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Study the Opinions of Patients Towards the Secondary use of their Personal Health Information via an interview study

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Abstract - The gathering and use of PHI is crucial in the current age of healthcare for the purposes of medical research, clinical decision making, and the development of healthcare technology. The secondary use of personal health information has arisen as a serious ethical, legal, and societal problem with the rising digitalization of medical records and the expansion of data-driven healthcare systems. In this article, we explore the varied perspectives of patients on the secondary use of their health records. The term "personal health information" refers to a wide range of details about an individual, such as their medical history, diagnosis, treatment plan, test findings, and even their genetic makeup. Researchers in this report spoke in-depth with contemporary Saudi healthcare consumers through semi-structured interviews. The interviews focused on a wide range of information-related topics, each of which was introduced via a fictional scenario. Key issues for providers and researchers to reflect on when utilizing patient health information for secondary purposes have been outlined in this study to guarantee that such usage is patient-informed.

Keywords - Healthcare, patient, personal health information, care, treatment.

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1. INTRODUCTION

Technology's pervasive presence in today's world has had a profound effect on the healthcare industry, resulting in the creation and storage of massive volumes of individually identifiable health information (PHI). All of this data has tremendous potential to enhance patient care, medical investigation, and the development of healthcare systems more generally, from medical records and diagnostic reports to treatment strategies and genetic profiles. However, the secondary use of this PHI has created an important discussion about ethical implications, patient autonomy, data security, and the possible advantages of such procedures beyond direct patient treatment. Patients' attitudes on the secondary use of their health information are receiving more attention since they touch on issues of privacy, medical advancement, and the public good.[1]

For reasons other than treating patients, "secondary use of personal health information" describes how medical records are put to use. This might include a wide range of activities, such as basic science, clinical trials, epidemiological studies, public health monitoring, and the creation of new health policies. The digitization of medical files and the widespread use of electronic health systems have allowed for the collection of enormous databases that may be mined for previously inaccessible insights. However, there are significant ethical concerns raised by the use of such data. Patients' worries about privacy breaches, possible exploitation of their sensitive information, and the loss of control over their own health data must be considered with the evident benefits of secondary data utilization.[2]

The problem of patient permission is important to the secondary use of protected health information. Oftentimes, patients who provide their data do so thinking it will be utilized only for their own treatment, and they may be unaware of the possibility for wider uses. There should be clear and informed consent procedures, and this raises problems regarding openness. How may patients be made aware of how their information may be used? Do we need to get permission for every possible secondary use, or is blanket permission okay in principle? Finding a happy medium between protecting patient privacy and fostering research is a major obstacle in this field.[3]

Patients' perspectives on this issue are varied and complicated. Some patients may be eager to provide their information in the hopes that it would hasten the development of novel therapies. It's possible they see their data as a resource that may help not just them, but others in the future as well. However, some people may be hesitant to provide their information for fear of its misuse or abuse. Some people may strongly disagree with any secondary use of their data due to security concerns, such as the possibility of a data breach, identity theft, or unauthorized access to sensitive health information. A careful strategy that values patient autonomy and prioritizes strong data protection procedures is necessary to strike this delicate balance.[4]

Also, people's perspectives on the secondary use of their health information are heavily influenced by the cultural setting in which they live. Views on data privacy, medical research, and the respective roles of government and business in healthcare differ widely between cultures. Patients' perceptions of the advantages and hazards of sharing data may be influenced by cultural norms, previous experiences, and the amount of confidence in organizations. A culture that has a history of actively participating in medical research may also be more likely to consider data sharing as a civic obligation and demonstrate more favorable views in this area. However, people in nations where privacy issues are more pressing may be reluctant to share medical records, even if doing so would benefit society as a whole.[5]

Concerns concerning the safety of patients' private health data have grown in recent years due to the prevalence of data breaches and situations involving the improper sharing of data. In recent years, there have been a number of high-profile healthcare data breaches that have exposed patients' personal medical histories, contact information, and even financial data. As a result, patients are now even more wary about secondary data usage since their faith in data custodians like healthcare providers and organizations has been damaged. Patients' reluctance to agree to data sharing may impair important research efforts if they become more aware of the hazards involved.[6]

