality questioned)<br><br>(Nursing Journal) | <ul style="list-style-type: none"> <li>• Title: Living with breast cancer: Iranian women’s lived experiences</li> <li>• Feelings of loss – in health and appearance</li> <li>• Lose of breasts cited as a reason for divorce (spouse initiated)</li> <li>• Experience of cancer diagnosis and treatment contributed to a heightened sense of constant fear and threat</li> </ul>   |
| Shrestha, K.       | 2012 | Nepal   | Gadamerian<br><br>(General medical journal)                    | <ul style="list-style-type: none"> <li>• Title: Psychological impact after mastectomy among Nepalese women: a qualitative study</li> <li>• Numerous psychological impacts, including fear of death, fear of disfigurement, pain, feelings of guilt (punishment from wrongs committed in previous lives), impacts on sexual activity, discomfort, financial burdens creating additional stresses, physical side effects of chemotherapy leading to social isolation due to feeling unwell/embarrassment</li> <li>• Concerns of discussing diagnosis with male doctors – intimate area of the body</li> </ul>  |
| Doumit, M. et al.  | 2010 | Lebanon | Utrecht School of Phenomenology                                | <ul style="list-style-type: none"> <li>• Title: Living with breast cancer, a Lebanese experience</li> <li>• ‘Living with Losses’ – breast, hair, normality. Hair loss described as most traumatic, even though it was expected</li> </ul>  |

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|                             |      |          | Van Manen<br>(Nursing Journal) | <ul style="list-style-type: none"> <li>• “fear that the genetic predisposition that exists with breast cancer might stigmatize the future of their daughters and granddaughters; in addition to the feeling that they are the ones who started this disease in their families</li> <li>• hereditary guilt</li> </ul>  |
| Sirisupluxana,<br>P. et.al. | 2009 | Thailand | Heidegger<br>(Nursing Journal) | <ul style="list-style-type: none"> <li>• Title: The meaning of complementary therapy from the perspective of Thai women with breast cancer</li> <li>• Complementary therapies included eliminating toxins through diet/detox, taking antioxidants or beta-carotene, vitamins, shark cartilage, pollen, restricting intake of saturated fats etc</li> <li>• Mind/body strengthening and therapy</li> <li>• “The participants expressed that CT could be used in a number of ways. These included as a main treatment, as a supplementary treatment, or as a combination with conventional treatments”</li> <li>• Some women preferred herbal/traditional remedies and used as main treatment method – chemotherapy as complementary – not the other way around</li> <li>• “The combination of the two methods is advantageous. I believe the treatments have to be mixed. If I rely on only one, it might not be as effective.”</li> </ul> |
| Demir, F. et. al.           | 2008 | Turkey   | Heidegger<br>(Nursing Journal) | <ul style="list-style-type: none"> <li>• Title: Patients’ lived experiences of excisional breast biopsy: a phenomenological study</li> <li>• Women described fear that the lump was cancer, fear of surgery and fear of the removal of her breast/s</li> <li>• Fear resulted in some avoidance and delay</li> <li>• Some women described relief in having surgery – surgery would remove the lump quickly, the woman would have no more worries</li> <li>• Misinformation about treatment process, and poor information sharing post-discharge</li> </ul>   |

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| Fu, M. et. al.         | 2008 | China  | Husserl<br><br>(Nursing Journal)                               | <ul style="list-style-type: none"> <li>Title: Making the best of it': Chinese women's experiences of adjusting to breast cancer diagnosis and treatment</li> <li>Emotional distress</li> <li>Acceptance of diagnosis, support networks, having confidence in medical techniques and knowing others who survived cancer cited as coping mechanisms. Access to women who had lived long and healthy lives post-diagnosis and treatment was important</li> </ul>   |
| Vargens, O. et. al.    | 2007 | Brazil | Heidegger<br><br>(Nursing Journal)<br><br>(Quality questioned) | <ul style="list-style-type: none"> <li>Living With Breast Cancer. Its Effect on the Life Situation and the Close Relationship of Women in Brazil</li> <li>"The 4 themes that were interpreted and identified were as follows: gaining a positive attitude for life, wanting to be recognized as a woman with certain needs, considering body image/self-image, and making efforts to hide. The findings of the study point out the importance of the fact that illness elicits more than fitting the body into traditional community expectations or surrendering the body to professional medicine."</li> </ul>  |
| Lam, W. & Fielding, R. | 2003 | China  | Moustakas & Colaizzi<br><br>(Psycho Oncology)                  | <ul style="list-style-type: none"> <li>Title: The Evolving Experience of Illness for Chinese Women with Breast Cancer: A Qualitative Study</li> <li>Women more knowledgeable about breast cancer were quicker to seek biomedical consultation after feeling a lump in their breast</li> <li>Many women in study described temporary denial – breast lump too small etc – inaction</li> <li>Many women assumed BC was a disease for more elderly women – denial, and a challenge when they received diagnosis</li> <li>Stress cited as casual factor</li> <li>"As these women stepped into the biomedical system, they endured the Westernized process of diagnostic confirmation and the uncertainty this brings. Diagnostic confirmation is a</li> </ul> |

