Mapping of Stakeholder Perspectives in Cancer Screening

by

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Mapping of Stakeholder Perspectives in Cancer Screening

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Graduate School of Business

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and have found that it is complete and satisfactory in all respects,
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ABSTRACT

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This study addresses the contentious issue of widespread population screening for cancer, which has led to significant variations in screening guidelines and their application in clinical practice. While guidelines should be based on medical evidence, their impact on actual practice remains limited. The study aims to construct a theoretical framework to understand the reasons behind these variations, exploring heterogeneity in screening tests. Previously collected qualitative evidence is employed, including a focused review of qualitative data analysis techniques in healthcare. Interviews with healthcare professionals, including patients, academics, clinicians, media and science reporters, and policy makers from guideline issuing organizations that were conducted in previous research are employed, with data processed using the Atlas.ti software. The research is a second coding that focuses on the evolution of over and under-screening, considering the decisions and perceptions of stakeholders, including the influence of advocacy groups, media, policymakers, and academics. The findings emphasize the complex decision-making process and the interplay of various factors between these groups. The study aims to uncover trends, variations, and emerging themes in screening guidelines and their actual practices.

ÖZETÇE

Kanser Taramasında Paydaş Perspektiflerinin Haritalanması
Başak Tavşanoğlu
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Bu çalışma, klinik uygulamalarda ve tarama kılavuzlarında önemli farklılıklara yol açan yaygın kanser taraması konusunu ele almaktadır. Kılavuzların tıbbi kanıtlara dayanması gerekirken, gerçek uygulama üzerindeki etkileri sınırlı kalmaktadır. Bu çalışma, tarama testlerindeki heterojenliği araştırarak bu farklılıkların arkasındaki nedenleri anlamak için teorik bir çerçeve oluşturmayı amaçlamaktadır. Sağlık hizmetlerinde nitel veri analizi tekniklerinin odaklanmış bir incelemesi de dahil olmak üzere nitel ve nicel kanıtlar kullanılmıştır. Daha önceki araştırmalarda sağlık çalışanları, hastalar ve politikacılarla yapılan görüşmelerden yararlanılmış ve veriler Atlas.ti yazılımı kullanılarak işlenmiştir. Araştırma, savunucu grupların, medyanın, politika yapıcıların ve akademisyenlerin etkisi de dahil olmak üzere paydaşların kararlarını ve algılarını dikkate alarak aşırı ve yetersiz taramanın gelişimine odaklanan ikinci bir kodlamadır. Bulgular, karmaşık karar alma sürecini ve çeşitli faktörlerin karşılıklı etkileşimini vurgulamaktadır. Çalışma, tarama kılavuzları ve uygulamalarındaki eğilimleri, varyasyonları ve ortaya çıkan temaları ortaya çıkarmayı amaçlamaktadır.

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Chapter 1

INTRODUCTION

The implications of widespread population screening for diseases have long been a subject of controversy and debate. While guidelines for routine screening should ideally be based on medical evidence, the impact of that evidence on actual practice is often limited. This has resulted in ongoing conflicts and controversies among scientists, clinicians, and patient advocacy groups regarding appropriate screening guidelines. Significant variations in clinical practice have been observed, including instances of over-screening for certain diseases such as breast and prostate cancer, as well as under-screening for others like a colonoscopy. Moreover, the criteria for screening, such as the age of initiation and thresholds for positive test results, have fluctuated over time, leading to further heterogeneity in guidelines and actual practice Atun (2012).

Existing studies have primarily focused on the medical evidence supporting different screening guidelines, often neglecting the broader contextual factors that influence the adoption and adherence to evidence-based guidelines by clinicians, advocacy groups, and patients. This study aims to develop a theoretical framework that explores the reasons behind the observed variations in screening guidelines, actual practice, and the gaps between them. Additionally, it seeks to contextualize this heterogeneity across different screening tests for various diseases (such as the PSA test vs. mammography). By utilizing qualitative evidence, this study aims to document and analyze variations in guidelines and actual practice across these dimensions Byass (2011).

Given the extensive magnitude of cancer research, qualitative data analysis in the health sector, and cancer screening have garnered significant attention from re-

searchers. However, conducting an exhaustive review of the literature in this vast field is impractical. Hence, this study initiates with a focused review of the general concepts of qualitative data analysis techniques applied in healthcare. While the review only covers select relevant research on cancer screening, it provides essential insights into the techniques employed. Examples from the healthcare system and health policy areas are provided to demonstrate the applicability of similar techniques used in this research Wong et al. (2022).

Furthermore, this research highlights similar data collection methods and equivalent data processing tools. The present study, along with the mentioned research, utilizes various interview techniques involving health workers, patients, and politicians as the primary data sources. Tools such as Nvivo and Maxqda are employed for data processing, serving as alternatives to the Atlas.ti tool utilized in this study. Template, thematic analysis have emerged as guiding frameworks for qualitative studies which we used in the study Chebli et al. (2023).

The core objective of this research is to analyze the evolution of over and under-screening based on the decisions made by patients, clinicians, and doctors, while also investigating how the perceptions of these groups influence one another. In addition to doctors and patients, advocacy groups such as media/science writers, press members, journalists, and writers have a significant impact on screening practices. Policymakers and academics also play crucial roles in making judgments, formulating regulations, and conducting analyses on screening criteria. To achieve these objectives, interviews conducted by Karanfil (2016) with these groups serve as a valuable resource. Building upon Karanfil's investigation of trends and sources of variation in screening guidelines and practices, this research utilizes the qualitative dataset collected in that study, conducting coding and analysis of the interviews. Independent second coding was performed to revise the conducted interviews.Karanfil and Sterman (2015)

Doctors hold their own philosophies regarding early detection, influenced by local practices among peers, patient expectations, and concerns about potential litigation. Patients, on the other hand, have their own perspectives on screening

and early detection. Doctors are aware of patients' perceptions and are influenced by them. Media and science articles have the power to shape patients' perceptions, highlighting the significant impact of media on patients. Additionally, the ideas of politicians, academicians, and doctors often find their way into press articles, which patients easily access in their daily lives. It is evident that these various groups have mutual effects and are mutually influenced, underscoring the importance of understanding changes in screening guidelines Blanchet et al. (2014).

To address endogeneity, this research analyzes interviews conducted with physicians, clinicians, and patients. These expert opinion interviews provide valuable empirical data, which will be subjected to formal thematic qualitative analysis focusing on the drivers and determinants of screening. The initial coding framework will be developed based on key issues identified in the interview outline and the collected data. As subsequent stages of analysis unfold, new themes will be added to the coding framework. Qualitative software packages will be utilized to implement this qualitative analysis.

The decision-making process surrounding screening is dynamically complex, with doctors deciding whether to offer screening and patients deciding whether to seek it, all while operating with limited information about the potential benefits and harms. Despite the importance of this decision, the limited availability of comprehensive information impedes the construction of a fully comprehensive decision-making model. Various actors, including clinicians, doctors, patients, academics, advocacy groups, and the media, influence each other's ideas and perceptions. Each group has its own benefits and concerns, and their decisions have meaningful implications for others, reflecting the interdependent nature of their relationship. Fluctuations occur due to changes in determinants of screening, fear, and risk perceptions, which can be considered endogenous effects. Interactions between these groups cause shifts in perception Behr et al. (2022).

In conclusion, this research seeks to analyze how over and under-screening evolves based on the decisions of patients, clinicians, and doctors and the influence of their perceptions on one another. It recognizes the impact of not only doctors and patients

but also advocacy groups, media professionals, policymakers, and academics on screening practices. By conducting interviews with these groups, the study aims to investigate trends and understand the sources of variation in screening guidelines and actual practice. Major emerging themes, areas of disagreement, and perceived biases will be discussed, summarizing the main issues, controversies, and patterned variations observed in respondents' viewpoints and preferences.

Chapter 2

BACKGROUND & LITERATURE REVIEW

Due to the extensive research conducted on cancer and the significant attention given to qualitative data analysis in the health sector and cancer screening, conducting a comprehensive literature review is impractical.

We will first start with a review of the literature regarding the general concepts in context of qualitative data analysis applied in healthcare. We will only cover some of the relevant research thus giving a knowledge of Qualitative data analysis techniques in this part. Qualitative data analysis methods are used in diverse relevant health sectors for different aims. Here we would like to give research examples from the healthcare system and health policy areas which uses similar techniques as we used in our research.

Additionally, similar data collection methods and equivalent data processing tools point out in this section. In our research and as well as these researches we mention/refer to give examples from used several interview techniques on health workers, patients, and politicians which construct most part of the data. The data is processed by tools like Nvivo, and Maxqda as an alternative to the tool that we wield Atlas.ti. Template, thematic analysis, and FRAM model appeared to guide the qualitative studies.

2.1 Methods & Techniques

Expert qualitative opinion interview study is a research method that involves conducting in-depth interviews with individuals who are considered experts in a particular field or topic. The goal of this type of study is to gain a better understanding of the expert's perspective and insights on the topic, as well as to identify important themes and issues related to the subject matter.

In an expert qualitative opinion interview study, the researcher typically uses open-ended questions to elicit detailed and nuanced responses from the interviewee. The interview may be conducted in person, over the phone, or via video conferencing, and may be recorded or transcribed for later analysis.

The data collected from the interviews are often analyzed using qualitative methods, such as thematic analysis, to identify patterns, themes, and other important insights. The results of the study may be used to inform policy or practice in the field, or to generate hypotheses for further research.

Expert qualitative opinion interview studies are often used in fields such as healthcare, education, and social sciences, where insights from experts are highly valuable in understanding complex phenomena. However, it is important to note that the findings from this type of study are often based on relatively small sample size and may not be generalizable to the larger population.

Template analysis is a widely used qualitative research method that provides a systematic and structured approach for organizing and analyzing qualitative data. The method involves sorting and categorizing data into predefined categories or templates, which can then be used to identify patterns and themes within the data.

In template analysis, data is collected from a variety of sources, such as interviews, focus groups, surveys, or existing documents. This data is then transcribed and reviewed to identify relevant information. Next, the researcher defines the templates, which can be thought of as categories or headings, and codes the data by assigning each piece of information to the appropriate template.

Once the data has been coded, the researcher can analyze the patterns and themes that emerge within each template. This process helps the researcher to identify relationships and connections between different pieces of data and to gain a deeper understanding of the phenomena under investigation Sabounchi et al. (2023).