Patients' concerns about the secondary use of their health records must be addressed in a way that takes into account ethical, legal, and technological factors. Patients' rights and privacy are being protected by more stringent legislation and legal frameworks like the General Data Protection Regulation (GDPR) in the European Union. These rules highlight the significance of transparent permission methods, anonymization of data, and stringent security protocols. Patients should be kept in the loop by healthcare providers and researchers to ensure they are aware of the goals and possible advantages of using secondary data. Patient concerns and research requirements may be better aligned with open lines of communication.[7]

A crucial aspect of the larger discussion on healthcare data sharing and research ethics is people' attitudes on the secondary use of their personal health information. Striking a balance between individual privacy rights and the potential advantages of data-driven medical research remains a significant concern as technology breakthroughs continue to transform the healthcare scene. To establish ethical and successful methods for utilizing the power of personal health information while keeping the trust and confidence of individuals who commit their most sensitive data to the healthcare system, it is crucial to understand and respect the varied perspectives of patients. Society can only protect individuals' rights and advance medical research and patient care by taking a holistic approach to the secondary use of personal health information.

2. MATERIAL AND METHOD

The purpose of this research was to investigate how patients feel about applications of their health data outside the scope of their treatment. This research was an observational survey of a major secondary care health district in Saudi Arabia, using semi-structured interviews with actual service consumers. The research project was given the go light by the Saudi Health and Dis- ability Ethics Committee. The Saudi Health Ministry approved the study. Reporting in accordance with the Consolidated COREQ, this qualitative interview research seeks to gain insight into patient preferences and viewpoints using a broad inductive methodology.

Context

This research was carried out in one of Saudi Arabia's twenty public health districts. The public health care system provides free inpatient and outpatient secondary care services. Each health region is accountable for the safety and security of its patients' records. After a rigorous lockdown at the start of the trial owing to an epidemic of the delta version of COVID-19, limitations were loosened towards the conclusion of data collecting.

Procedures

Due to COVID-19 government enforced public health constraints, all research processes had to be completed electronically, precluding in-person recruiting within the health service. Instead, doctors were contacted in the hopes that they would be able to identify prospective participants and get consent from those individuals for further research contact. After that, the researcher called up prospective volunteers to explain the study, field any questions they may have, and get their verbal agreement to take part.

A female researcher-interviewer (RD) with significant expertise conducted all interviews. The interviewer was not acquainted with any of the people being interviewed. Participants were interviewed over the phone or via zoom, depending on their option, and may spread out their interviews across many sessions if they wished. In appreciation for their time, each participant received a token voucher. We kept recruiting until we had enough information to draw conclusions, we had a representative sample across demographics and health services, and the quality of the conversations suggested a high enough degree of informational power. Audio recordings of interviews were made, transcribed by a separate transcriber, and de-identified prior to analysis.

Interview guide

The interviews were planned to provide some degree of organization to them. The participants were given six scenarios and encouraged to talk on what they found interesting, disturbing, or otherwise problematic about the situations. Participants were also asked if their opinions would change if the material concerned a member of their family and whether or not their health records will be utilized after their deaths. Supplementary File 1 contains the interview instructions, and below are brief descriptions of the six cases:

1. The Current State of Health Data Use: A patient's medical record serves as the basis for the present care they are receiving. They advise other healthcare providers, such as the patient's primary care physician or specialists at another facility, about the patient's condition. Statistics based on their anonymized data are used to keep tabs on the health care system and make sure everything is working well. In most cases, a person's permission is required before their health records may be used for purposes beyond treatment and care, including research; if the subject declines or cannot be reached, the records cannot be used for such purposes.

2. **AI and machine learning**: The use of ML or the creation of AI to the field of medicine. The future detection of breast cancer will be more accurate, faster, and cheaper than existing approaches by leveraging data from a large number of patients who have already had a mammography to build computer programs that can analyze mammograms of individuals who undergo breast screening. Within this situation, we also investigated:

- Connecting the past and the future of medical records.
- Third-party firms collaborating on program design and utilizing collected health data to produce software for use by a variety of healthcare organizations.
- Third-party corporations that benefit from the software's sale.