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|  |  |  |  | <p>drawn out process, often requiring two or three different tests, with days of waiting. During this period, the inability to predict the diagnostic outcome made maintaining emotional control difficult. They were preoccupied with intrusive thoughts of death and images of physical distress resulting from the treatment”</p> <ul style="list-style-type: none"><li>• Feelings of ambiguity / lack of information on the seriousness of the diseases – lined problems regarding financial decisions etc</li><li>• Many women viewed health as more important than losing a breast</li><li>• Social stigma – one woman had to leave her job over fears that cancer was contagious</li><li>• “none felt that losing their breast would have a detrimental effect on their marital relationships”</li></ul> |
|--|--|--|--|---|

**Appendix Item 7F: Data Table. Thematic analysis and key quotations from interviews with women with a breast cancer diagnosis.**

| <b>Selected Thematic Quotes</b>   |
|---|
| <b>1. Knowledge and screening practices</b>   |
| <p>B - “Information about breast cancer is scarce. People usually don’t think you can get cancer there”</p> <p>B - “The people here often hide it, so I didn’t know much about breast cancer. I started to know about the disease only after I got it”</p> <p>B – “There is too much information (online) so it’s kind of confusing. Some says it’s possible, some says not. You can’t tell which source of information is correct, or which is official. So it’s quite confusing”</p> <p>D - “I didn’t have the knowledge. I thought it was only dangerous when it hurt. In the countryside people rarely go to see a doctor”.</p> <p>D - “In my hometown, when people hear cancer they think 100% you will die, there’s no way you could live. Some says it costs too much to die. You don’t get any better so why do you keep doing that (traveling and paying)”</p> <p>H - “Before detecting the disease I didn’t care. It means that I still read the information from newspapers, I knew the symptoms but I didn’t participate in any screening programme”</p> <p>H - “I just remembered the concept of doing a self-examination. I don’t remember the symptoms. After being diagnosed with the disease, I just learnt and checked whether the symptoms are consistent with what I have”</p> <p>H – “When I need something (information), I just searched for it on the internet. I do not know which sources are reliable”</p> <p>K - “In the company it’s too crowded, so the doctors can’t check carefully” (company provided health checks)</p> <p>K - “In the beginning, I didn’t understand cancer very well. I only knew it is incurable disease so I had to learn a lot to take care of myself”.</p> <p>M – “I heard about cervical cancer more than breast cancer. I didn’t have any notion about breast cancer. I would only care when I reach the age of my mother.”</p> |
| <b>2. Concerns about health, avoidance, and delays to seeking professional help</b>   |
| <p>D - “I said jokingly that if I feel sick too we were going to starve to death, because in the countryside you have to work every day for food you know”</p> <p>E - “I didn’t really lose weight. I did study the symptoms, you should lose weight, your skin should be bumpy and should change colour. But I didn’t feel anything. I only felt pain in my arm”</p> <p>L - “Because I was fine (I delayed going to the doctor). I didn’t feel any pain. So I didn’t go for a health check. When I went for a health check, I had the disease and everyone was surprised”</p> <p>M – “Young people like me are busy with work so they hesitate to go for a health check-up”</p> <p>M - “When I found the lump, I was reluctant and waited for 1 month before going for a health check. I still went to work, I didn’t feel pain. Actually I didn’t care about my health, because I didn’t feel my health decline.</p>  |
| <b>3. System delays: administrative, procedural, referrals</b>  |

D - "Going to the hospital is a very tiring process you know, and you will feel very heavy-hearted before a radiotherapy session. We are from the countryside, it's very tiring to come and go"

D - "Procedures at hospitals are very complicated, so patients can't feel at ease. I am lucky because I have my husband but most people come alone, and they have to go to this place and do things, they have to go out and make photocopies, they have to go to that place to submit and they to come back again. It's like they are being chased. As long as the procedures are complicated patients can never feel at ease"

M - "The administration procedure is too complicated. The doctors are also busy, so I have to meet the doctor to take the medicine, to buy the medicine. Sometimes the doctor is not in the Department"

#### **4. Reaction to breast cancer diagnosis**

A - "When I heard I had metastasis, suddenly I felt weird. My ears were ringing. I couldn't hear what the doctor said. I only knew I had metastasis. Then I walked out. I didn't hear anything else from the doctor"

E - "I was informed I had cancer; I felt like I was splashed with cold water"

K - "When I knew that I had cancer, I still felt shock"

K - "I thought that cancer can't be cured, it is a fatal disease, so I was shocked. I was depressed".