Template analysis is particularly useful in a wide range of qualitative research areas, including health and social care, education, sociology, and psychology. It is also often used in mixed methods research, where qualitative data is analyzed alongside quantitative data King (2012).

One of the advantages of template analysis is that it provides a structured and systematic approach for analyzing qualitative data, which can help to reduce the subjectivity and bias that can sometimes occur in qualitative research. Additionally, the use of templates allows for consistent coding and analysis of data, which can increase the reliability and validity of the findings King (1998).

A **mixed-methods approach** for data collection involves combining both qualitative and quantitative methods to collect data in a research study. This approach is often used when researchers want to gather a deeper understanding of a phenomenon by looking at both numerical data and the lived experiences and perspectives of individuals involved.

Quantitative data is collected through structured surveys, experiments, or statistical analyses to measure trends, patterns, and relationships among variables. Qualitative data is collected through in-depth interviews, focus groups, observations, or open-ended surveys to gain insight into the experiences, feelings, and perspectives of the research participants Sandelowski (2000).

By using both quantitative and qualitative methods, researchers can provide a more comprehensive and nuanced analysis of a research question. The mixed-methods approach allows researchers to triangulate their findings, meaning that they can cross-validate results from different methods to increase the overall validity and reliability of their findingsCreswell (1999).

Thematic analysis is a widely used qualitative research method that involves identifying, analyzing, and interpreting patterns or themes within qualitative data. The method is used to analyze a wide range of data sources, including interviews, focus groups, written texts, and observational data Braun and Clarke (2012).

Thematic analysis typically involves several stages, including:

1. Preparation: This stage involves transcribing the data and familiarizing oneself with the content.

2. Initial coding: In this stage, the researcher begins to code the data by breaking it down into smaller, manageable chunks and assigning labels or codes to these

chunks.

3. Theme development: The researcher then identifies and names the emerging themes based on the coded data.

4. Review and refinement of themes: This stage involves reviewing and refining the themes to ensure they accurately capture the data and address the research questions.

5. Theme interpretation and analysis: Finally, the researcher interprets and analyzes the themes in relation to the research questions and broader literature.

Thematic analysis is a flexible and adaptable approach that can be used in a wide range of qualitative research areas, including health and social care, education, sociology, psychology, and many others. It is often used in mixed methods research, where qualitative data is analyzed alongside quantitative data Vaismoradi et al. (2013).

One of the key advantages of thematic analysis is its ability to identify patterns and themes in the data, which can provide insights into the experiences, perspectives, and behaviors of the participants. Additionally, thematic analysis can help researchers understand the relationships and connections between different data pieces and gain a deeper understanding of the phenomena under investigation.

Quotation analysis is a method used in qualitative data analysis to identify and analyze recurring themes, patterns, or meanings in the data. This method involves selecting and categorizing direct quotations from the data and examining them in detail to extract deeper insights into the experiences and perspectives of the participants.

Quotation analysis is often used in qualitative research, such as in interviews, focus groups, or open-ended survey responses, to help the researcher understand the meaning behind the participants' words. The quotations serve as "data chunks" that the researcher can examine to identify patterns, themes, and relationships within the data. This helps the researcher to identify the most significant and relevant

information and to make inferences about the experiences, beliefs, and attitudes of the participants.

In short, quotation analysis is a useful tool for qualitative data analysis as it provides a way to delve deeper into the meaning behind the participants' words and to gain a more nuanced understanding of the experiences, perspectives, and attitudes being studied.

Sentiment analysis, within the context of qualitative analysis, refers to the process of examining and understanding the emotional tone, opinions, and attitudes expressed in textual data. It involves systematically analyzing qualitative data, such as interviews, surveys, or social media posts, to determine the sentiment or subjective perspective conveyed by the participants.

In sentiment analysis, qualitative researchers aim to uncover the underlying emotions, beliefs, and evaluations expressed by individuals within the collected data. This process often involves identifying keywords, phrases, or linguistic patterns that indicate positive, negative, or neutral sentiments. Researchers may also consider the broader context in which these sentiments are expressed to gain a deeper understanding of participants' viewpoints.

Qualitative sentiment analysis requires careful interpretation and contextualization of the data, as the analysis is not solely focused on the frequency or intensity of sentiments but also on the meanings and nuances associated with them. Researchers may employ various qualitative analysis techniques, such as thematic analysis or content analysis, to identify and categorize sentiments, identify patterns, and explore the reasons behind the expressed sentiments Wolstenholme and Coyle (1983).

The goal of sentiment analysis in qualitative research is to provide insights into participants' subjective experiences, opinions, and perspectives. By understanding the sentiment expressed in qualitative data, researchers can gain a richer understanding of participants' attitudes and emotions, enabling them to uncover deeper insights and inform their research findings.

The Van Kaam method, also known as the Van Kaam method of existential analysis, is a qualitative research method used to study the subjective experiences of

individuals. It was developed by Adrian van Kaam, a Dutch-American psychologist and existentialist philosopher, and is based on the principles of existential psychology and phenomenology.

The Van Kaam method involves the systematic analysis of an individual's experiences and how they understand and give meaning to those experiences. It involves a process of self-reflection and introspection, where the participant is asked to describe their experiences in detail, as well as their thoughts, feelings, and perceptions related to those experiences. This information is then analyzed in a structured way to identify patterns and themes that can shed light on the participant's subjective experiences Anderson and Eppard (1998).

In qualitative research, the Van Kaam method is often used as a tool for understanding human experiences and subjective realities, particularly in the areas of psychology, education, and human development. The method can be used to study a wide range of experiences, including personal and emotional experiences, spiritual and religious experiences, and experiences related to physical and mental health.

The Van Kaam method is seen as a valuable tool for qualitative research because it allows researchers to access the subjective experiences of participants in a way that is not possible through more traditional research methods. By examining the ways in which individuals understand and make meaning of their experiences, researchers can gain a deeper understanding of their subjects and the complex and diverse ways in which they experience the world.

The "FRAM" model stands for **Function-Behavior-State Model**. It is a systems engineering and software engineering methodology used to define and describe complex systems. The FRAM model provides a structured way to describe a system's functions, behaviors, and states, as well as the interactions between them. The model is used to analyze and understand complex systems, identify and manage system requirements, and support the development of high-quality software and systems. The FRAM model can be used in a variety of domains, including aerospace, defense, transportation, and healthcare Patriarca et al. (2020).

Causal loop diagrams (CLD) are a type of diagram used in system dynamics,

a field of study that examines the behavior of complex systems over time Sterman (2010). In system dynamics, causal loop diagrams are used to represent and analyze the causal relationships between variables within a system. Forrester (1997)

In qualitative research, causal loop diagrams can be used to analyze complex data and help researchers understand the relationships and interactions between different variables. The diagrams provide a visual representation of the data, making it easier to identify patterns and relationships between variables.

To create a causal loop diagram, the researcher first identifies the key variables and relationships within the data. Then, they draw arrows to represent the causal relationships between these variables. The arrows can represent either reinforcing relationships, where an increase in one variable leads to an increase in another, or balancing relationships, where an increase in one variable leads to a decrease in another.

Once the diagram is complete, the researcher can analyze the relationships between the variables and identify feedback loops, which are circular relationships between variables that can cause the system to behave in unexpected ways. The use of causal loop diagrams can help researchers to identify the drivers of change within a system and understand how different variables interact to shape its behavior over time.

In qualitative research, causal loop diagrams can be used in a wide range of fields, including health and social care, education, sociology, psychology, and many others. They can be particularly useful in cases where the relationships between variables are complex and difficult to understand, as they provide a visual representation of these relationships that is easy to interpret and analyze.

Second coding is a method used in qualitative data analysis to increase the accuracy, reliability, and validity of the coding process. It involves having two or more coders independently analyze the same data and then compare their results to identify any discrepancies or disagreements in their coding.

In the second coding, each coder independently applies the same set of codes or categories to the data, and then the results are compared to identify any differences.

The goal of this process is to increase the reliability and validity of the coding by ensuring that multiple coders have independently come to the same conclusions about the data. This helps to reduce the influence of personal biases, interpretation errors, and other sources of subjectivity in the coding process.

Second coding is often used in qualitative research to increase the rigor and reliability of the coding process. By having multiple coders independently analyze the data, the researcher can be more confident in the accuracy and validity of the coding results. This can be particularly useful in studies where the data is complex, rich, or sensitive, and where it is important to ensure that the coding is as accurate as possible.

In short, second coding is a method used in qualitative data analysis to increase the accuracy and reliability of the coding process by having multiple coders independently analyze the data and compare their results.

2.2 Software Tools

Atlas.ti, MAXQDA, QDA Miner, and NVivo are all computer software programs designed for qualitative data analysis. However, each of these software programs has its own unique features and strengths.

Atlas.ti is a flexible and user-friendly software package that provides a range of tools for coding, memoing, visualization, and reporting. It is widely used in various fields, including social sciences, health sciences, and market research.

MAXQDA, on the other hand, is a comprehensive software package that supports qualitative, quantitative, and mixed methods data analysis. It is known for its user-friendly interface and a wide range of features to support the coding, categorizing, and analyzing of qualitative data.

QDA Miner is a software package specifically designed for the analysis of qualitative and mixed methods data. It is known for its user-friendly interface, ease of use, and ability to handle large amounts of qualitative data.

NVivo is a software package that provides a range of tools and features to support the coding, categorizing, and analyzing of qualitative data, including text,

audio, and video files. It is known for its user-friendly interface, flexibility, and its ability to handle large amounts of qualitative data.

When comparing these software programs, it is important to consider your specific needs and research questions, as well as your budget and personal preferences. Some researchers may prefer one software package over another based on their specific research needs and the features that are most important to them. Ultimately, the choice of software will depend on the individual researcher's needs, preferences, and goals.

2.3 Review of the Relevant Literature

These are the techniques and methods that related literature used, in qualitative research for healthcare. We summarized how these are applied in the literature. Then explain how and why we interpret and wield in our own research.