3. **Registries:** The process of adding anonymous health data to registries. Clinicians and researchers may use this information to better understand things like who is experiencing heart attacks and how effective particular therapies are for certain populations. The following were also investigated inside this scenario:

- People on the register being approached by someone who isn't part of their medical or clinical team about potential new treatments, services, or research projects.

4. **Calculators for medical use**: Developing Saudi-tailored calculators using aggregated, anonymized data from all eligible patients. The health department in Saudi Arabia would require access to the medical records of everyone who has had the illness, alive or dead, in order to develop Saudi-specific calculations. Consenting each person for this usage of their data is impossible.

5. **Research**: The practice of using anonymized information in scientific study. Researchers interested in the effects of hip replacement surgery on patients' quality of life would benefit from having access to the medical records of all patients who received the procedure at a certain hospital during a given year. De-identified data may still include personally identifiable information such as demographics, medical history, test findings, drug use, allergic reactions, and surgical outcomes. The next step may be an attempt to enhance the service, followed by data monitoring to determine whether or not the modifications were effective. In this case, the recipient(s) of the participant's health information would profit more than the person themselves. The following were also investigated when working with this scenario:

- Including collaborators from other institutions, such as researchers or doctors, in the study and use of the de-identified data.
- Having a doctor who isn't a Saudi national see your medical records is a major concern.

6. Health care system: Information exchange for the purpose of monitoring COVID-19. This required the health service to disclose personally identifiable information to other entities within the larger health system, some of which would later release the de-identified data to the public and media.

Questions were also asked about (1) how, when, and where patients ought to have access to their own hospital held health information; (2) how, when, and where consent to use health information should be obtained; or (3) how health services should communicate regarding the use of personal health information following the discussion of the scenarios.

Self-Aware Proclamation

RD is a senior research fellow and doctoral-level psychologist, RW is a professor and public-health physician, and HW is a doctoral-level psychologist and the head of a department dedicated to health research. All are now employed in a variety of health-related fields and institutions, including the health district where this research was conducted.

Analysis

The examination of transcripts was done by means of thematic content.In the beginning of the analytic process, one team member (RD) read through all of the interview transcripts, made a list of key concepts, and began to code the data across the board. Next, two members of the team (RD, RW) compiled the initial codes into prospective themes and double-checked the themes against coded extracts and the data set. Two members of the team (RD, RW) conducted in-depth investigation to further develop the themes, which included giving them formal names and setting forth precise definitions. The study group as a whole was consulted on the finalized titles and descriptions of the themes, and their input and clarifications were adopted. Participants were given a rundown of the findings, including the themes and their definitions, and encouraged to provide input. No one who was provided a transcript took advantage of the opportunity.

3. RESULTS

Between October 2022 and February 2023, a total of 12 interviews were performed with the 16 people who were recruited for the research. Only one of the other four referrals could not be reached, and three others refused to take part. The median interview was 57 minutes long and the range was 26 minutes to 121 minutes. At the time of recruitment, participants were using a wide variety of health services, and their ages varied from 25 to 77. The participants' use of medical treatment varied widely. Table 1 displays participant demographic information.

Table 1: Participants' demographic data

	n	%
Age group		
≤34	**2**	**17**
35-54	**4**	**33**
55–74	**4**	**33**
≥75	**2**	**17**
Age (Mean (SD), range)	**55.08 (15.86)**	**25–77**
Gender		
Male	**4**	**33**
Female	**8**	**67**
Locality		
Rural	**3**	**25**
Urban	**9**	**75**
Encounter at time of recruitment		
Renal services	**3**	**25**
Physiotherapy outpatient services	**2**	**17**
Emergency department	**2**	**17**
Cardiology services	**1**	**8**
Dental service	**1**	**8**
Haematology service	**1**	**8**
Mental health services	**1**	**8**
Maternity services	**1**	**8**

Helping others, the need of sharing data, trust, and respect were highlighted as the four overarching themes characterizing the key concerns of the participants. Ten distinct topics emerged from the analysis of these four overarching themes. Each topic is broken down into its own section below, with supporting quotations provided.