#### **5. Communication with healthcare professionals**

C - "At the Oncology hospital if you have connections they would be a little bit nicer to you. But if you asked too many questions they would scold you. You can't blame them though because there are too many patients at the Oncology hospital"

D - "They are simply overloaded. But I could not feel any empathy from the nursing staff. It's just work for them. When I came to ask, they yelled at me. They kept telling me to wait, wait, wait"

H - "I want the doctors to be more dedicated, which means they should me more advice on the stage of my disease or which medication I need to buy or what I should do. Now, they only answer what I ask, they don't actively consult me which medicines I should and shouldn't use. They don't explain it to me in detail"

J - "The doctor asked me if I wanted to remove everything or just cut a part. I didn't know anything about medicine so I asked the doctor to do the best way. Then they removed everything"

K - "The nurses were nice, they were gentle with the patients"-

M - "It was the lack of information. I had to find out information myself. I didn't receive any reassurance or enthusiastic advice"

#### **6. Medical errors (diagnosis)**

B - "I don't really know what to say. The doctors all studied ultrasound before, and they have practiced on many patients.. But back then my disease was not detected. I did have a mammogram but it was still not detected.. That's why when they knew about my disease, they told me to go to upper level hospitals for treatment"

I - "In the first test they concluded that the lump was benign, but when I took the test again, it was cancer"

#### **7. Reflections on hospital environment**

E - "I didn't have a place to sit or lie down. I was having fever but there was no where I could sit or lie down. Every time a wheelchair passed by I had to hold my feet up to give way"

H - "It was too crowded like in a market. It's terribly crowded. Patients having chemotherapy there can be at least two people sharing a bed"

I - "I waited from 4am in the morning, and it wasn't until 11am that I had a health check. I need to be sympathetic with the old people who queued the day before. It's overcrowded. Overloaded. In that room, there must be 3 or 4 people sharing bed, but it's still lacking beds. They need to borrow beds and lie outside"

M - "It was overcrowded. The doctors can't take care of the patients"

### **8. Barriers to treatment (financial)**

A - "30 million per week, not to mention food costs and other medicines. Not to mention pain relievers, supplement infusion, this and that costs. That's only for the chemicals. Also the money on commuting. You have to spend millions per hour during a hospital visit"

A - "The ladies, they sold their houses. They have houses in the city but they had to sell them.

A - "People with money think about dying because of the disease. People without money think about dying because of not having money".

D - "When I heard about being hospitalised I started to worry. I only cried then because I was afraid, I could not afford it. Also that day we didn't bring a lot of money. I was not afraid of dying".

D - "If you have a house then you can sell your house, but if you don't then what can you sell to get money for treatments"

E - "Since I'm ill we have sold everything"

H - "The most difficulties for patients are their economic situation".

I - "I have only peanuts to eat"

### **9. Support**

A - "If we know your condition, we (in the cancer patients support group) will send you a message asking how you are. Nobody knows anyone's face, but we are very close since we have the same disease. People would visit me, this day and that day. It doesn't matter if we know each other or not"

A - "The ladies here are very kind. When they see me having difficulties, they care a lot. I don't have my family with me"

B - "I read other people's experience (online, in support group pages) about what to eat, or what I can do"

D - "Without him (husband) I would not have been able to go there. I vomited all the way from the hospital gate to the chemotherapy room and from the chemotherapy room to the gate. I vomited all the way to guesthouse"

E - "In general, you have to be financially capable. Like in my case, my family is not that poor. My children also contribute... My daughter said she would sell her house to take of me"

E - "Ever since I joined the club, we cheer each other up. You see, P. used to be healthy but she's incurable now, the cancer has spread to her brain. Plus, she was abandoned by her husband, so she's very miserable. I have joined in the last 4 months. Before I didn't know about it. Ah, I knew but it's not the patient's habit to open up. You don't want anyone to know you have cancer. Also you don't want to go out. You just stay at home. Ever since joining the club my life has completed

changed. I became more cheerful and healthier. I gained weight. My skin got better. Before I looked awful. Now I'm in a good spirit. I go jogging in the park. My husband bakes. I can't knead the dough because my arm hurts, so my husband does it for me. I only do the decorations, and process the orders (baking business). In general we are both happy. My husband used to drive a container truck, but ever since I got ill he had to stay home to take care of me".

H - "My friends visited me"

K - "My relatives also encouraged me. I wanted to give up the treatment many time. The pressure was coming from myself. The doctor told me there are many patients who gave up the chemotherapy treatment. After a while, they had to come back to the treatment"

M - "Yes, I received a lot of mental support. I took back the spirit quickly. I was just panic for one or two days, then I felt normal. The doctor and my relatives also encouraged me. In general, I had to reassure myself"

M - "My husband's family and my husband are very supportive. That's my motivation to fight back with this disease"

### **10. Lack of support (social, stigmatisation etc.)**

B - "They are not (caring). They only think I'm ill because of what I have done. But it's not true"

D - "The people in my hometown are outdated, when they hear cancer and surgery they think you will die. They cannot imagine what it's like to have a removal surgery. Many people said if they got cancer they would jump off a bridge".