D'Arcy et al. (2019) conduct a descriptive study on the empowerment of lay health worker (LWH) programs. Evidence information on understanding the factors influencing the program effectiveness which empowers the program is lacking. The qualitative case study explores how enables and barriers apply to the empowerment of the LWH models. Two types of data were collected: online LHW activity logs (n=7) and semi-structured face-to-face interviews (n=7). The data was collected after 6-7 months of program implementation. Activity logs have filled in information about LHW activities, which provide a detailed description and helped to identify what to be improved. Interviews were done with LWH to explore the content of their activities. A hybrid deductive–inductive qualitative analysis was used for the identification of the themes. The template analysis method guides this process. Data were read several times and coded with Nvivo qualitative data analysis software. The research explores potential recruitment barriers for the LWH groups by developing an innovative design. As a result, the study indicates that empowerment is an enabler for effective program implementation. Although the small sample size according to the low participation rate limits the study, the current results fill the research gaps in the context of evidence-based descriptive studies D'Arcy et al. (2019).

Another research held by Mason et al (2017) for overcoming barriers to implementing electronic health records in rural primary care clinics. This phenomenology study aimed to explore rural primary care physicians and physician assistants' lived experiences regarding overcoming barriers to implementing electronic health records. The conceptual framework is formed by complex adaptive systems. Qualitative phenomenological research is conducted to recognize and comprehensively define particular occurrence-based participants' accounts of their lived experiences. Face-to-face interviews from a sample of 21 physicians and physician assistants across 2 rural primary care clinics constitute the data. Interviews continued until no new theoretical understanding was attainable and data saturation was reached. NVivo software was used to facilitate and capture the collected information from the interview with long in-depth open-ended semi-structured questions. The software incorporates the interview responses into emerging themes. In addition, the interviews were analyzed using the methods, procedures, and practices of phenomenological research analysis with the modified van Kaam method Anderson and Eppard (1998). However, the study has infrastructural limitations; unfeasibility of interviewing every rural care unit, low participation rate, and not covering all stakeholders' experiences. As a result, recommendations emerged from the study. Adopting these recommendations might enable healthcare providers and healthcare leaders to mitigate disruptions Mason et al. (2017).

A thematic analysis used by Byrne et al (2020) for exploring the nurse navigator role. As Byrne states unnecessary hospitalization increases the incidence of poor health outcomes in patients with complex chronic conditions. Navigation healthcare models are mechanisms for improving the health of people with complex conditions. Nurse navigator programs are being conducted under these models. The paper explores how nurse navigators manage client care. The 84 vignettes were collected from 109 nurse navigators between November 2018 and August 2019. The vignettes were thematically analyzed using template analysis, which allows the researchers to read the data with preconceived ideas of what might form the major ideas within the text. Through conducting the template analysis method, the themes reported

do not necessarily represent all that the respondents have reported. The researcher approaches the data with some initial ideas of what they are looking for and seeks to confirm these. The data were independently reviewed by six members of the research team. A meeting was then held to discuss and collate themes based on the consensus of the independent reviews. Following a consensus of all collated themes, they collapsed these into major themes. The results of the study provide insight into the new role by illuminating the work nurse navigators achieve, despite system complexities. On the other hand, there were some limitations affecting the research. One of them is the data for this study were limited to the first 6 months of a 2-year study. Also, the review is limited to the information provided by the navigator in the role Byrne et al. (2020).

Mason used the interview technique and Nviovi software for qualitative research. The journal article focuses on the implementation of electronic health records (EHRs) in rural primary care clinics and examines the experiences of rural healthcare providers in overcoming barriers. The study identifies four main barriers: limited finances for EHR support, health information exchange challenges, lack of business education, and insufficient change management in rural medical practices. Participants expressed concerns about healthcare legislation, feeling it threatens their autonomy as decision-makers and providers. The article highlights the need for further research to understand regional and specialty-specific differences in perceptions and suggests assessing changes in healthcare providers' attitudes toward EHRs over time. Overall, the study emphasizes the importance of addressing the unique challenges faced by rural healthcare providers to successfully implement and use EHR systems Mason et al. (2017).

Decision-making methods are also used in qualitative research. Rimer conducted Informed decision-making (IDM) and shared decision-making (SDM)on Cancer screening. The journal article explores informed decision-making (IDM) and its significance in cancer screening. IDM involves individuals understanding the disease or condition, comprehending the clinical service, considering their preferences, and making decisions aligned with those preferences. The study distinguishes IDM

from shared decision-making (SDM) and informed consent. The evidence suggests that IDM and SDM interventions, such as decision aids, improve knowledge, beliefs, and risk perceptions. However, there is limited evidence on whether these interventions lead to patient participation in decision-making based on their preferences or impact patient satisfaction with the decision-making process. The effects on screening behavior vary, with some studies showing decreased screening when evidence is insufficient and others encouraging screening for conditions with strong evidence.

The article stresses the need for more research to assess the benefits of IDM/SDM interventions and tailor them to individuals who desire and would benefit from them. It also highlights system barriers to IDM/SDM and the lack of adequate tools. The authors advocate for further research on integrating IDM into clinical practice and examining potential negative consequences.

Overall, the article emphasizes the importance of IDM in complex decision-making scenarios, especially as advanced screening technologies may necessitate personalized approaches to meet individual screening needs. The authors recognize the necessity for interdisciplinary research to advance IDM/SDM theories and address diverse populations' needs when implementing these approaches effectively Rimer et al. (2004).

Healthcare problems consist of non-trivial, complex, socio-technical systems, McNab applied the functional resonance analysis method for the participatory design of an improvement intervention for the primary care management of possible sepsis. Sepsis is a life-threatening condition that primary health care units are responsible for in the treatment process. Primary Healthcare is a complex system consisting of many dynamic and interacting components that are affected by rapid changes in conditions. This study was conducted as a part of a healthcare improvement project to understand the complexity of current work and consider interactions between proposed interventions and the existing systems. Healthcare professionals and administrators in a single regional health board were involved as participants in the study through semi-structured, face-to-face, and group interviews. In addition, random 50 patient cases are selected from the hospital admissions ADOC

computer system as anonymized data. Multiple clinical, management and administrative perspectives on potential systems improvements were identified and themed from this data collection. So mixed method approach was used for data collection and analysis then all the responses were coded with QDA miner. Afterward, research continued with Functional Resonance Analysis which used the information and the outputs to model the system. FRAM is a method to model and understand non-trivial, complex socio-technical systems. The researchers applied FRAM to study the relationships within the system by exploring the potential interactions between functions. Functions are the activities that are required to produce a certain outcome. Each theme of the data was analyzed to identify aspects of each function. Then the system functions and aspects are uploaded to FMV software to assess the variability of function output. The FRAM model seeks to understand and improve the overall performance of the complex system from the interactions McNab et al. (2018).

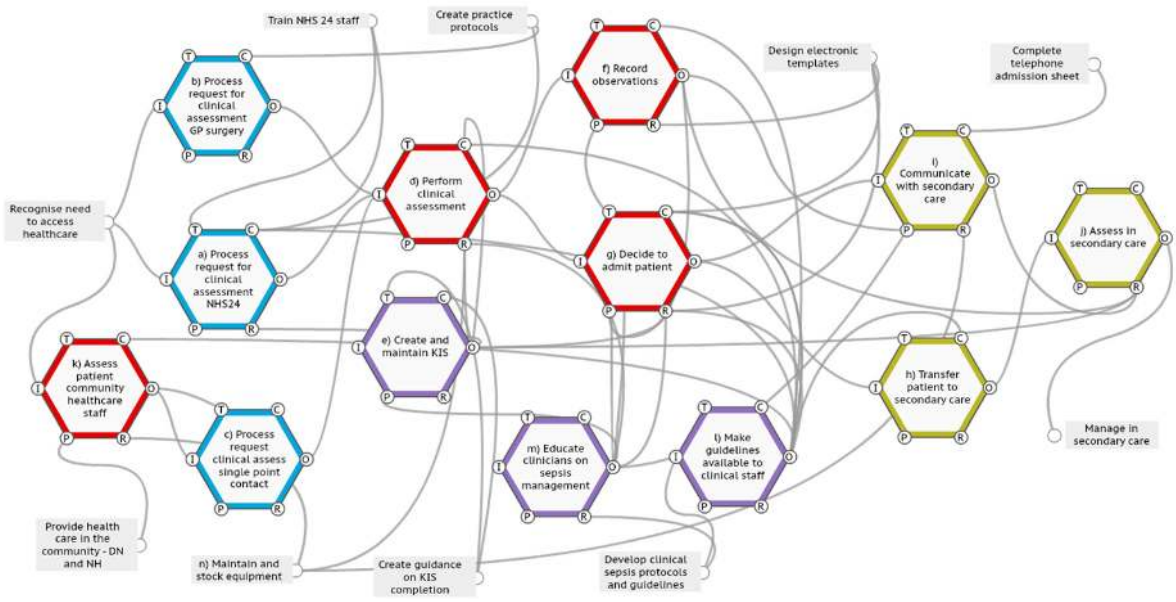

Figure 2.1: Example of FRAM Method

(McNab et al., 2018)

Qualitative studies aim to investigate the perceptions of policy-makers, academi-

cians, and experts. AlKhaldi carried out his research regarding the health research system (HRS) concept. Inspecting the perceptions of the system performers is crucial to understand the strengths and limitations of the improvement in the health research system. The study is part of a larger investigative research project which provides an overview of three diverse and relevant sectors' understanding of the HRS concept. The descriptive situation analysis was conducted based on the data collected through qualitative methods in six months by using MAXQDA qualitative data analyzing tool. 104 experts from 3 fields (public health, medical/ biomedical, economic/political) were selected through 4 different sampling techniques (criterion, critical case, snowball, homogeneous sampling) to ensure knowledge saturation. Political key informants participated in 52 In-depth interviews (IDI) and technical expertise assigned to 52 focus group discussions (FGD). Both IDIs and FGDs focused on 5 themes of open-ended questions laid out in relevant literature. Results of the qualitative research admitted that HRS understanding among health experts in Palestine is inadequate. Awareness and the culture of the HRS should be strengthened by central governance coordination AlKhaldi et al. (2018b).

AlKhaldi continued the research to examine policymakers', academics', and experts' satisfaction with overall health research system (HRS) performance, while also investigating their perceptions about political will and attention towards health research. Ultimately, the study wants to identify gaps related to performance and generate insights on how to move forward for HRS performance strengthening. Data processed by MAXQDA for thematic research. The data used in the study is the same as the previous one, but researchers pursue the study on the performance of HRS. Their approach serves to both observe the system's performance and its processes. The aim is to offer a platform to identify system improvements. Considering lacking standards or quantitative indicators to monitor and evaluate research and its societal benefits, this study fills an important knowledge gap because it focuses on performance and its deficiencies which are rarely addressed in Palestine. As a different method, a qualitative cross-sectional descriptive situation analysis approach was used by conducting data analysis which is thematic content analysis. Themes

and codes were inductively established and guided by the conceptual framework developed by the relevant HRS literature AlKhaldi et al. (2018a).