Theme 1: supporting others

In every case, participants stressed the importance of sharing their health data for the greater good.

> *When something is for the larger benefit, I don't object to it.*
>
> *If it helps save lives, then I'm all for it.*
>
> *"I don't believe that's a horrible concept, particularly if it would aid our people, and not only the current generation but the future one as well, since we're progressing, not regressing. That's good news for the now and the future, I suppose."*

In order for them to feel at ease with the hypothetical uses of their health data, such hypothetical uses have to be beneficial to others. As a result of its perceived value to others, its usage was justified in certain situations despite the user's objection. For instance, some have mentioned feeling embarrassed by the sharing of health information in regard to public health efforts, but they believed this pain was important since the potential benefit to the public exceeded the embarrassment.

> *"It would be best if I didn't interrupt them while they were working. Other people care about it a lot."*

In addition to the obvious advantages of assisting others, participants noted a plethora of other advantages to sharing health data, all of which contributed to improved community results. They explained how data-driven ML and AI may improve service delivery, freeing up physicians' time to focus on other aspects of patient care.

Paying it forward

In the past, participants benefited from secondary use of patient health information, and they were aware of this. They understood that sharing information about their health and the care they were getting will help advance research for new therapies and enhance existing ones for the benefit of everyone in the future. People who profited from the system saw sharing their data as a way to give back to it.

> *“I agree that it's an excellent plan. You're still helping out, since your treatment is likely based on the data of others who came before you. So, once again, I believe it would be a worthwhile contribution to the neighbourhood.”*

> *“In my opinion, it's great since many of us likely suffer from health problems that have been passed down from generation to generation. In my opinion, that would be quite useful.”*

Many of those surveyed believed that their medical records may be useful even when they were no longer alive. They realized the long-term importance of protecting their health data. Participants in the clinical calculator scenario, for instance, seemed to appreciate the need for inclusion of all relevant data, even that of patients who had undesirable outcomes such as death.

> *“though it helps other people after your death, that's a good thing, even though it's sad for you. it.”*

Intent

It was evident that the original purpose of the secondary use of the information required to be to benefit or aid others for participants to feel satisfied and comfortable with the usage.

> *“The why, the how, and the objective behind it all must be clear.”*

Participants were aware that, in the context of COVID-19, decisions about the dissemination of health data needed to be taken swiftly and on an unprecedented scale. Although they were quick to point out when they thought mistakes had been made, they were understanding since they knew the intentions were good and others' privacy would be protected.

> *“In the 20th century, pandemics and their management were novel concepts for everyone involved. So, it all boils down to why the information must be utilized in the first place.’*

> *“My opinion is that it is crucial in the event of a pandemic. People are concerned about their own safety and want to know whether they have been exposed to any danger by being in the same places as this person or if they are quite safe.*
>
> *It was in everyone's best interest to be informed during the epidemic, I believe. There's no use in trying to pull the wool over anyone's eyes in a scenario like this.*

Participants' comfort levels with the usage of their health information decreased when they realized that the motivation behind it would no longer be to aid others but rather to generate a profit.

> *“Then clearly they are solely interested in financial gain. Rather than aiding others.”*

Communication

Participants reported sentiments of contentment and joy upon learning that their health data may be useful to others. Participants often complained that they were not informed whether their health information was being utilized for purposes outside their immediate care, despite the fact that the thought of assisting others by doing so was something that made them feel good. It was evident that there was a need for more transparency when it came to sharing health data for secondary reasons, such as when doing so had benefited society at large**.**

> *"The key is to complete the feedback loop."*

> *‘Having someone let me know when my health records were useful to others would be fantastic. So did the newspaper's health page back in the day.”*

Theme 2: The value of sharing

Participants reported that it was normal practice and both essential and important for de-identified data to be shared for secondary purposes. It was agreed that secondary data utilization was essential for the betterment of services and scientific progress, particularly in the areas of treatment and technology development.

> *“Improving the system is the ultimate goal, right?”*

Advantages of Cooperation

Beneficial secondary uses of health data were mentioned by participants, and not simply in the context of aiding others. advantages to patients obtaining better or more timely treatment were mentioned, as were secondary advantages such as improved service efficiency and the ability to allocate physicians' time more effectively.

