**Pakistan Oral Cancer Collaborative- Analysing barriers and obstacles to oral cancer diagnosis, treatment and prevention in Pakistan.**

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Conflicts of interest: None.

Funding: Funded by The Global Health Challenge Fund, UK.

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**Keywords:** Pakistan, oral cancer, mouth cancer, head and neck cancer, prevention, awareness, barriers to diagnosis.

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**Abstract**

Oral cancer is a global health problem with increasing cases numbers worldwide and no significant improvement in prognosis over the last few decades. It is one of the most common cancers and the leading causes of death in Pakistan, although the number reported are significantly under-reported due to lack of a national cancer repository and the true magnitude of this challenge is not known. Bilateral discussions and workshops funded by the Global Challenges Research Fund Workshop brought together a number of like-minded researchers and clinicians from the UK and Pakistan to analyse the status quo and plan the future course. This article reviews some of these discussions as well as barriers to oral cancer diagnosis in Pakistan, and makes recommendations to investigate the magnitude and develop measures that may help tackle this devastating disease.

134 words

## Introduction

Oral cancer is among the leading causes of death in South Asia (Pakistan, India, Sri Lanka and Taiwan) and has a high prevalence worldwide. It is the 16th most common cancer in the world with 354, 864 new cases in 2018.[1] In the UK, oral cancer is amongst the twenty most common occurring cancers.[2] However, in low and middle-income countries like Pakistan, it is the second most common cancer after breast cancer with 16,959 new cases (9.5% of all cancers).[3,4] It is a major public health problem due to its increasing incidence and mortality rates.[5] The known risk factors include alcohol, smoking, tobacco chewing, old age although oral cancer is on the rise in younger people without these well-known risk factors with a predilection for low socioeconomic groups particularly in the developing countries.

## Pakistan: A myriad of customs, attitudes, socioeconomic standard, patriarchy and beliefs

Pakistan has an entirely different social and political context to the West with at least 10 different languages spoken across the country. As a result, perceptions about health and disease also differ. The social and demographic profile of Pakistan may also significantly shape how people react towards advice on screening for a cancer, diagnosis and strategies to cope with disease. Socioeconomic status and literacy levels may also have an impact on living with cancer in a society with various cultural, religious and social beliefs; with cancers considered a punishment from God, a social stigma and a taboo alongside other diseases such as diabetes and epilepsy.[6,7]

## Synonymy of a cancer diagnosis with death

Cancer signifies death for the majority of people in Pakistan because it is considered an absolutely fatal disease and this belief is seen even in Pakistanis who have become naturalised in other countries.[8] This may largely be because of reflections (or an ingrained social belief set) derived from their culture and religious beliefs or most importantly because of experience of previous cancer patients and their families.

**Stigma**

Another prominent aspect related to the perception of cancer is how it is considered a stigma and how this can have adverse effects, in particular on women. The growing cancer burden worldwide, especially in low and middle-income countries has pronounced effects on women because of gender discrimination, cultural taboos and stigma.

**Cost of treatment and affordability**

The diagnosis of cancer is not only devastating news because of the nature of the disease but also because of its constant and long term monetary strain. Research from Canada reveals that despite state support, the patients and their families have to bear a significant financial burden.[9] In the UK, although the NHS offers free treatment for people with cancer, Macmillan reports that 83% of people diagnosed are £570 a month worse off when living with the disease.[10]

In countries like Pakistan, the majority of households still depend on the income of one family member, which is typically the eldest male member of the family. There is a lack of assistance from the government and the entire treatment costs (including direct and indirect costs) are borne by the patients and their families as the country lacks an organised and free healthcare system available to everyone. As a result, low-income families are often unable to afford cancer treatment.[11] For example, almost 73% of participants in a study on recently diagnosed head and neck cancer and breast cancer revealed that the cost of their treatment was much more than they had anticipated and a cause for concern.[11] The situation can often become difficult for female patients as the majority of women rely on male family members for financial assistance and healthcare may be considered a luxury. Likewise, if a male who is the sole breadwinner for the family is diagnosed with cancer, financial support and sustainability becomes very challenging.[11] Even with the advent of an NHS-like state sponsored insurance in the form of health cards through the state (in some parts of the country), possibly the most important modality i.e. surgery is often not covered with an

allowance made only for radio and chemotherapy, as oral cancer is considered a 'dental issue'.