Schwartz used the survey method as another qualitative research method in the healthcare context. The journal article investigates the impact of lowering the diagnostic threshold for common conditions like diabetes, hypertension, hypercholesterolemia, and being overweight on disease prevalence in the U.S. adult population. The study uses data from the Third National Health and Nutrition Examination Survey (NHANES III) to analyze the number of new cases that would be identified under the proposed new definitions compared to existing ones. The results indicate that adopting the new definitions would significantly increase disease prevalence, with millions of new cases being identified. However, the potential benefits and risks of early detection and treatment for these mild forms of disease remain uncertain. The article emphasizes the need for further research to understand the implications of changing disease definitions and its potential impact on healthcare policy Schwartz and Woloshin (1999).

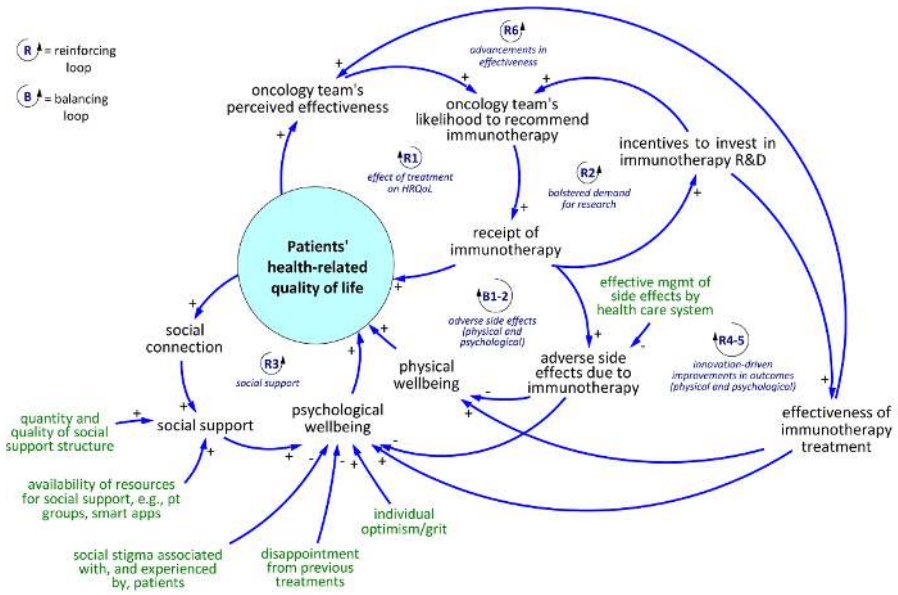

Figure 2.2: Simplified Causal Loop Diagram

(Beaulieu et al., 2022)

Causal loop diagrams (CLD) are another tool that provides a systematic perspective and allows the identification of a complex interplay of factors with multiple feedback mechanisms present in the system. A wide set of variables can be identified to present a discussion of the components to understand the complex interplay of factors. Beaulieu used CLD to understand the health-related quality of life (HRQoL) in cancer immunotherapy which is defined generally as medicinal strategies that harness the immune system to prevent or treat disease. Also, the report provides an example of expanding the application of CLDs to analyzing the underlying dynamics of quality of life in other health problems. Beaulieu modeled the CLD through interviews with subject matter experts, including the new treatment options; digital tools; remote monitoring; patients' choices and contributions; and patients' advocacy groups. As a result, Several feedback loops are identified that span clinical experiences and oncology teams' perceptions of immunotherapy. The CLD shown in Figure 2.2 illustrates thought experiments regarding how a change anywhere in the system can ultimately worsen or improve patients' HRQoL, and visualize systematic trade-offs Beaulieu et al. (2022). Rigorously interpreted quotation analysis for evaluating causal loop diagrams in late-stage conceptualization.

Tomoaia-Cotisel presents a formal method called "Rigorously Interpreted Quotation Analysis" (RIQ) for evaluating causal loop diagrams (CLD) during late-stage conceptualization. RIQ analysis uses a systematic and explicit interpretive process to compare the CLD with stakeholders' verbatim descriptions of their experiences in complex dynamic situations. The method aims to confirm or disconfirm all diagram elements based on qualitative data, resolving any discrepancies and building confidence in the structural aspects of a dynamic hypothesis. By presenting RIQ results alongside a CLD, researchers can share supporting data in the natural language of the data source and document the interpretive process, allowing for reproducibility and further disconfirmation. RIQ analysis offers scientific and practical value for different project contexts and stakeholders, enhancing communication among team members and ensuring stakeholders' voices are formally captured in the resulting model. It also allows qualitative modeling work to be evaluated, replicated,

and disconfirmed by peers, contributing to the improvement of CLDs' quality. The article emphasizes that RIQ analysis can be easily implemented by novices and experts alike, providing rigorous understanding for building confidence in conceptualization. It contributes to the field of system dynamics by responding to calls for more robust qualitative methods and facilitates rigorous evidence-based testing of diagrams, improving projects' empirical rigor and policy impact. RIQ analysis helps in understanding dynamically complex structures across stakeholder groups, providing a countermeasure against reductionism in addressing complex problems Tomoaia-Cotisel et al. (2022).

We used the expert qualitative opinion interview study of Karanfil et. al. (2016) which consisted of in-depth and semi-conducted interviews in order to collect important pieces of qualitative evidence. Then we conducted Thematic analysis and quotation analysis on these interviews. Analyze, and interpret patterns and themes in the data, and split participants into focus groups using Atlas.ti. The software incorporates the interview responses into emerging themes. Actually, our research is a second coding of Karanfil (2016). Independently analyze the same data and then compare our results to identify any discrepancies or disagreements and also to increase rigor and reliability Karanfil and Sterman (2020).

Chapter 3

METHODS

In this study, we want to analyze how over and under-screening evolves according to the decisions of the patients, clinicians, doctors, advocacy groups, and media/science writers. Also, we want to understand how these groups' perceptions affect each other. Not only doctors and patients but also advocacy groups such as media/ science writers, press members, journalists, and writers have an impact on the practice of screening. On the other hand, there are the policymakers and academics who make judgments, regulations, and analyses on practice screening criteria.

To achieve this goal, Karanfil conducted interviews with the aforementioned groups to explore trends and identify sources of variation in screening guidelines and actual practices Karanfil (2016). Inspired by the research, our study utilized the qualitative dataset obtained from these interviews, which we subsequently coded and analyzed. Additionally, as part of an independent second coding process, we carefully reviewed and revised the conducted interviews

3.1 Expert Opinion Interviews

In order to collect vital pieces of qualitative evidence, the expert opinion interview study method involves in-depth and semi-structured interviews to carry out thematic analysis for qualitative research.

Karanfil used this method, involving in-depth and semi-structured interviews. The composition of interview participants is categorized under five significant headings i.e. 1) policy maker, 2) clinician, 3) academic, 4) patient, advocacy group member, and 5) media/science reporter. The interviewees have some expertise or experience related to the practice guidelines.

We divided our interviewees into six groups; Academic, clinician, media/science writer, patient, advocacy group, and policy maker. Also as another arrangement, we investigate them by evidence-based and specialty/ advocacy group perspectives. So we analyzed our interviews in two different ways. We categorize our participants according to their field into six, and as another alternative category, we group them by their perspectives into two. First, we identify all 32 interviews in these classes. An interviewee can be a member of several types. Therefore participants can wear multiple group hats.

As shown from Figure 3.1 the distribution through interview groups, most of them, 26% have an academic background. Also, 24 % are clinicians, so half the population has solid experience in guidelines and uses them daily. By adding the advocacy group we reach 65% of the total. Patients 10% and policymakers 6% constitute a minority of the composition.

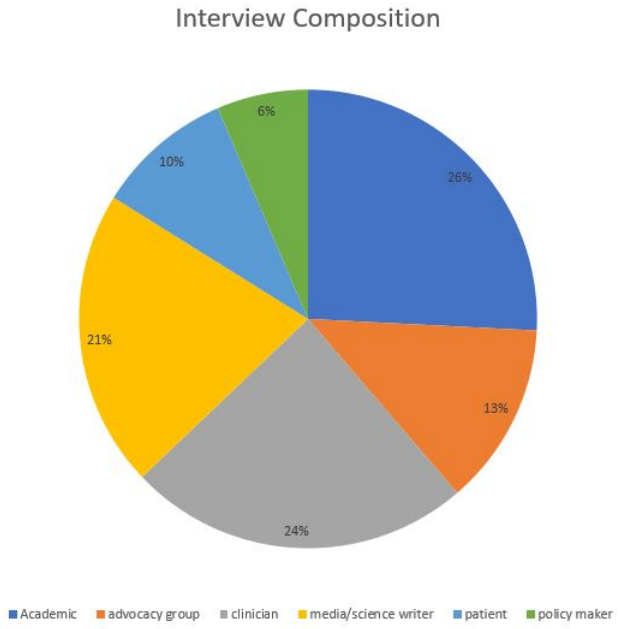

Figure 3.1: First interview composition according to field of Expertise

Some participants overlap between the categories, reflecting the fact that most of the participants tend to wear multiple hats in influencing the screening decision. For example, approximately half of the clinicians interviewed have an academic title,

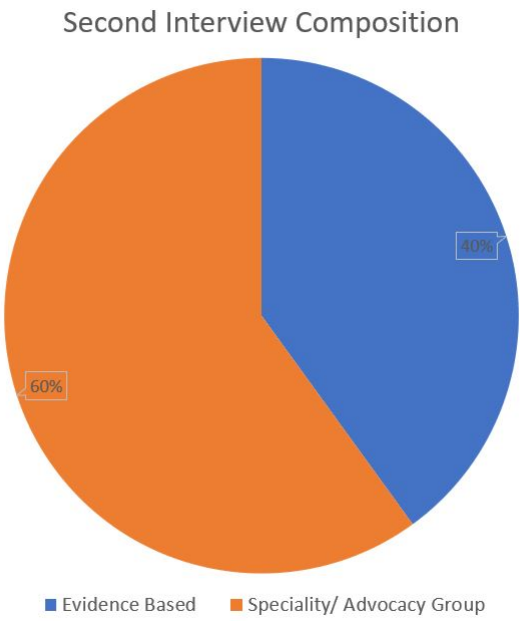

Figure 3.2: Second interview composition according to perspective

and half of the academics play a major policy role in influencing the development of clinical practice guidelines. There is also a noticeable overlap between clinician and policymaker categories. We can highlight this as the primary drawback. Even though these groups affect each other, they can also be members of several groups. So, this makes our analysis more complicated, and understanding the point of view of specific groups is harder.