G - "Many people got hopeless and did not go to the hospital to be treated. There are also people who said they did not have money and even if they were treated it's not going to work"

G - "People with the disease have low self-esteem. People without disease don't want to come near people with disease. They are scared so there is some distance. People don't want to stay close to you and are not friendly. This kind of disease makes you feel isolated"

H - "There were whisperings. Since I was diagnosed with the disease, I have rarely gone out of my home" – people didn't understand, and the whispering made her unhappy

J - "I have an uncle having cancer and died 2 years ago. People in my countryside think that using Western medicine cause death more quickly, using traditional medicine can resist the disease"

J - "people having cancer must avoid meeting women just having a baby and attending funerals"

J - "People said in a previous life I was evil so I have to be punished in this life"

J - "My relatives told me sooner or later I will die. If I do the treatment, it wastes a lot of money"

I - "I divorced with my first husband. My second husband has a son and lives with his son. He doesn't live with me. I got married to have a child. I don't receive help from my second husband"

J - "My brother asked me why I did chemotherapy without asking his opinion. He didn't want me to do chemotherapy because he thought that I would die more quickly.

J - "My husband family is poor. My relatives told me sooner or later I will die. If I do the treatment, it will waste a lot of money. So from 2015 till this October, I used traditional medicine.

L - "My husband left me. I have to manage myself. When I woke up he was gone"

**11. Impacts, reflections etc.**

B - "Among people here, there are those with similar disease but they are scared, they hide it. They don't say that they have that disease. But I don't hide it. I say it out loud that I'm ill. I don't hide it. I don't care what people say because I live for myself"

I - "Remove everything. Now my situation is difficult, I don't have money to make beauty"

M - "Breast cancer affects the mentality of women. They feel inferior about their appearance"

K - "It would be fine if this disease only created pressure on work. however, this disease creates pressure on the family, married life, your aesthetic. The treatment takes a lot of time and money"

## 7G: Rapid Analysis and Debriefing Framework

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|---|--|
| <b>Interview Number</b>   |  |
| <b>Date</b>   |  |
|   |  |
| <b>Theme: Detection of Bodily Change</b>  |  |
|   |  |
| <b>Theme: Point of perception as having symptoms and needing the speak to HCP</b> |  |
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| <b>Theme: First consultation with HCP</b>   |  |
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|-------------------------------------|
|                                     |
| <b>Theme: Diagnosis</b>             |
|                                     |
| <b>Theme: Treatment</b>             |
|                                     |
| <b>Other Events? eg. Screening?</b> |
|                                     |

|   |
|---|
|   |
| <b>Post Treatment – if applicable</b>                                 |
|   |
| <b>Processes: Self-management, appraisal, decision making factors</b> |
|   |
| <b>Challenges and Barriers</b>  |
|   |

|                         |
|-------------------------|
|                         |
| <b>Additional/Other</b> |
|                         |

## **7H: Data Analysis Code Book**

### **A: Personal and background information**

A1: Family

A2: Life before breast cancer

### **B: Detection of Bodily Change**

B1: When first noticed/aware of bodily changes

B2: If changes detected through screening program (details; any changes noted before screening)

B3: If changes detected by woman herself (what were the first signs, perceived cause, feelings about this)

### **C: Point of perception as having symptoms and needing the speak to HCP**

C1: When and why were signs considered serious

C2: Main reason for seeing clinician

C3: Reasons for not previously seeing clinician

C4: Other people/places consulted pre or post doctor

### **D: Scheduling an Appointment**

D1: With who?

D2: Barriers/challenges (making/keeping appointment)

D3: Outcomes of first appointment (eg. referral – to whom?)

### **E: Diagnosis**

E1: By whom

E2: Communication with clinician

E3: Reaction/Emotions

E4: Supports given (formal or family/carers)

E5: Challenges/Mistakes

### **F: Treatment**

F1: What treatment and where

F2: Barriers to treatment

F3: Communication with HCPs

F4: Emotions

F5: Supports

F6: Hospital environment

F7: Use of alternative/complementary treatments

### **G: Additional/Other barriers not already mentioned**

G1: Insurance/Finances

G2: Social stigma

G3: Family

G4: Travel

G5: Other

### **H: Post-treatment**

H1: Outcomes

H2: Feelings/Reflections

H3: Support

### **I: Other relevant information**

## **Appendix Item 8A: Focus Group Discussion Guide for study on roles and unmet needs of cancer carers in Vietnam (Carers Focus Groups)**

### Focus Group Schedule for Informal Carers

Introduction: Interviewer to introduce their name, role and an overview of the research. The researcher should revisit issues in relation to consent and confidentiality.

1) Can everyone tell me a few lines about their caregiving experiencing?

\*Prompt; who do you care for, what type of cancer does the patient have, how has cancer made an impact?

2) How did the family decide you were the main person to provide care for a patient with cancer?

\*Prompt who in a family needs support? Who should we extend support to?

3) Can you tell me the impact that cancer has had on you personally?