> *"If this procedure frees up doctors to focus on other patients and allows for more funds to be allocated to actual care, then it's definitely a good thing."*

It was agreed upon by the participants that the potential for immediate and secondary benefits should not be overwhelmed by secondary hazards, which was a major reason why secondary usage was important. More damage than good may occur from using AI to improve cancer detection, for instance, if such improvement did not also lead to faster treatment for specific patients.

> *"If it meant more people could be diagnosed, and treatment was available, then I may be okay with it."*

Informing the patient

There was an understanding that information would be shared, but participants believed that if their data was being used in this way, the patient should be made aware of it as well. It was reported that patients requested quick and simple access to their health records.

> *"In addition, I think I need to be provided with a copy of the present system. That's not really done, in my opinion.*
>
> *Every time I've been released, I've requested for my records, but I've never received them until now, and not until at least a few weeks following my release. I must say that I strongly disagree with it.*

The Risks of Hoarding

Participants believed it was important to share their experiences because keeping quiet might have negative consequences such as fostering more discrimination and stigma. This became more apparent while discussing the need of sharing information for public health purposes, since failure to do so might prompt individuals to seek the relevant data from less reputable sources. Moreover, despite the need of handling sensitive information properly, there is a risk that patients would experience additional stigma if they use such services because of the lack of legitimate reasons for providing such information.

> *"N no. People will conduct their own research on Facebook to find [out] if government health services don't, and then it will have an effect; then you'll have vigilante lynch mobs pitching in to aid. The individual and their loved ones are afforded some measure of security as a result."*

Theme 3: trust

It was clear that those using the health service wanted to feel confident that their information would be handled with care and kept confidential.

> *"Perhaps I'm naive, but I think their only motivation is to assist and benefit people in the long run when they say they desire this. The only way to go ahead is to consider all of the facts at your disposal.*
>
> *"I mean if they were handing it on to businesses to try to encourage me, if those businesses were to contact me to try to encourage me to go and be with them so that they can make money out of me, then I would have something to say," he said.*

Participants, for instance, indicated a high degree of confidence with regards to health information being utilized for ML/AI, despite their general lack of familiarity with these technologies. Patients said they didn't always know how their data was being used in ML/AI developments, but it didn't make them uncomfortable about the practice or make them think their health data couldn't be shared in this fashion. In spite of their lack of comprehension, they hoped the health care would utilize their medical records appropriately and protect them from danger.

> *This is something we would have to accept on faith, you know what I mean. That's why, with those qualifications, when I say that I'm okay with it, I really mean it."*

It was explained that trust was something you had to work for, and once broken, it would be very difficult to get back.

> *"Trust is something that must be gained and, of course, once it is broken, it is extremely difficult to repair."*

Governance

Trust in the health service to care for and preserve participants' health information required appropriate governance and control of the access and use of health information. Transparent protocols and permissions for its usage were a part of good governance, as were audits and constant monitoring. The necessity of independent governance was examined, with participants agreeing that it should include more than simply the administration of health care institutions.

> *"That it be subject to thorough quality control across the board, and that it be audited and approved by an impartial party (likely a third party) before it is*

> *implemented; this would serve as a seal of approval upon which skeptical individuals like me might rely."*

> *"We need a pack of tough guard dogs. My only hope is that the panel includes some strong, outspoken watchdogs who aren't necessarily drawn from [health care] administration. Finding some ferocious guard dogs with respectable credentials would be the next step."*

It was crucial to have local leaders and authorities keeping an eye on things. In order to prevent the misuse or abuse of data and the resulting damage, this was deemed necessary. In the study case at hand, although the Saudis acknowledged the potential benefits of international research using Saudi data, they also voiced worries that foreign researchers would not have a firm enough grasp of the local context to properly use and interpret the data.

> *"If there were any particulars concerning Saudi Arabia that needed to be accommodated, I would put my faith in the [Saudi] team members to do so. There may not be that many distinctions between Australia and Saudi Arabia, but there would certainly be between Saudi Arabia and, say, the United States. It's not up to [international researchers] to determine what they are; I have faith in the [Saudi] team to handle it."*

Concerns about the data being shared or used in other ways were raised by participants. Including Saudia was thought to be a deterrent against this occurring.