Figure 3.3 shows the final composition of interviewees. Significant overlaps occur between policymakers, clinicians, and academics. In addition, specialty/ advocacy group participants are diverse mostly academics, clinicians, and policymakers. Some participants are science media writers but also had a thought-provoking experience as breast cancer patients. specialty/ advocacy group participants are diverse mostly academics, clinicians, and policymakers.

The second interview composition that we group between evidence-based and specialty/ advocacy groups is shown in figure 3.2. 60% of them is member of a specialty/ advocacy group. In the second grouping, interviewees do not wear multiple hats. An evidence-based member can not be a specialty/ advocacy group mem-

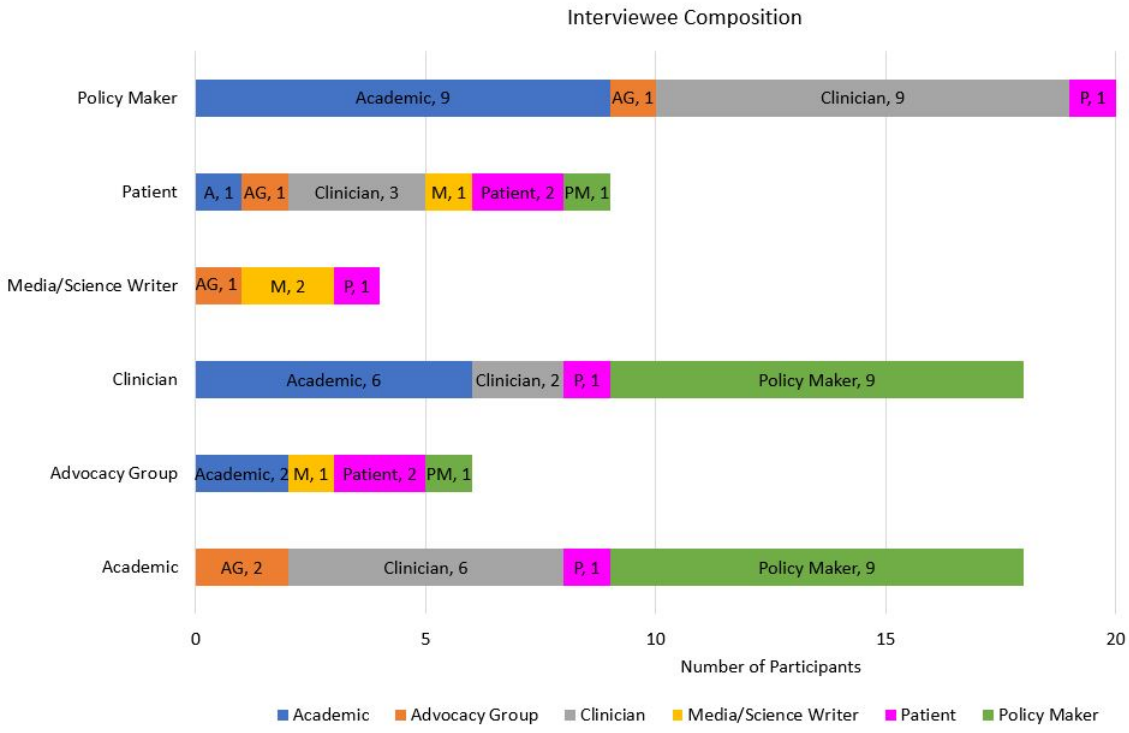

Figure 3.3: Interviewee Composition 1

ber. However, We can see the distribution of their fields in figure 3.4. The figure shows us the academician, clinician, media/science writer, patient, and policy maker distribution in both groups.

Interviews ranged in duration from 20 minutes to 2 hours and 35 minutes, conducted by Karanfil both by phone and in person. Some of them were audio-recorded, de-identified, and transcribed verbatim. These interviews were semi-structured and the outline was given to the interviewees before the meeting. The outlines varied according to the categories of the participants, therefore some questions were modified, but the main outline remains. Karanfil (2016) You can find the details of the main interview in the Appendix.

Interviews consisted of four main parts as;

1. Informed Consent

2. Project Background

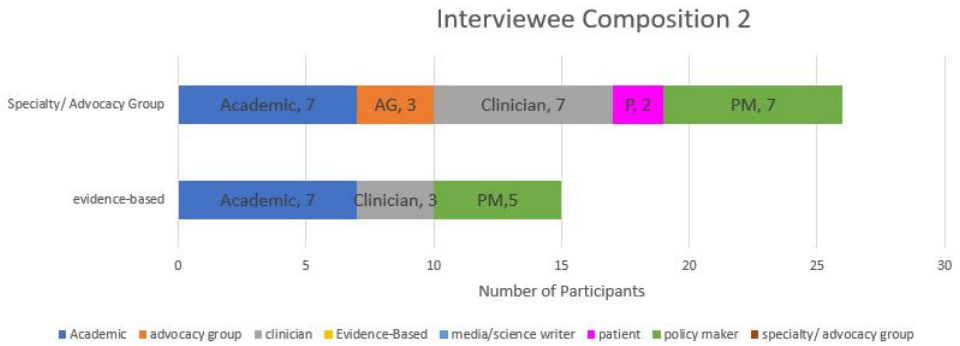

Figure 3.4: Interviewee Composition 2

3. Background of Interviewee

4. Questions related to the study (as appropriate to the interviewee's knowledge)

After getting the consent of the participants, Karanfil gave brief information about the research. She conducted the interviews using the snowball method so asked the interviewees' opinions about who to talk with next also asked questions to the participant to learn more about his/her background. These questions helped to modify and consulate the specific research questions in the last part, according to the experience and expertise of the interviewee.

3.2 Data and coding

Doctors have their philosophy about early detection, what their peers are doing locally, and the patient's expectations, combined with anticipated litigation concerns. On the other hand, patients have their views about screening and early detection. Doctors also know about patients' perceptions, they are affected by them. Media and science articles change patients' perceptions. Therefore, media has a great impact on the patient. Besides the ideas of politicians, academicians, and doctors are written and published by the press. These articles are easily accessible by patients in daily life. As you can see all of these groups have their effects and are affected by each other. So, these groups represent the importance of understanding the changes in the guidelines.

A method that we are going to use to deal with the endogeneity is to analyze the interviews with physicians, clinicians, and patients is thematic analysis. This expert opinion interviews a means of collecting parts and pieces of empirical data. Using the collected interview data, we are going to undertake a formal thematic qualitative analysis as it relates to drivers and determinants of screening. First, we will develop an initial analytic framework from the identification of the key issues within the interview outline and the data. This initial coding framework can be used to analyze the interview data, with themes added as new issues emerge in subsequent stages. Free qualitative software packages are going to be used for implementing this qualitative analysis.

Our composition of interview participants can be categorized under six and two major classes such as policy maker, clinician, academic, patient, media/science reporter/advocacy group member, and specialty/advocacy group, evidence-based. Most participants were active in multiple domains (e.g., academic and clinician; policy expert and academic; advocacy group member and patient; in the case of more than two roles, we picked the most relevant two categories). Participants were asked about the major determinants for how much screening happens, their views of the usefulness of the screening test, harms, and benefits, and what they think about changing guidelines. To explain more precisely, some sample questions are provided below:

- Which factors do you think contribute most to the doctor's decision on screening?

- What are the major determinants of how much screening happens?

- What are the potential benefits and harms of screening?

These selected questions are ones that we emphasized more in our research. We discuss in detail the answers of the interviewees to these specific determinations of screening, the harms and benefits of screening, and the factors of the screening decision. Our research is the second coding on Karanfil's study. The prior study results,

points out harms and benefits and determination of screening, these questions shows the divergence between evidence-based and specialty/advocacy groups in the former research. Also point out the source of variation between these two main groups' perceptions so we focus on them. Answers given by the participants to these specific questions highlights the disparity between evidence-based and specialty/advocacy group.

These specific modified questions conduct/direct Karanfil to constitute the themes for coding. We reconstruct these themes in our second independent coding celebration and create a plainer model while being unaware of the prior researchs' hypothesis. In our research, we keep the themes but collect them under more generic ones. We have eight code groups as themes. These themes are arranged into 23 sub-themes. On the other hand, Karanfil divided themes into 12 main and 75 subthemes. We rearranged them and collided some of the themes together. We regard some of the major themes as significant; guidelines, screening, cognitive factors, threshold, and feedback constitute five of our eight themes. The remaining themes, treatment, reliable information source, and interpretation of evidence are sub-themes in Karanfil's research which we want to investigate deeply in our second independent coding study. Therefore some differences emerge between our studies but there is meaningful overlap and we look over these coincides.

Screening: Determine how the screening decision was made, the outcomes of the screening, and the usefulness of it during the treatment

- Screening Decision
- Usefulness
- What are the determinants?
- What are the harms and benefits?

Threshold: Detect the main screening types' thresholds for practice that mentioned in the research

- Age of Mammography

- Age of PSA
- PSA cutoff or biopsy threshold

Treatment: Identify the technologies and the treatment trends during the treatment process and also decide on a particular treatment option

- Technology
- Treatment Decision
- Treatment Trends

Guideline: Ascertain the utilization of the guidelines

- Adherence
- Mammography Guidelines
- PSA Guidelines
- too much change / missing communication

Reliable Information Source: Specify the information sources

- Media/Science writing
- Other Source

Cognitive Factors: Designate the factors upon guideline/ screening decision making

- Hard to Communicate (with the public)
- Effect of Industrial Conflict
- Not intuitive
- Speciality Bias

Feedback

Interpretation of Evidence: Analyze and evaluate data to draw conclusions or make inferences about a particular phenomenon or event.