\*Prompt: Physically, Psychologically, Socially, Finance / employment

4) What type of care do you and your family provide to the patient?

\*Prompt: Physical/ food/ nutrition / counselling / washing / financial

5) Can you tell me the greatest issues or problems that people face when a patient is diagnosed with cancer?

\*Prompt: What are the main issues you worry about? What are the main issues you need help to manage? Health Insurance / finance.

6) Where do carers access information and support?

\* Prompt: Online / from peers/ written / from health care professionals and from other patients

7) What do carers want or need for support / information services?

\*What components should an intervention contain? In what form should information be delivered?

8) What are your views regarding the development of an online resource for cancer carers?

\*Prompt: Useful/ not useful?

9) Have you any advice or guidance that you would give to us developing an online intervention for people providing care for cancer patients.

\*Prompt how would you like information: videos / storytelling / written

**Appendix Item 8B: Focus Group Discussion Guide for study on roles and unmet needs of cancer carers in Vietnam (HCP Focus Groups)**

Focus Group/ Interview Schedule Health Care Professionals

Introduction: Interviewer to introduce their name, role and an overview of the research. The researcher should revisit issues in relation to consent and confidentiality.

1) What impact do you think that cancer have on informal cancer carers?

\*Prompt: Physically, Psychologically, Socially, Finance / employment

2) What type of things do carers do for the patient?

\*Prompt: Physical/ food/ nutrition / counselling / washing / financial

5) Can you tell me the greatest issues or problems that informal carers face when a patient is diagnosed with cancer?

\*Prompt: what are the main issues carers worry about? What are the main issues that carers need help to manage? Health Insurance/ finance. Are these issues different dependent of stage of trajectory e.g. diagnosis/treatment.

6) Where do carers access information and support?

\* Prompt: Online / from peers/ written / from health care professionals and from other patients

7) What do carers want or need for support / information services?

\*Prompt: What components should an intervention contain? In what form should information be delivered?

8) What are your views regarding the development of an online resource for cancer carers?

\*Prompt: Useful/ not useful?

9) Have you any advice or guidance that you would give to us developing an online intervention for people providing care for cancer patients.

\*Prompt how would you like information: videos / storytelling / written

**Appendix Item 8C: Information & Consent forms (English version) for study on roles and unmet needs of cancer carers in Vietnam.**

Information sheet Cancer Carers

**Information Sheet : Cancer Carers**

**Adapting an online support system to meet the needs of Vietnamese cancer caregivers.**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information.  
*Thank you for reading this.*

**Part 1**

**What is the purpose of the study?**

The purpose of this study is to explore the support needs of families affected by cancer and how we can develop an online resource to meet these needs.

**Why have I been chosen?**

You have been chosen because you provide informal care to a patient with cancer.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you or the patient you care for

**Part 2**

**What will happen to me if I take part?**

If you do decide to take part we will ask you to sign a consent form. We will then ask you to take part in a focus group, this will involve discussing your experiences of caring and need for support

in a group with other carers. This discussion will take place in the hospital. In total it will take about 60 minutes- 120 minutes. The focus group will be digitally recorded. If you decide to participate in a group discussion with other participants it will involve a loss of privacy, however your participation will be kept as confidential as possible. All participants will be asked to keep the discussions within the groups confidential and not disclose any information to other people who were not at the meeting.

### **Consent**

A copy of the written information and signed informed consent form will be given to each participant to keep. If you agree to participate you can withdraw from the study at any time if you change your mind.

### **What are the possible benefits of taking part?**

We cannot promise the study will help you but the information we get may help improve the support of people and families with cancer. We hope that there will not be any negative side effects from taking part in this study. Although if you find any aspect of the discussion distressing you can talk about this with the facilitators of the focus group.

### **What will happen to the results of the research study?**

The results of the research study will be presented at international and national conferences. The results will also be published in peer reviewed journals so that the staff working with and caring for people with cancer can more fully understand its impact.

### **Study Contact**

#### **Who do I contact for further information?**

For further information and if you have any questions please contact Prof Ho Thi Hien  
Assoc. Prof. Ho Thi Hien, MD., PhD.  
Deputy Head, Faculty of Clinical Medicine  
Ha Noi University of Public Health  
1A Duc Thang road, North Tu Liem district, Ha Noi, Viet Nam  
Email: [hth1@huph.edu.vn](mailto:hth1@huph.edu.vn)

## PARTICIPANT CONSENT FORM

**Title: Adapting an online support system to meet the needs of Vietnamese cancer caregivers.**

Participant ID

|  |  |  |
|--|--|--|
|  |  |  |
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Please initial each box

1. I confirm that I have read and understand the information for the above study. I have read the information sheet? and have had the opportunity to ask questions which have been answered fully.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my care being affected. I understand that if I decide to withdraw following participation in a group discussion my data will not be able to be removed.
  