> *"Some Saudis, in my opinion, should remain active. To some degree, I believe they should, and I am curious as to what will happen when the data is put to use. What happens if a request is made for Australia to share this information with a nation other than Australia?"*

Participants agreed that some degree of independent oversight and audit was necessary, but ultimately the onus for ensuring the secure handling of patient data should rest with the health care provider. In this manner, the health provider that first gathered the data was held responsible for ensuring that it would not be used in a way that may cause damage to patients. This meant that the initial health service had to be engaged in any subsequent uses of the data.

Participants also stressed the need for clinical control of data use and data production in addition to strong governance. Patients, for instance, acknowledged that AI had promise for the future, but that they needed their clinicians to monitor and back the technology in action before they could feel at ease with it. Participants also voiced opposition to removing doctors from clinical care or eliminating patients' freedom to choose whether or not to visit a doctor in person.

Security and anonymity

The correctness of de-identification and the safeguarding of individuals' privacy were crucial to building confidence. There was unanimous agreement among participants on the need of keeping personal data secure and auditing who has access to it. Patients would feel more at ease with any of the scenarios involving the secondary use of their health information if they had confidence that this was being done.

> *"Again, I'd say it's OK with me as long as your identity is changed. Therefore, your privacy will be respected. If they don't have any way of knowing who you are, I don't see any problem with utilizing your data."*

If the patient's privacy could not be preserved or the data could not be effectively de-identified, then the use of this information would need the patient's express permission. This included not just personally identifiable data like contact details, but also sensitive data where an individual or group might be stigmatized or injured.

Participants preferred that their original health provider re-identify them if they were offered additional treatments or research projects that required re-identification, such as researchers re-identifying patients from a registry.

> *"I agree, that's not the right tone to strike. It seems like the original team you authorized to hold your data would need to be the one in touch with you, even if it's only forwarding an email from a different researcher. Although I like of the concept in principle, I would prefer that it come from the original connections, to the people that you initially granted permission to, rather than out of the blue. Rather than expecting that from a single doctor or nurse, I would hold the service to that standard."*

In a discussion on making public health data available, the issue of privacy as a cornerstone of trust was raised. It was crucial that health data released to the public did not include any personally identifying information, but also any data that might be used to track specific individuals, neighbourhoods, or communities.

> *"If information has to be shared with health officials, that's OK with me. As you said, it is imperative that they track down the*

> *patient and do follow-up interviews. That works out well. The question then becomes how much information to provide to the public and commercial organizations that aren't necessarily engaged in the patient's treatment or follow-up. I don't believe it's appropriate to provide the media details like names or racial backgrounds. It should read, "a person in the area — visited those places on those dates." The media and the public may take it from there. It makes no difference whether they attend church or not."*

Safekeeping and archiving

In addition, confidence required guarantees of safe data storage. Concerns regarding security, hacking, and unauthorized access were expressed by participants when questioned about issues they had with the present usage of their health information.

> *"As I said previously, the hacking issue is the only real cause for alarm. That is my one real worry.*
>
> *As long as the data is safe, in my opinion. In particular, I'm considering [insert name of health service here]. What it meant for the dissemination of knowledge, I cannot say. I don't agree with it and think the [health service] needs to streamline its operations".*

It was thought that by storing health records digitally, they may be safer against loss or theft. However, participants noted that this was not the case when discussing the confidentiality of vocally transmitted health information.

"So, one thing that worries me is that once you enter the hospital system, everyone from the ward clerks to the emergency department wants to know: "What's your name?" "What's your problem?" "The nurse comes out to you in the waiting room," and so on. Therefore, from a privacy standpoint, your medical condition will be known by all other patients in the room even while the physicians are doing their rounds. This is where I believe the system has a major flaw. We claim to value confidentiality, yet you've already shared your identity and the nature of your issue. With the screens up in the ED waiting area during Covid, it is necessary to raise your voice to be heard. Thus, secrecy is now completely gone. …It's when everyone in the room can hear your conversation with the physicians and you have to "shout out" your information."