**A 'protective' attitude?**

The families of the cancer patients may also pose a challenge for physicians. It is very common for a number of family members to 'get involved' in diagnosis and treatment discussions and they may wish to keep some of this information from patients for 'protection' from a negative state of mind (which is a cultural norm). e.g. children may not inform their parents of a cancer diagnosis and similarly parents do not disclose diagnosis to their children.[8] It is also believed that information about cancer can cause mental trauma to the patient and worsens their quality of life as they are already struggling to deal with their deteriorating health. There is also a strong cultural belief that letting the patient know of their cancer diagnosis will hasten death.[12]

**Delays in presentation and diagnosis**

Research reveals that cancer patients in Pakistan tend to hide their health issues for as long as possible and until they become apparent. There could be various reasons for delays in seeking help such as the fear of cancer at large, affordability, lack of diagnosis/treatment availability close by, adverse effects of cancer treatment as well as lack of understanding or mistrust in the medical system and doctors. Patients have also been reported to avoid diagnosis because they wish to avoid becoming a financial or emotional burden on the family.[12]

**Lack of support**

Many of the patients also do not disclose their diagnosis or seek help when they have symptoms because they are unsure about what sort of support they would get from their families and the community around them leading to delayed diagnosis and treatment.[8]

## Beliefs

In a questionnaire-based study on the influence of cultural practices and religious beliefs on decision making in 241 cancer patients in Pakistan, it was found that almost 60% believed that by performing certain religious rituals, they will be able to get rid of cancer.[13] Of those that responded, 5.7% regarded cancer as an infliction that had resulted from past sins, as a punishment from God or not believing in a higher power. Negative beliefs like a curse, not following religious practices, ill wishes, the evil eye and immoral behaviours were also regarded as causes of cancer. It was also found that women participants were more influenced by such beliefs suggesting that they may well be predisposed to the use of alternative therapies.

## A disjointed health care system

Pakistan relies on many religious, traditional and professional sources of health care ranging from local 'quacks' to modern hospitals and clinics with highly qualified doctors and dentists. According to the WHO (2017), almost 70 % of the Pakistani population especially those from rural areas use traditional or complementary and alternative (CAM) medicine.[14] Traditional and herbal remedies (such as Yunnani Tibb and Hikmat) and spiritual healing are the most popular in Pakistan. In the case of cancer particularly, these methods are used before seeking any medical treatment because they are regarded as non-toxic, inexpensive and quick by the patients.[15]

## Spiritual/Faith Healing and Religious Beliefs

Spiritual healing is the second most common method of treatment delivered by presumed spiritual and holy men known as 'Piirs', providing spiritual therapy either personally or through a designee.[16] Low socioeconomic groups in Pakistan do not report to medical services because they take illness as a blessing or punishment from God and instead of availing medical therapies, start planning on 'setting their deed right' and contacting faith

healers.[17] From mental health issues to fertility issues, the first point of contact is faith healers who have a tremendous psychological influence on patients as well as their families.[18] The majority of the clients of these faith healers are uneducated women. This finding is consistent with previous findings reporting that most of the traditional faith healing was employed by the women who were uneducated, under-privileged and vulnerable.[19] Similarly, a study conducted on 387 mental health patients in Karachi, Pakistan. found that 45% of patients had consulted the faith healers as a result of family recommendations, belief in spiritual healing and the belief that medical physicians would be unable to cure them.[20] Other studies also suggest that traditional faith healing is the most popular choice for people with mental health problems in Pakistan.[21]

In terms of curing physical ailments like cancer, people in Pakistan (particularly those from a low socioeconomic background and with lack of education) often visit the shrines and tombs of saints and piirs. Most of these people are of the view that cancer is a disease caused by an evil spirit (or jinn), who has cast a shadow on the person. It is believed that only these 'piirs' can manage this situation via amulets or by reciting holy verses on the patient. Some cancer patients may even undergo physical torture as treatment (as the piirs believe these patients to be 'possessed' performing exorcisms as treatments). For example, red-hot iron bars have been known to be placed on the patient's chest or abdomen as a part of the treatment in an attempt to hurt or scare the spirit and cure the cancer.[16]

People living in the remote areas of Pakistan mostly use spiritual and faith healing instead of conventional medical therapies because of their easy availability, closeness to where they live, family pressure and affordability.[22] It can be argued that although a lot of time is wasted in consulting the local healers and homeopathic treatments, (which are comparatively cheaper and affordable), if people living in remote areas of Pakistan are to access proper cancer treatment centres, there need to be more resources with attention paid to awareness campaigns, the infrastructure of the country, and more focus on supporting people who are unable to afford healthcare. At present, all of the high quality cancer hospitals and treatment

centres are within 3-4 main urban areas meaning that patients also have to consider travel and accommodation costs for coming to a city far away from their homes.