3. I understand the study is being conducted by researchers from Queen's University Belfast and Hanoi University of Public Health and that my personal information will be held securely on University premises and handled in accordance with the provisions of the Data Protection Act 1998.
  
4. I understand that data collected as part of this study and will be digitally recorded and there is the potential for anonymised direct quotation to be used in reports and publications.
  
5. I agree to take part in the above study.

Name of participant

Date

Signature

Researcher

Date

Signature

**Appendix Item 8D: Thematic analysis and key quotations from interviews with carers and healthcare professionals**

| <b>Thematic Analysis and Selected Quotes from Carers FGDs</b> |   |
|---|---|
| <p>A. The Context and Role of Carers</p>                      | <p>“My wife has not been able to walk after the surgery only after 5-6 days later. In 1-2-3 days after that, I have to help her to use potty, feed her, and I was still asked to get out. Sometimes I got mad, I said, “now you don't have anyone to care for the patient, but you still throw us out, we do not want to lie here, but it is compulsory, if we are not here, who's holding the potty”? That is the first stage after operation, later, it's not like that. So I am asking: if those guard asked me out, do you find it reasonable? Do doctors and nurse ever take the potty for the patients?” (C/HN)</p> <p>“So we have to say that we have to eat little by little, we could only spent litle by litle money, because we could not afford. To be honest. We are farmers who do not have any salary. We have just a few children, and the one who has money will give us some, but on average, they are not financially good. So it leads to more difficulty. So we need to keep fighting with the nutrition issue, so we eat whatever we have. Maybe it makes us more sick. The one who could afford can avoid the disease better” (C/HN)</p> <p>“I have to work in the field, but now I have to leave my rice field. The farmer works on some acres of square rice field then leave for hospital to take care of our family member.” (C/HN)</p> <p>“The rooms are crowded, they do not have a place to lie down, they lie outside or rent a place outside the hospital, until the exam time”</p> <p>“ The patient is painful, not happy. At times, people say “dead and buried” but then at that time, it was like 50-50. Painful but still alive. But it was very painful, beating his head against the wall with bleeding, it must be very painful. But one want to die but they cannot die. In other countries, there are 1 or 2 countries where people have the right to choose the death.” (C/HN)</p> <p>“When it was discovered, the doctor told me about that but my mind was messy, I also did not care. After one week, when everything was less stressful, we were more stable, we had accomodation and other things, then I had spare time to look around to read. On the first, second, or third days,</p> |

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|  | <p>everything was very messy including finance, the way to go around, the clinic, family calls, it was messy.” (C/HN)</p> <p>“ So because we lived far away, sometimes we had hemorrhage, the wound looked bad, the patient was frightened and just wanted to die. Because it was very painful. I have just seen a doctor, the doctor has to stop bleeding by giving us the drugs or tell us how to handle the problem on time, but the patient was very painful, he kept asking for death. The hospitals or medical centers in Vung Tau are low quality, the medicines there were bad too.” (C/HCMC)</p> <p>“I had to be physically and emotionally healthy so as to make my father and my mother better. Everyday I also have to call my mom, she is living in my home town, to make sure she thinks positively. I also called my relatives because although my brother is the only one got sick, but everyone in my family was sad, I had to spend 1-4 hours to talk to this person, and that person. I said, it’s OK because you need to be strong to fight with the disease, the emotion will affect this disease a lot” (C/HCMC)</p> <p>“ And I made up what I said to my dad so that he’s not sad. I only told based on my knowledge, on what I heard, I read. For example, when you are happy, your body will create antibody to fight with sickness. I just made it up and I don't have any professional knowledge to talk deeply.” (C/HCMC)</p> <p>“ My brother wanted to give up with the treatment. But just recently it was hospitalized for emergency because too much bleeding, he insisted to ask for death.” –(C/HCMC)</p> |
| <p>B. Emotional and Support Needs of the Carer</p> | <p>“It is said that patient could not die because the disease but the psychological issue. Almost all patients, every family member have heard this sentence already. Therefore, the psychological support for patients and family members is very important, I am telling you that. “ (C/HN)</p> <p>“Because now the cancer could happen with any age. Young children who are very young, young children still have cancer. The psychological issue for the young people is serious, but it also it affects the family. In one family if a wife is ill or her husband is sick, the psychological atmosphere is like crisis, and yet, without knowledge, it makes them worried a lot, dont you think. There is one old saying that, the less you undrstand, the more worries you have. And vice versa the more you understand, the less you are worried.” (C/HN)</p>  |

“Actually, the psychology problem is that their relatives are sick. Second, we have to follow the patients all the time we are so tired.” (C/HN)

“I went to the coffee house after that, I went to the second floor to cry hourly, because she was diagnosed at the late stage, my mother is so old, she may die on the operating table. Then with such surgery she cannot live long either. It is very miserable psychologically but the financial problem is a common one. I determined that for my family health is the number 1 priority, so we should not go to other hospitals only focussing on medical examination and treatment. Talking about difficulties, there are many.” (C/HN)