Open dialogue and honest interactions

Last but not least, the requirement for openness and communication around the use of participants' health information was cited as a determinant in participants' confidence in their health service.

> *"To succeed, talk to each other. Maintain open lines of dialogue. Communicate well with your patients."*

As was seen above, there was a need for more open dialogue on the secondary uses of health data. Purpose, intended usage, and expected results should all be part of any explanation. Consent forms, it was emphasized, should be regularly updated to reflect new possibilities for usage.

Theme 4: respect

Participants hoped that their privacy and medical records would be protected. This includes honouring the data's worth, the data subject's right to privacy, and the confidentiality of their permission.

> *"It's crucial that people listen to you if you say, "Look, I don't consent to these people having information about you" in the midst of an episode."*

All knowledge is precious.

People who took part in the study had a firm grasp of the economic potential of health data. Due to the sensitive nature of patients' medical records, they must be kept confidential and not shared with anyone outside of the healthcare system. Many respondents, it seems, assumed that any profits would be returned to the health care system or themselves.

> *"I believe they need to figure out a way to compensate me for the usage of my data, and that's how it should work. In my opinion, the person should be compensated. In my opinion, it is only fair that the be compensated and that the individual who provided the data receive some sort of payment for his or her efforts, since (a) the data is being used and (b) it takes time to compile and store it. In my opinion, yes, and it ought to be rather large. I suppose their margins are huge, so there's room to exploit it if you want to."*

Participants stressed the significance of all health information being valued equally, with no item being seen more important than another. There was some acknowledgement of the need to handle sensitive material with care, but there was also consensus that failing to do so would be disrespectful and add to existing prejudices and stigmas. The secondary use of health information was seen as crucial to the development of healthcare, and hence if it was not done in all areas of health, including sensitive ones, those sectors would be left behind.

> *"When it comes to seclusion and constraint, for instance, I believe that information may be utilized even in [mental health care]. Those numbers are crucial... If it were up to me, those numbers would be tallied... yes, particularly if you're making progress toward your goal of providing better healthcare to the general public."*

Informing the patient

It was obvious that patients, in order to feel valued, need access to their own health records. Information of any kind that the healthcare system has access to should be disclosed to the patient first.

> *"Your data is valuable, and I believe the public should have access to it.*
>
> *Nothing about me, without me; that's a phrase among those of us who have actual life experience. That, to me, is obviously crucial."*

It was emphasized once again that all patients and forms of health information should be treated with dignity and that everyone should have equal access to all sorts of health information.

> *"It's safe to assume that most people don't go about telling everyone they know that they had a positive mammography test and now have breast cancer. You're correct; your rights in this area of health care are limited compared to other areas of law. They don't take you seriously, and you don't have the same rights [to your data] as they have."*

Patients were not only interested in receiving access to the health care system but also in actively participating in the care they received. They hoped to be able to provide input and update their profile. Several respondents voiced worries about the veracity of online health resources, including instances in which inaccurate material had been utilized several times. They said there were no defined channels for getting things fixed or even a forum to discuss the problems. Therefore, it was crucial to establish ways to track down sources and update or have their data evaluated.

> *"There seems to be a lot of copying and pasting, in my opinion. If they make even one mistake, the problem will persist."*

Safekeeping and archiving

One important aspect of protecting data privacy was taking precautions to keep it safe. Storage locally provided the necessary security. Patients preferred that their information stay inside the Saudi healthcare system, rather than being moved outside, where it may be misused.

> *I don't believe they should be allowed to transfer that data to another country; if they must save information, it should be kept in Saudi Arabia.*
>
> *That seems like a Saudi source to me"*

Many people were concerned that disseminating medical data outside of the healthcare system would deprive it of the necessary context for accurate use and interpretation. The importance of situating an issue was emphasized by respondents, who noted that the whole picture, including sociocultural considerations, would be lost without it.