For thematic analysis, there are qualitative software packages for data analysis. In our research, we prefer to use Atlas.ti version 9 Coding serves as a fundamental task in ATLAS.ti, enabling users to identify significant elements within their data. The primary objective of categorizing data is to assign tags that provide definitions or organization. During the categorization process, data segments are compared to identify similarities, allowing for the grouping of related elements. By assigning names to these groups, we simultaneously conceptualize and frame the identified elements.

Atlas.ti is an alternative to MaxQDa free package that Karanfil has used. It differs from MaxQDa with its extra analysis choices that the software presents to the user. One of them is the sentiment analysis that we conducted. As an alternative method differing from Karanfil's research, we used sentiment analysis and have 3 more themes negative, positive, and neutral in addition to 23 main themes. In total, we coded 1149 segments without the sentiment analysis. If we include sentimental analysis our coding increases to 4578 segments. Each word is categorized in sentimental analysis, which greatly raises our segmentation. On the other hand, Karanfil coded over 2400 segments.

Figure 3.5 shows us the distribution of the coding themes in each group. Interviewers primarily emphasize screening so we coded screening the most. Treatment and cognitive factors ensue.

As we can infer from the Figure 3.5 screening has a major dominance over the other themes. It is the most coded theme. This indicates that the screening theme with its sub-themes; screening decision, usefulness, harms/ benefits, and determination of screening decision has a significant effect.

Cognitive factors are one of the significant themes that we can observe from figure 3.5. We try to designate the factors upon guidelines or screening decisions. The importance of risk perception in screening decisions emerges to be an important category, this includes cognitive factors as coded by me. Its sub-themes are

"hard to communicate", "the effect of industrial conflict", "not intuitive", and "specialty bias" expressions are coded. These coded segments reveal the importance of cognitive factors in our research. We try to investigate the effect of industry on interviewees' perceptions. We coded the communication between groups in the "hard to communicate" sub-theme to understand how the guidelines or screening decisions are understood by the public. Also when we investigate Karanfil's research, these categories emerge there too which proves the cognitive factors' magnitude Karanfil and Sterman (2020).

Figure 3.5 also shows, that scientific evidence can be interpreted differently. Interpretation of evidence codded approximately 50 times, even if it doesn't have a sub-theme. This depicts us that the interpretation of evidence is different than row evidence and it is much more meaningful. Scientific evidence can be interpreted differently Sterman (2006).

Additionally, reliable information sources are coded over a hundred times. 60% of the codes are segmented as media/science writing. This sub-themes 70% is media writing which is mentioned mainly by policy and clinician groups. 25% of this media science writing referred by patients, and 20% acknowledged by academics. Media writings include newspapers, white papers, and medical pages of magazines. Science writing includes academic journals, and science magazines which are prepared by clinicians and academicians. Sub-themes "other" under reliable information sources include colleague ideas, patient remarks, and sources from internet blogs.

Most coded emerging themes are the ones that significantly emerged in Karanfils study too, these code groups screening decisions, cognitive factors, treatment, and guidelines are the major themes in prior research.

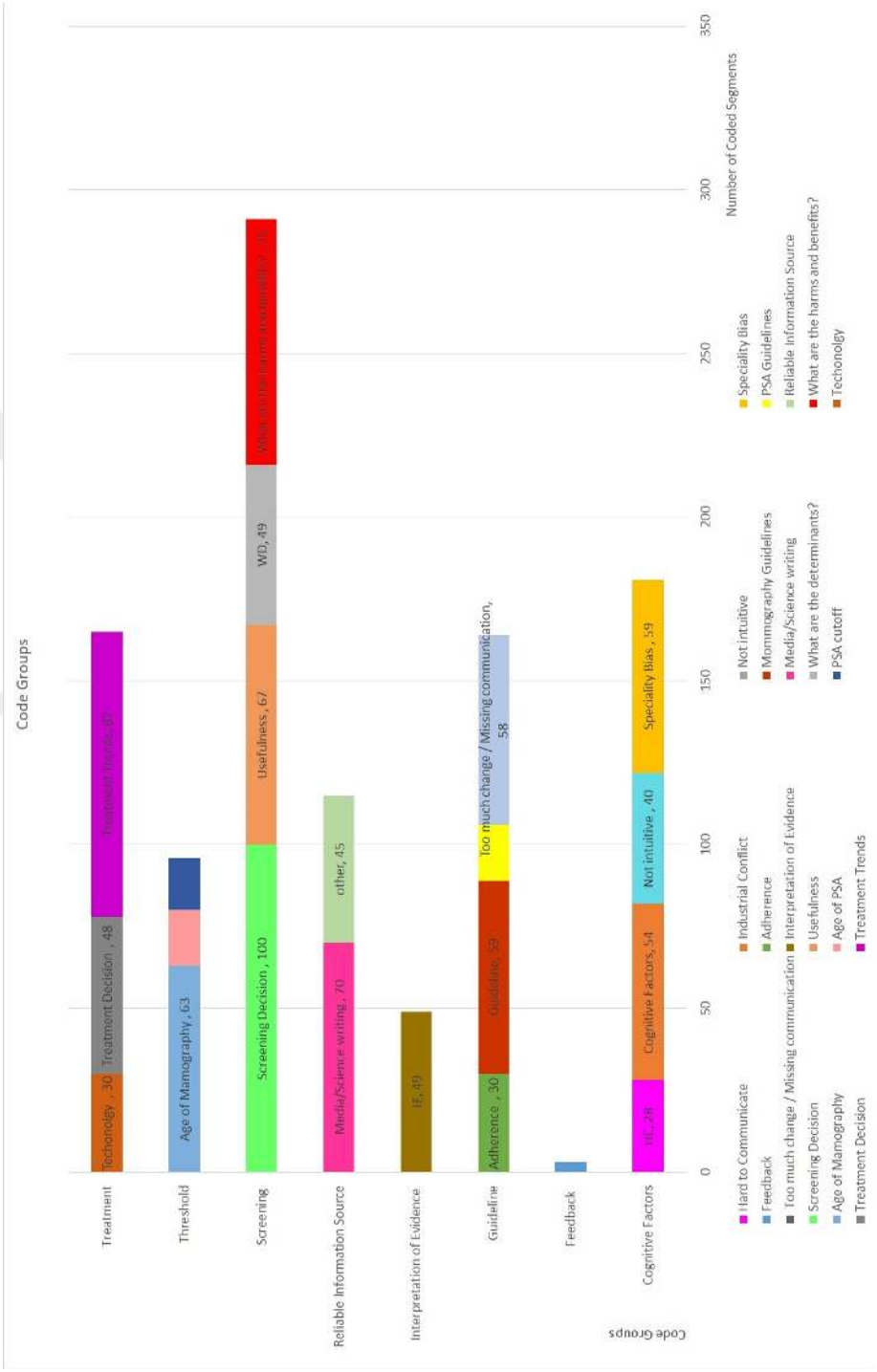

Figure 3.5: Code Groups

Chapter 4

ANALYSIS AND RESULTS

As we objectively look at the practical situation going on at present; the decision of doctors to offer screening, and the decision of patients to seek the practice are dynamically complex situations. Hence, screening is made with limited information about the test's potential benefits and harms, although it is an important decision. A result of the limited availability of information is that it makes it impossible for anyone to construct a fully comprehensive model of the decision-making situation. Actors affecting the decision-making policy are clinicians, doctors, patients, academics, advocacy, and media. All of them affect each other's ideas and perceptions. Each group has its harms and benefits, and their decisions affect the others; thus, they have a meaningful relationship. Determinants of screening, fear, and risk perceptions change. This is why the fluctuations happen, which is the endogenous effect. Interactions between groups cause an endogenous effect and induce a shift in perception.

In this research, we analyze how these over- and under-screening evolve according to the decisions of the patients, clinicians, and doctors. Also, we want to understand how these groups' perceptions affect each other. Not only doctors and patients, but other advocacy groups such as media advisors, press members, journalists, and writers have an impact on the screening practice too. On the other hand, policymakers and academics make judgments, regulations, and analyses based on practice screening criteria. For this purpose, we conducted interviews with these groups. With the help of these interviews, we investigate trends and understand the sources of variation in screening guidelines and actual practice.

Our primary focus is to understand the different sources of variation in screening guidelines and actual practice and to gather expert opinions surrounding screening

decisions. As we investigated trends and understood the sources of variation in screening guidelines and actual practices, we came up with some major merging themes. In this chapter, we are going to mention areas of disagreement and emerging themes. We listed perceived biases and problems with areas of disagreement. We are going to explain major emerging themes in the interviews conducted, summarizing the main issues, controversies, and observed patterns of variation in respondents' viewpoints and preferences.

4.1 Area of Disagreements

According to our interviews with our groups, we believe that perceived biases and problems are the same for each interview group. These problems & biases are mainly because of (mis)perception of risk, lack of long-term thinking, cancer survivors' feedback asymmetry in screening decisions, understanding uncertainty, risk aversion, and specialty perspectives.

As a result, there are too many guidelines, and they are not unified. Also, it is difficult to translate these for the patients. Screening benefits are oversold and hard to undo. Another problem is the fear of litigation that doctors are going through. One major conflict is between the cancer industry and the medical community. So we need individualized and flexible screening guidelines, but each group disagrees and compromises. These biases and problems cause disagreement between evidence-based and specialty groups in screening decisions.

- How harms & benefits are listed
- How much value to assign
- Perceived test effectiveness
- Most reliable sources of information
- Media influence

- Advocacy influence
- Early detection paradigm.

We found these emerging themes in the area of disagreement between evidence-based and specialty/ advocacy group perspectives. When we investigate each perspective, they have other priorities to mention. These groups assign value to harms and benefits differently from each other.

Before going into depth on the harms and benefits of screening, we have to explain what happens after the screening test and testing process. Figure 4.1 explains the screening test, biopsy, and alternative test flow. Figure 4.1 is reproduced from Welch et. al. (2004). Cancer testing is more complex than just screening tests. Results are not just positive or negative; they can be in between. In-between results may lead to in-between tests as alternative tests. These alternative tests are more thorough than screening tests but are a few steps short of a biopsy. When results are inconclusive, it is occasionally advised to repeat the screening test once a few months have passed Welch (2004).