“Just to share with you, I am young but unfortunately father died when I was small. So I am very worried when mother has a problem. The day that my mother was here, was the day my mother had surgery, I had a psychological preparation for the cremation already. It means that we need to prepare the psychology, to prepare who will help me at home solve that problem. That is, the psychology is so heavy/stressful.” (C/HN)

“I need more than the sick person. The patient just lies in one place, but I am suffering.” (C/HN)

“ There are a lot of needs. But when I was in the hospital to provide care for the patient, my mind is anxious for things, but one thing adds on the anxiousness is the thief. We are already very tired, but when we got in hospital we have to report to the guard, and they also warn us, so we were worried all the time. I waited for patient when he is in the operating room, I have to watch, I could not sleep. So I can get disease by taking care for patient.” (C/HCMC)

“ Yes, patients often feel uncomfortable. Husband and wife also fight sometimes argue... so we need to calm down, pat them. Some couple in the ward fight, swear to each other, and I told the wife to forgive for the husband because he has disease and is under pressure, he denied to take drugs, swear and asked for death. So you have to say nice words, persuade him. So if the patient hears difficult words, it is more uncomfortable in for him.” (C/HCMC)

“ A lot of these kinds of problems, brothers and sisters in the family have to encourage the patients and the carers because it is very negative experience. All of us were very fearful of bad consequences, that's why we are are very worried, all of us were scared.” (C/HCMC)

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|---|---|
|   | <p>“ I am is more optimistic, my younger brother is very pessimistic, I also encouraged him, we will do our best, do everything we can because it it is too bad now, I do not know what to say anymore. The wound opened inside how do we know. I did not dare to tell him the bad thing, I just said good things to make him more optimistic.” (C/HCMC)</p> <p>“</p>   |
| <p>C. Information Needs for the Patient</p> | <p>“Since patients have to be in the hospital for the treatment of illness for several months, I also want to have a program for their patients to connect to each other, they forget the pain in the disease. That's the most important psychological thing.” (C/HN)</p> <p>“ At the beginning, the information is too confusing” (C/HCMC)</p> <p>“Sometimes people needs the operation but they didn't know why they has to have operation, they might think operation means they have a serious condition, it cannot be the light thing. Like my father he didn't agree to have an operation but then the doctor said there is no other solutions better than surgery, and hat if he takes oral pills it only helps for a while. Then he is open and accept to do operation. So the counselling fro doctor like that will help the patient to have more trust in treatment” (C/HCMC)</p>   |
| <p>D. Information Needs for the Carer</p>   | <p>“We needed to choose a place to get treatment. For cancer, there are many places but how to find the best and most suitable, that is very important, because there are also many hospitals that have the ability to treat, like here they focus on cancer treatment. I have to look around so that I know that here is the hospital specialized in cancer. Before I don't now the difference between hospitals. So I think it is important to choose a treatment place.” (C/HCMC)</p> <p>“Even though we are family members, our knowledge about the field of cancer is still very limited. Now I have to take care of nutrition, psychological health, and I am telling you my experience of patient care is very limited ” (C/HN)</p> <p>“So I could just search on the internet, what makes white blood cell increase, what doesnt, we do not really know, just searching on internet, but actually information that it is not official. When asked the experienced people, people say that oh, what I found is not good. And that does not have specific evidence.” (C/HN)</p> |

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|  | <p>“Apart from the treatment during the time in the department of the hospital, at home we do not know about the treatment related to psychology, nutrition, fitness and rest. All of these problems we have almost no official information, we often only go online. It means we are taking care of my mother in such a way. That’s my story.” (C/HN)</p> <p>“The doctor is not able to advise you carefully about nutrition, they only consulted the drug or the daily necessities, then I had to search internet. But the information from internet is not the same.” (C/HN)</p> <p>“But while we are blind on psychology and nutrition issues, after treatment here when we go home, we have no k knowledge of nutrition, psychology we cannot improve our resistance (suc de khang) that prolong our living time, I think is’s a waste (lost opportunity)” – C/HN</p> <p>“I wanted to know how to feed her, the first time I did not know whom to ask, really. Later on, I heard there is a nutritionist, but had to wait until the right day to ask. Many times what I want to ask what is good for patients, but dont know who to ask so that I have information in time.” (C/HN)</p> <p>“ Basically I'm not a person in the field so I do not have the knowledge but the knowledge on the Internet is too wide, so the knowledge we learn from internet is difficult to apply for the care of our family patients. What to eat, what not to eat, milk is allowed or not... Our information is not good if you don't know what to select to hear.” (C/HCMC)</p> <p>“ Not only in this hospital, many hospitals, we don't know what stage the patient is in, in many cases, they are in stage 4, the patient cannot live any longer but we still trust the doctor, we think that our patient will recover. It is good for the family members, that they still have a trust even at the last stage. But when the relative die, they have a lot of shock. So it is important for them to have awareness.” (C/HCMC)</p> <p>“ Even if I read myself online I do not know what information to find, The best is to ask the doctor. Do not listen to what the other person does, it's best to listen to the doctor. Because the information is too general and like you say every condition is different, then the doctor will examine them and they will know how to do.” (C/HCMC)</p> <p>“ The causes of the disease, what are the consequences, it can be cured or not, if not then how much can be cured, whether it is recurrent or not, is it contagious from one person to</p> |
|--|---|