Currently, there is only basic data available on the use of alternative practices in terms of oral cancer in Pakistan. None of the existing findings have attempted to explore or understand the underlying decision making process for delays in diagnosis. Also, the effectiveness of traditional and spiritual therapies in oral cancer has not been the subject of research. It may be because there is an underlying reluctance to question or test anything that has spiritual or religious elements.

**The Status Quo- 2019 Workshop and Discussions in Sheffield**

Based on funding received from the Global Challenges Research Fund (GCRF; https://www.ukri.org/research/global-challenges-research-fund), a three-day workshop was organised at the University of Sheffield in April 2019 to provide a discussion platform with regards to oral cancer diagnosis, treatment and challenges in Pakistan as well as brainstorm for solutions to overcome these hurdles. GCRF is a £1.5 billion UK Government initiative and forms a part of the UK's official development assistance (ODA) to maximise the potential and impact of ground breaking research to address everyday challenges faced by low and middle income countries and improve lives.

The workshop was called 'Pakistan Oral Cancer Collaborative' and aimed to bring like-minded researchers and clinicians from the UK and Pakistan together to tackle the challenge of rising oral cancer numbers and delayed diagnosis as well as developing ideas and networks for future work. The workshop started with a welcome address from Dr Syed Ali Khurram and an introduction to the GCRF initiative followed by plenary presentations. These included: an update on cancer (and oral cancer) diagnosis, on-going research and challenges in the biggest cancer hospital in Pakistan (Dr Asif Loya, Medical Director, Shaukat Khanum Memorial Cancer Hospital and Research Centre. SKMCH&RC, Lahore, Pakistan), a real world experience of management of head and neck cancer patients in

limited resource settings (Professor Adnan Aslam, Consultant Oral and Maxillofacial Surgeon, Margalla College of Dentistry, University of Health Sciences, Rawalpindi, Pakistan). The complex healthcare system in Pakistan and issues surrounding access to and awareness of oral health and oral cancer, and the potential for public health strategies for its prevention were also highlighted (Dr Omar Niaz, Dental Public Health Spcialist, Foundation University College of Dentistry, Islamabad). Importantly, the role of social determinants in pakistani patients seeking treatment were also discussed by Dr Mariam Khokhar (University of Sheffield/University of York, UK) who undertook her PhD field work in Pakistan. The state of the art mechanisms was shared in the form of National Health Service cancer care and ideal referral pathways, as well as the potential for screening as a tool for early identification of oral cancer (Professor Paul Speight, University of Sheffield). The potential for digital technologies and artificial intelligence (AI) for oral cancer diagnosis and triaging was also discussed (Dr Hassan Aqeel Khan, SEECS, National University of Science and Technology, Pakistan). These presentations provided a springboard for the identification of key themes and issues for further discussion during the workshop.

Discussions from the first day highlighted that oral health as well as oral cancer awareness unfortunately were not high on the national agenda despite a prescribed National Health Vision (2016-2025) from the Government of Pakistan which mentions key points; including establishment of early detection or surveillance programmes for early treatment of patients, improvement of care pathways, development of health information systems, improving governance and linking of surveillance programmes, public health measures and community outreach and consideration of electronic and digital health technologies.[23] However, it does stop short of specifically highlighting oral health or a national dental vision. There is lack of a national cancer registry although some regional registries exist, the knowledge is not assimilated or shared at a national level. The delegates also learnt that the Pakistan Health Research Council has had the mandate to create a national registry for a little while but only

collects data from eight hospitals which do not include the two big cancer centres in Pakistan.