Following a screening test, the majority of people will be on the first negative arrow: they will completely avoid this intricate cycle. At the same time, far more people than ever before will be on the positive or in-between arrows. Because we do not yet have flawless assays, screening naturally includes false positives and inconclusive results. Following the abnormal screening test results, screening may repeat, this process can continue between three and six months. During this period, the patient goes through anxiety, and if the test result is false positive, then it is an unnecessary and distressful period. On the other hand, with screening and alternative tests, patients can be assured about the situation and, after the negative results, continue with peace of mind.

To represent an example, Welch et. al. (2004) mentions some of the most known screening tests and, if the result is not positive, their following treatment patterns. Figure 4.2 shows some of the screening tests and their alternative tests following biopsy.

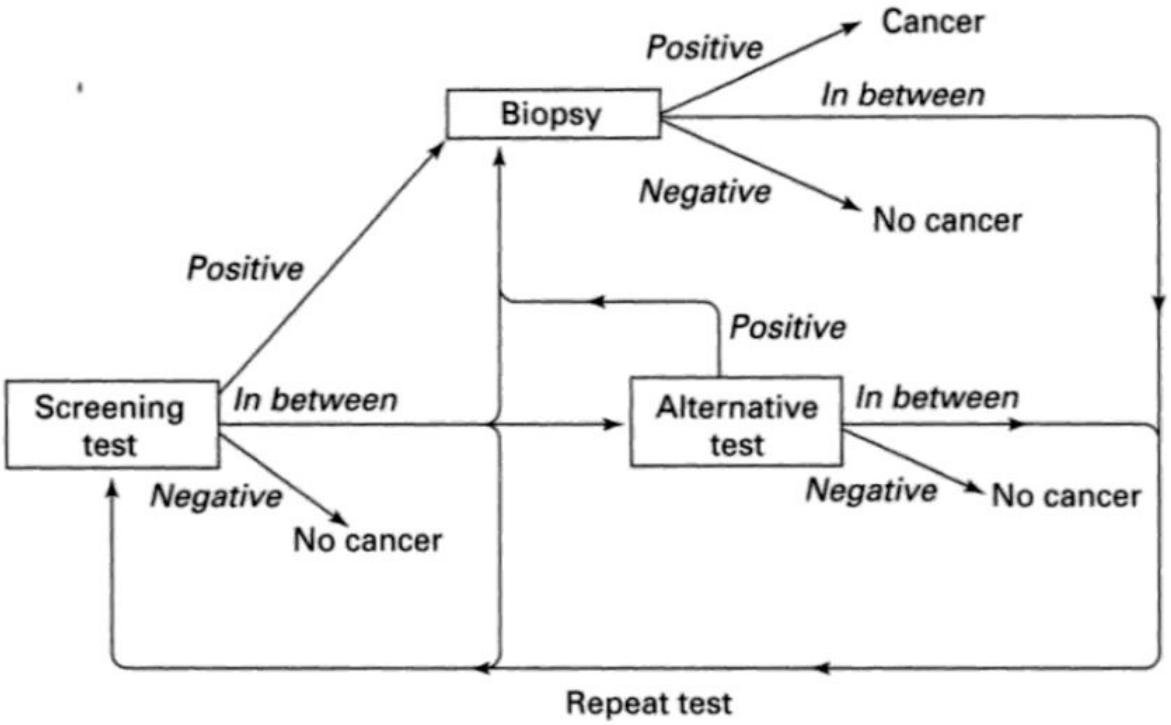

Figure 4.1: Testing Process

(Welch, 2004)

We investigate the harms, benefits, and determinants of screening between our interview groups. The benefits of screening are mainly a high percentage of saved lives and patients peace of mind, but harms can be listed as unnecessary biopsies, distress, and over-diagnosis as described in Figure 4.3.

4.1.1 Evidence Based versus Specialty/ advocacy group perspectives on harms and benefits of screening

Advocacy groups, by definition, look at the problem from a limited perspective and do not consider a broad range of policy options and implications. Their point of view is that screening reduces cancer deaths at the expense of everything else. "Early detection saved lives" inspection/paradigm is a common public perception. In addition, survivors usually join advocacy groups and help spread the word about

Screening test (target cancer)	*Early repeat examination*[1]	*Alternative test*[2]	*Biopsy*
Mammography (breast cancer)	yes	Ultrasound	Needle or excisional biopsy
Fecal occult blood (colon cancer)	not recommended	Barium enema; sigmoidoscopy; colonoscopy	Forceps biopsy during sigmoidoscopy or colonoscopy
PSA blood test (prostate cancer)	yes	Ultrasound	Needle biopsy through rectum
Chest X-ray (lung cancer)	yes	CAT scan	Needle biopsy through chest or during bronchoscopy
Pap smear (cervical cancer)	yes	Colposcopy; test for virus	Forceps biopsy during pelvic exam

Figure 4.2: Confirmatory testing for abnormal screening results

(Welch, 2004)

screening, again undermining the harms over benefits argument.

A media science writer clarifies the circumstances as follows:

"It's really weird when you think about it. Women are, they've been made very, very afraid of breast cancer. Way more proportionately afraid of it than they should be. There's this whole idea of misfearing, which is fearing the wrong thing....Women's misfirings. Women ought to be afraid of heart disease, right? That's what they should be afraid of, that's what's probably going to kill them. But they're super afraid of breast cancer because we've made everybody so damned aware of it with the pink ribbon first of all, and secondly, because we've created this whole new class of survivors through mammography, the so-called survivors. So there's a lot of women who have had it all over the place all of a sudden, so it's much more seemingly prevalent, and there was an authentic rise of course of breast cancer in the '70s and '80s and '90s..." *Media Science Writer & Evidence Based*

Fear of cancer is mentioned as a determinant in screening decisions, which is the major cause of distress in patients. The major harm of screening is the false-positive rate, which causes anxiety. Patients and patient advocacy groups see false positive test results and anxiety as the main drawbacks of screening. But they usually do not take it into account while making decisions. Belief encompasses a

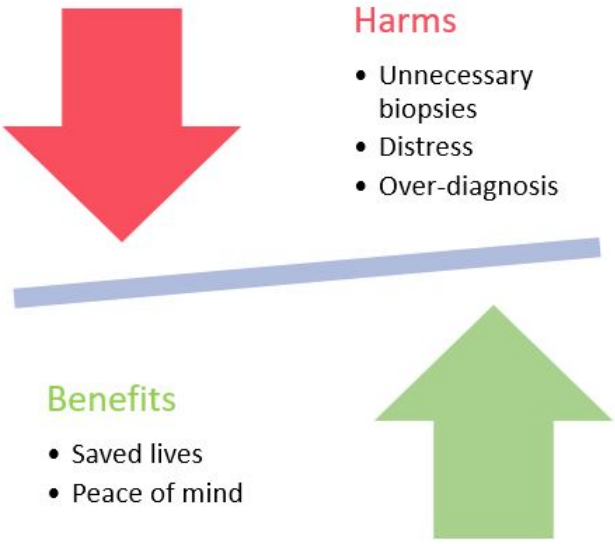

Figure 4.3: Harms & Benefits

substantial aspect of human cognition and perception. Figure 4.4 demonstrates how often specialty/ advocacy groups and evidence-based participants mention the harms and benefits of screening. It shows us that specialty groups comment significantly less about harm's benefits. This can be interpreted as them not considering the harms and benefits while making the screening decision. The trend also continues when we investigate the interpretation of evidence, which can be seen in figure 4.5 It demonstrates that evidence-based groups mention the interpretation of evidence more than specialty/advocacy groups that support that specialty/ advocacy groups do not interpret the harms of screening.

Evidence-based group members mention the harms of the screening tests, including the possibility of false positive rates, unnecessary biopsies, anxiety in patients, and the damage of overtreatment or overdiagnosis on patients. 28 coded segments, which are shown in Figure 4.4 consist of these mentioned harms. As the screening rate increases, the false positive rate rises. False positive test results come out as unnecessary biopsies, which can lead to overdiagnosis and overtreatment. These unnecessary biopsies and overtreatments cause persistent damage to patients' health.

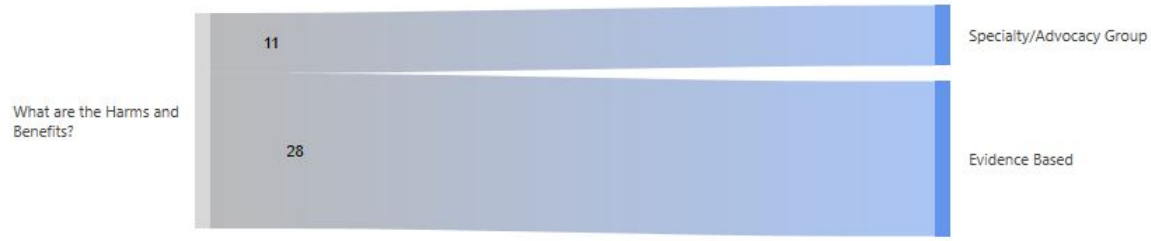

Figure 4.4: Distribution of Perceived Harms and Benefits

This whole process causes the patient anxiety and distress. Interviewees try to acknowledge and highlight the harms while answering the "What are the harms and benefits?" question in our 28 coded segments. Specialty and advocacy group members only recognize the false positive rate as a harm.

We observe it from the 11 coded segments in Figure 4.4. These 11 coded segments under the harms and benefits theme also specify the benefits as saved lives and peace of mind. Even though it is a long process performing tests to identify potential disease situations, diagnosing the condition early, starting therapy before it becomes life-threatening, and saving the patient's life. Specialty group members try to emphasize these in their answers to the interview questions. The patient feels relieved after undergoing a screening exam which is the other benefit mentioned is peace of mind. Specialty group highlights screening advantages Instead of having to cope with the cancer danger, it is preferable for the patient to get tested and live his/her life with assurance.