> *"When analyzing the data, researchers in Saudi Arabia or New Zealand may need to account for cultural differences and differences in behaviour among Saudis and, say, Australians or people from any other country."*

Open dialogue and honest interactions

Respect required openness and dialogue, just like trust. It was thought to be crucial to be forthright about the data acquired, the methods used to keep it, and the potential proactive applications of that data.

> *I have no problem with their goals; in fact, I think it's great that they have them. There must be openness. So, it's important to know why they need the information, what they intend to do with it, and what effect it will have. Thus, once again, that transparency is key.*
>
> *I believe they need to talk about it... You need to know the rationale for gathering this data, the intended goal of doing so, and the expected results in order to make informed decisions.*
>
> *I believe that the doctor has a duty to be open about the information at their disposal. If you go to the dentist, a medical clinic, or a doctor's office, it's obvious that they'll keep a record of your visit; if you've just had a heart attack, however, that may not be so obvious."*

It was disrespectful to withhold information, including technical data, concerning a patient's health and how that information was used. Although a sufferer may not comprehend the information, just being aware of its existence is crucial.

> *"While some may not be interested in reading about such security measures, I most certainly would."*

Discussion

Based on the responses of the study's participants, the researchers were able to identify four primary concerns they had with the secondary use of their health records: People want to trust the health service to respect, protect, and responsibly use their data without sharing it inappropriately because they believe (a) health information should be used for the benefit of others, (b) sharing of de-identified data for secondary purposes is essential and significant, and (c) personal health information is valuable.

Although the results of this study are consistent with those of other studies[8], the Saudi context, the emphasis on patients' experiences with the health service, and the timing of the study after the beginning of the COVID-19 pandemic all make it a valuable addition to the literature in this field. Previous research and our own polls have both shown that consent to the secondary use of health data is conditional.[9] Patients are more likely to approve of secondary uses of their health data if they feel their data will be protected and used responsibly and if they believe the secondary use would benefit society as a whole. There must be guarantees that the secondary use of health information will not cause either immediate or secondary damage, and that the information will only be used for the benefit of others. While previous research has proven that public and patient trust are crucial to understanding how their health data will be used in research[10], this study shows that this is an issue that extends well beyond the realm of medical inquiry. Trust in the health care system is essential, and services must strive aggressively to earn and keep it.

People's primary worry when addressing the secondary use of their health information is protecting their privacy, which is consistent with the results of prior research.[11] For patients to feel safe, they need assurances that their information will be de-identified appropriately, maintained securely, and governed well. Beyond protecting one's own privacy, it's also important to protect the privacy of one's family and friends. This became clear during a conversation about collaborating on COVID-19 monitoring by exchanging medical records. Patients believed that, where possible, their community's privacy should be considered alongside the privacy of the individual case while discussing health records. This research showed that individuals need to have faith that their health service will de-identify their data to the best of their abilities, even when it is difficult to do so.

All of the people who took part in the present research were aware of the moral dilemma that surrounds the secondary use of health records.[12] People wanted to feel that they had some control over what was done with their medical records, but they understood that this would not guarantee they would have final say over every application. Because they wanted to help others and because they knew it could be difficult or unethical to completely remove their information from a dataset, these participants did not mind having their de-identified data used for other purposes without their permission. Individual consent was known to increase the likelihood of bias among participants.[13]. They understood that the health service did not need to contact them personally about the use of their de-identified data, but they did expect good governance and approvals over its use, as well as open communication and transparency from the health service regarding its use of health information, both now and in the future. This is not a new phenomenon; in fact, the need for transparency and improved communication surrounding the use of health information has been well documented in the literature for years[14], though the participants' lack of awareness regarding the use of their health information in this study suggests that progress in this area has been slow. Health information dissemination strategies were discussed, and it was determined that a combination of approaches was necessary to make sure everyone in the community had access to the data they needed, when they needed it (for example, in the event of a cyberattack or a new diagnosis) rather than expecting constant updates.[15]

4. CONCLUSION

Users of medical care today are generally willing to share personal health records in order to benefit society as a whole and further scientific inquiry, but they have caveats. Patients must have faith that their health information will be safeguarded and treated with respect by the healthcare provider. Key concerns for services, researchers, and physicians to reflect about when utilizing patient health information for secondary purposes have been found by this study.

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