It was discussed how the biggest cancer hospital in Pakistan, SKMCH&RC caters for the majority of cancer cases in Pakistan. There is a complete lack of referral pathways and most of the patients presenting to SKMCH&RC do it through the walk-in clinics of this hospital on a self-referral basis. The hospital has four walk-in clinics and 200 plus laboratory collection centres across the country. Despite relying on charity, this hospital offers free treatment to 75% of patients with over 237,289 outpatient visits, 12,635 admissions, 53,567 chemotherapy sessions, 15,497 surgical procedures, 65,165 radiotherapy session, 160,987 imaging studies and 5,109,465 pathology tests indicating the magnitude of the workload. Despite this huge workload, SKMCH&RC runs 77 medical education programmes as well as breast cancer and anti-tobacco campaigns. Oral cancer is the 2$^{nd}$ most commonly seen overall, and the most common cancer in males with most patients presenting at a late stage leading to a poor prognosis. This is a key issue as SKMCH&RC's data indicated a 10-year survival of 70% for stage I OSCC compared to only 19% for stage IV highlighting the need for early diagnosis and treatment. The hospital has its own surgical facilities but despite the huge amount of excellent work, the service efforts of SKMCH&RC are only reaching a small proportion of the public and the surgical/oncological capacity cannot cater to the huge demand.

The experience of treating oral cancer patients in low resource settings outside a specialist cancer hospital however is remarkably different and even more challenging. There appears to be a correlation between socio-economic status and late presentation for treatment as the government-based hospitals providing free treatments are already overwhelmed despite having limited/outdated resources and absence of critical human resources, and if patients were to explore other options there are significant financial costs which act as a deterrent to presentation. There is a severe dearth of trained clinicians, hospitals, infrastructure, facilities

as well as supportive and palliative care options which severely compromise treatment and contribute to the poor prognosis and quality of life. It also became apparent that tumour boards or multidisciplinary team meetings (MDTM) are not the norm even in most specialist hospitals resulting in lack of standardised treatments and evidence based care.

Numerous challenges and shortcomings related to access to healthcare facilities in Pakistan also became apparent during the discussions. Some of the determinants of health and oral health include the low GDP, poor literacy and unemployment with a large proportion of the public living below the poverty line.[24] Another interesting point of discussion was how despite the large number of oral cancer cases, the cost of a pack of cigarettes was the lowest in the region in Pakistan whereas smokeless tobacco is almost entirely untracked and unpoliced further aggravating the situation.[25] The complex and mixed healthcare system comprises public, para-state and private facilities with the latter including quacks and hakeems (herbal healers). The oral cancer situation in Pakistan is rapidly worsening due to unaffordability, redundant primary care centres and lack of availability of specialist services as well as cultural barriers. However, it was encouraging to know that some institutes are trying to run pilot outreach programmes with undergraduate dental students to promote oral health in the rural areas of Rawalpindi. The social and cultural deterrents appeared to be a recurring point of discussion with some of the work from the group members highlighting the importance of a lay perspective both for the prevention and treatment of oral cancer. There are several social determinants such as gender, socioeconomic status, religious beliefs and beliefs in complementary and alternative medicine that influence patient presentation and contribute to delayed diagnosis and high mortality associated with oral cancer.

The potential for oral cancer screening was also discussed at length. A number of studies have been reported in the literature and at present it appears that there is inadequate evidence that a national level screening programme would result in a decrease in mortality

from oral cancer.[26-28] However, results from one of the largest studies carried out in Kerala, India, suggests that targeted screening in high risk groups may have some benefit.

However, patient identification is just the tip of the iceberg and appropriate referral pathways need to be in place, as well as capacity for surgical and oncological treatments for all patients identified through such screening programmes, standardised treatments, evidence based and multidisciplinary tumour board decisions and a central national cancer registry so that the patients can be followed up. In this regard, the potential for digital pathology, remote diagnosis, electronic solutions and artificial intelligence (AI) were also discussed to maximise output and reduce pressure on existing resources. Recent advancements show near human performance for AI algorithms that can enhance efficiency and performance, potentially making them ideal for under-served communities. This is supported by the huge abundance of AI talent in Pakistan and the recent establishment of a National Centre for AI. However, the application of AI to pathology and cancer (in particular oral/head and neck cancer) has been very limited even in developed countries and it remains an understudied and neglected area of research despite significantly worse prognosis than breast, lung and prostate cancer (Figure 1).

Discussions continued on the third day and the overarching emerging themes towards the end of the discussion included early detection and prevention, raising awareness of mouth cancer amongst the masses, better use and linking of existing resources, as well as utilisation of AI and digital solutions to develop referral networks and a central cancer/pathology resource or registry.

**Workshops in Rawalpindi and Lahore, Pakistan**

Some members of the POCC visited Pakistan in May/June 2019 to find out more about the situation on the ground and take the discussions forward. As part of this visit, a workshop was arranged in Rawalpindi to allow networking with like-minded clinicians. The discussions

and work to date was shared including plans for potential pilot projects involving referral pathways initially run by volunteer clinicians. The group also visited SKMCH&RC to meet the research and surgical teams and to learn about the impressive national breast cancer and tobacco awareness programmes run by the centre which includes school and public outreach health camps, walk in clinics, promotion through electronic, print and social media (Figure 2).