|                           |   |
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|                           | <p>another person, is it affected by the weather or food?" (C/HCMC)</p>   |
| E. Medical Training Needs | <p>"Actually, it's not much difficulty. By the end of the week, the doctors and nurses are busy. If I call, it took very long to be get here because they are busy taking care of many people. Sometimes I have to learn how to do it myself. Sometimes I even want to learn the way to <i>get the veins</i> myself. They are so busy that sometimes they make mistakes." (C/HN)</p> <p>" I have asked the doctor very carefully, so when the doctor came, I asked him what is the best way to stop bleeding and how to treat haemorrhage. The doctor also told us some methods, then it's temporarily stable now. But the thing is when I get home, I don't know how to treat then I have to ask the doctor how to stop bleeding temporarily so that I can bring the patient here." (C/HCMC)</p>   |
| F. Non-medical Needs      | <p>"Club is for patients. The patient's family is busy. The patients meet together and exchange, to change the atmosphere. I think it is possible for patients to meet each other and they will have fun chatting." (C/HN)</p>  |
| G. Logistical Needs       | <p>"We want Vietnamese hospital, K hospitlas have living places for patients so that patietns donthave to hire room when they come here for treatment. I am telling you the truth, this is very hard for the patients from provinces to rent rooms." (C/HN)</p> <p>"For example, we are from country side, taking care for patients for a very long time, there is no place for us. In many cases, I had to hide under the bed of the patient, sometimes we were asked to go outside. So that is the problem. We are also weak. We had to be out, all of us. We do not want to be in the hospital but our parents are sick so many times when they are weak, we are near them, we are there for them whenever they called for help, and we are ready. We need better condition for us, a little comfort, making rooms for the patient's to stay temporarily because most of the patients were with severe illness they should not be alone" (C/HN)</p> <p>" Some family member has no accommodation, they don't have no place to sleep, they can't do both caring and working at the same time. So it's better if the patient is in the general department.- The model on the other department is the service model, it is different from this department, the cost of the room cover the chair inside the ward. So here the room for 1 night is 200-300 thousand, with the other department,</p> |

the cost for one night is 800 thousand but include other things, so there should be no difference.” (C/HCMC)

“And there are so many difficulties, many things happened: eating, living conditions, many other things. For example, family members who have to wear clothes and they wash their clothes. But the hospital staff told us not to wash our clothes in the hospital. But where could we bring our clothes to wash? We are here for a month, should we not get changed, or not wash our clothes? So family member should have support, for example.” (C/HN)

“I think that most cancer patients come here are from provinces (countrysides), we face difficulties in time, and worse, is financial problem. The majority of cancer patients are in remote provinces and even in difficult conditions. They the lady here, you are correct. We eat charity rice, eat charity porridge. And even the patients must eat those things. So the charity food has not enough nutrition for them *to have treatment*, so that their resistance (*immunity*) is raised.” (C/HN)

“ I am telling you, the first time I spent up to tens million for renting motel out there. The first days, I dont know how to find the cheap motel, I came to Xa La place up there, it costed me 300,000 VND per day. Then I was shocked, it costed me a million for three days, without counting food cost out there.” (C/HN)

“ In the room there is a fan and a small bed, the roof was covere by some thick papers. So, that’s it, I had to leave him, I moved to another place. Not mentioning about the water condition. So I came to the second place, the water there was running so weak that I could not clean the soap on my body, I felt that. So I stayed there from the morning to the evening that day, I brought my suitcase to another place to rent. So the room before has TV, fan, aircon and that, but the water, I could not have a bath.” (C/HN)

“ my mom has car sick, she could not go by bus. So each time she went to Hanoi, we had to pay 4 million for taxi, 2 million for train. And with the train, we had to pay her train bed.” (C/HN)

“ The family member can only stay out, is not allowed to get in the ward, only came in the ward when is needed. Family member has to place the mat to sleep outside the corridor, and each time we came here for 25-30 days. I am the main caretaker. I sleep like that, also aches and pains but I have to suffer, I am tired to sleep.

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|  | <p>“(C/HCMC)</p> <p>“I did not have any problems in the hospital but the only problem I got is that my father had to take 6 hours to come here from our home. There is only my mom and my brother at home, my younger brother had to go to school far away from home, the mother is also old, she has a lot of diseases. So there are a lot of things happening in my family. She had to wake up at 4 o’clock in the morning to do housework. My older brother has two kids, that’s why my father had to come back and forth. That’s the only difficulty, no one is there to help my mom” (C/HCMC)</p> |
|--|--|