Evidence-based group member and academician summarized the situation;

"I think most women don't, and they don't understand it, and I think this is one of the things I try to explain with them when I talk to them, is that, you know, many people are going to be– about 19% of people who are diagnosed with cancer over ten years are overdiagnosed, and they're going to be treated for cancer, get surgery and radiation and maybe chemotherapy for cancer that would have never

caused them problems. And people sort of get that. I think they get it better with prostate cancer, with this idea that, you know, you're going to have your prostate removed or have surgery and be left with a high likelihood of erectile dysfunction, and a moderate likelihood of urinary problems, and all kinds of surgery complications. I think those people, I think it's a little bit easier to get their head around that, for prostate cancer because the side-effects are so long-lasting. I think women think a little bit differently about what it means to have their breast removed, but, you know, I think that overdiagnosis is increasingly understood by women, and I actually think that back when the USPTF made their recommendations, one of the biggest issues was that, when they were talking a lot about the benefits and the harms, they really focused on the harms of false positives and unnecessary biopsies, and I think women are more likely to say, you know, "I can handle a false positive. Even if it's scary, I can get over that, but I can't get over death." So they were trying to weigh this balance between false positives and the benefits, and they really should have said more about the overdiagnosis issues..." *Academician & Evidence Based*

Both advocacy and specialty/advocacy group members explain this risk perception and fear notion with these words;

"Unfounded beliefs resulting from manipulative persuasion, e.g., advertising, "awareness" campaigns, product placements, celebrity stories, fearful doctors, misplaced faith in medical technology, fear surrounding disease, overestimation of risk, tradition." *Academician & Advocacy Group*

Figure 4.5: Varying interpretations of evidence between evidence-based and specialty/ advocacy group

	Evidence Based 9 1647	Specialty/Advocacy Group 11 1591	Totals
Screening Decision 100	31	40	71
Usefulness 67	21	14	35
What are the Determinants? 49	16	19	35
What are the Harms and Benefits? 75	28	11	39
Screening 4 277	92	78	170
Totals	188	162	350

Figure 4.6: Code-Document table on screening theme with Evidence-based and Specialty /Advocacy groups

4.1.2 Evidence Based versus Specialty/ advocacy group perspectives on reliable information source and interpretation of evidence

We can investigate at a more general level how these two interview groups react to the screening by looking at Figure 4.6. The screening theme is one of the 8 coding groups in our research. Figure 4.6 compares how many times evidence-based and specialty/ advocacy groups respond to screening themes. Although the evidence-based group is smaller than the specialty/ advocacy group, they mention screening themes more in the interviews. Likewise, the usefulness of the guidelines is commented on more by the evidence-based interviewer. We can interpret these results as an evidence-based group that believes that there should be guidelines composed of interpretation of evidence and reliable information sources to consider harms in screening toward specialty/ advocacy groups. Also, Figure 4.7 goes along with our statement and advocates our assertion. Reliable information sources are mentioned more times by evidence-based interviewers. Figure 4.8 gives the actual number of how much these themes indicate and gives us a comparison between them.

On the other hand, medical culture and past practice direct clinicians to screening. Patients' expectations and litigation concerns determine doctors' decisions. Patients' biased opinions about screening affect clinicians. Whereas there is a noticeable overlap between clinicians and policymakers, as shown in Figure 3.3 which

Figure 4.7: Varying sources of information between evidence-based and specialty/ advocacy group

	Evidence Based 9 1647	Speciality Bias 11 1591	Totals
Media/Science Writing 70	11	9	20
reliable information source 45	12	7	19
Reliable Information... 2 108	22	15	37
Totals	45	31	76

Figure 4.8: Code-Document table on Reliable information source theme with evidence-based and Speciality/ Advocacy groups

causes endogeneity in decision-making, The overlap between advocacy groups, policymakers, clinicians, and patients contributes to the endogeneity effect, so the doctor's decisions are not evidence-based. We can observe how endogeneity affects the outcome of the Screening theme in Figure 4.9.

A clinician explains the situation as follows:

"A tumor board, it's the experts in the treatment of these various cancers. We don't talk about them often, but when they come up it's usually, I think there's I won't say lack of enthusiasm, but I think there's criticism. There's some almost, I don't want to say a missed opportunity, sort of the sense that things have gone wrong in terms of new guidelines. This is sort of vague recollection and hearsay, I think when the breast guidelines came out, like the family practice docs adopted them at OHSU fairly immediately and the radiologists were like, "Wait a second. Let's talk about this before you go and change the way we're screening OHSU patients," they wanted to try and do some more education of the family practice folks, the primary

care, I shouldn't say just family practice, the primary care." Clinician

"I have a very difficult time as the provider, being like, "You know you're going to die of your . . . [other disease], so we don't need to do the screening test." That's a very difficult conversation to have. I am screening simply because it's a very complicated, loaded emotional question to talk about, "You don't need screening because you're going to die of something else," that's really not an easy conversation." Clinician

Also, the endogeneity effect can be detected while constituting guidelines, public perceptions, and industry force it to play a significant role in policy-making, but evidence-based perception, including doing trials, and doing qualification, is cost-effective and does not fully contribute to the guidelines. Evidence-based guidelines are not followed by clinicians and patients, which causes significant over and under-screenings.

	Academic 16 3382	Advocacy Group 5 197	Clinician 13 1024	Media-Science Writer 4 597	patient 6 744	Policy 16 2618	Totals
Screening Decision 100	45	13	57	12	15	55	197
Usefulness 67	27	13	30	9	17	28	124
What are the Determinants? 49	29	8	25	4	20	28	114
What are the Harms and Benefits? 75	29	15	32	7	14	34	131
Screening 4 277	124	46	136	31	63	136	536
Totals	254	95	280	63	129	281	1102

Figure 4.9: Code-Document table on screening theme with all interviews

Perceived effectiveness is another area of disagreement among our interview groups. Public perception and industry play a significant role in forming the screening guidelines. Risk aversion and fear in patients direct them to screening. Fear of cancer is the foremost determinant in screening decisions. The clinician has to obey the guidelines, and because of litigation concerns and institutional protocols, they have to offer screening. The fear of cancer is created by unfounded beliefs, and manipulative persuasions of "awareness" campaigns, celebrity stories, the media, and fearful doctors. As a result, more people became scared around the world. The "Early detection saves lives" paradigm is exaggerated beyond its scope, and more screening takes place. As a result, overdiagnosis occurs. False positives cause

anxiety for the patient and mislead them into overtreatment. False positives is one of the harms of screening.

"...I think the major determinants are, I think, the commerce and industry and the perception of the public. That's not the case in Europe. I think in the US, I think these are, let's say, quite important... I believe in evidence. This is my major role and my major career..." *Academician & Evidence Based*

4.2 Emerging Themes

The listed themes provided are found out from the codings on the interviews. These themes shape our findings throughout the research.

- Risk Perception
- Speciality Bias
- Evidence Based
- Health Literacy
- Cancer Industry
- Advocacy
- Medical Culture
- Paradigm
- Conflict of Interest
- Communication
- Anecdotes
- Not intuitive

- Litigation
- Gender Issues
- Cancer survivors
- False positive
- Availability
- Coverage
- Cost
- Uncertainty
- Peace of mind
- Early Early detection
- Fear
- Awareness
- Word of mouth
- Disease industry
- Feedback asymmetry,
- Over-diagnosis / over treatment
- Disadvantage/ Advantage
- Anxiety

Chapter 5

CONCLUSION

In conclusion, the decision-making process surrounding screening for diseases is a dynamically complex situation. Limited information about the potential benefits and harms of screening tests makes it challenging to construct a fully comprehensive model of the decision-making situation. Clinicians, doctors, patients, academics, advocacy groups, and media mutually influence each other's ideas and perceptions, with each group having its own benefits and concerns. Fluctuations in determinants of screening, fear, and risk perceptions contribute to the observed endogenous effects, inducing shifts in perception. This research aims to analyze the evolution of over and under-screening based on the decisions of patients, clinicians, and doctors while considering the influence of other groups such as media advisors, press members, journalists, and writers. By conducting interviews with these groups, the study investigates trends, variations, and emerging themes in screening guidelines and practices. The findings reveal areas of disagreement, perceived biases, and problems, as well as major issues, controversies, and observed variations in respondents' viewpoints and preferences. The harms and benefits of screening, interpretation of evidence, reliable information sources, and the endogeneity effect are important factors that shape decision-making processes and contribute to the discrepancies in screening practices. Understanding these factors and the areas of disagreement can help inform the development of individualized and flexible screening guidelines that consider the diverse perspectives and concerns of stakeholders.

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Appendix A

INTERVIEW OUTLINE

Dynamics of Routine Health Screening

February 2015

Interviews will be semi-structured, and vary according to the particular knowledge of the interviewee.

The following general outline will be followed:

1. **Informed Consent**

2. **Project Background**

3. **Background of Interviewee**

   (a) Role (medical professional, health policy, clinician/ practitioner, other)

   (b) Role in screening policy, clinical practice and/or academia

   (c) Who else should I talk to?

4. **Questions related to the study (as appropriate to the interviewee's knowledge)**

   (a) In your opinion, what are the major determinants for how much screening happens?

   (b) Do you think are there any situations where people are screened too little/too much; or too early/too late?

   (c) Do you think PSA testing and/or mammography is overused or underused, or both?

      i. If overused, what are the possible reasons?

ii. If underused, what are the possible reasons?

(d) Which factors do you think contributes most to doctor's decisions on screening?

(e) Who makes the decision of screening mammography in a primary care setting? Doctor, patient, any others who contribute?

(f) **As a medical/ healthcare professional/policy maker/ academic** can you describe your own views on the importance of mammography and/or PSA testing? (If applicable)

i. What are your views of existing screening guidelines?

ii. What are the most reliable information outlets for the general public/ clinicians?

iii. When do you think mammography/ PSA screening needs to start for patients who are in average and high risk groups?

iv. How frequent do you think they need to be tested?

v. What are the potential benefits of screening?

vi. What are the potential harms of screening?

vii. How do you think about benefits and harms?

viii. What do you think about the role of media? Advocacy groups?

(g) **As a clinician/ practitioner**, do you recommend/prescribe routine testing? What are the criteria you use to recommend screening? (If applicable)

i. How do you make your decision?

ii. What else are you looking at (if any) other than screening results?

iii. Which treatment modalities do you recommend (If applicable)?

(h) **As a clinician/ practitioner**, have your patients ever disagreed with your views? (If applicable)

i. Have you had an experience where your patient asked you for testing that you didn't think were appropriate?

ii. Have you had an experience where you suggested testing where your patient didn't think it was appropriate?

iii. How did you resolve the disagreement?

(i) **As an individual** have you been screened/ had mammogram/ PSA test? Why or why not?

i. Can you describe your own mammography experience? (If applicable)

ii. Can you describe your own PSA testing experience (If applicable)?

iii. If you had received a high PSA test or positive mammogram, what would you do? (If applicable)