POCC members also approached the Tobacco Control Cell (TCC), Ministry of Health, Pakistan. The objective of TCC is to reduce prevalence of tobacco use in Pakistan by taking administrative, legislative and coordination measures for implementation of the Framework Convention of Tobacco Control (FCTC) Articles. Members of the group met with the Director of Tobacco Control Cell (TCC), Dr Ziauddin Islam who is a health economist and is extremely passionate about reduction of tobacco use (in particular smokeless tobacco). The discussions were very promising and encouraging and plans were made for collaborative working in future pending further funding.

**FUTURE PRIORITIES AND DIRECTIONS**

It was identified that oral cancer is a significant clinical and public health problem in Pakistan with its incidence and associated mortality on the rise highlighting the need for early detection, effective treatment and sustainable prevention strategies. There also appears to be a dire need for an awareness campaign for oral cancer and oral health through print, electronic and social media. As part of that, POCC members have been actively using social media with numerous awareness messages posted to highlight the devastating nature of oral cancer as a disease on the international anti-tobacco day (Figure 3). Plans were made to either join hands with the national anti-tobacco campaign of SKMCH&RC or plan events in November (mouth cancer action month).

All delegates agreed that there was a need for more robust research, examining the evidence for late presentation, referral pathways as well as barriers and obstacles to diagnosis. Social determinants and delayed cancer treatment in Pakistan appear to be interconnected and need to be considered when planning preventive programmes and treatment. Areas with low socioeconomic status and low literacy rate appear to have higher rates of oral cancer in Pakistan and a delayed presentation leading to poor prognosis. Although research and advancement of diagnostic and therapeutic techniques would be beneficial, a clear need exists for a proper health care system like the NHS and maximising the resources available. Use and linkage with existing resources such as outreach and community health workers is also an avenue worth exploring. Furthermore, despite the 'illegal and non-medical/dental status' of spiritual/faith and other alternative healers, they are unfortunately embedded deep within the society (particularly rural) and it would be prudent to reach out and engage with them for awareness and to allow oral cancer referrals in rural areas in a culturally sensitive way.

The consensus opinion was that prevention and oral health promotion should be the key initial focus to tackle oral cancer in Pakistan. The group decided that a systematic review is required to evaluate the existing literature in low and middle income countries to evaluate the importance of barriers to diagnosis, referral pathways and their correlation to delayed presentation. This review will also evaluate evidence regarding success of interventional measures such as involving the community, setting up outreach health camps, involvement of undergraduate dental and medical students as well as community Health Workers for initial and early identification of oral lesions.

Engagement with other like-minded initiatives such as the GICR (Global Initiative for Cancer Registry Development) at IARC (the International Agency for Research on Cancer, HEADSpAcE (conducting translation studies of head and neck cancer in South America and Europe) and ASTRA (Addressing Smokeless Tobacco and Building Research Capacity in

South Asia) will be very beneficial allowing expansion of the research and knowledge network and learning from their experience. Discussions with existing patient groups (such as The Swallows Head and Neck Cancer Charity) to generate relevant awareness materials in local languages is another avenue worth exploring.

The group also made plans to obtain further funding for Involvement of stakeholders at community, regional and national levels to highlight the seriousness of the situation and to facilitate future policy development and establishment of a cancer registry as well as diagnostic and referral pathways. Collaborative postgraduate research projects and fellowships for Pakistani researchers and clinicians will be a key component for future skill development and sustainable change.

**Conclusions**

Oral cancer is a debilitating disease with increasing numbers and mortality in Pakistan. Despite this, oral health and oral cancer remain largely neglected due to a myriad of issues including poor awareness, lack of facilities and manpower, lack of a national cancer registry and established referral pathways, social and cultural barriers as well as alternative therapies. Our work highlights how a multitude of complementary approaches will be required to formally establish the magnitude of these problems and tackling these will require further and more substantial funding to take this work forward for sustainable change.

**Figure legends**

Figure 1. Analysis of papers presented at the leading medical imaging, computer vision, machine learning and deep learning conferences over the last few years highlighting limited attention to head and neck cancers.

Figure 2. Members of POCC visiting Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore, Pakistan in May 2019.

Figure 3. Example of social media promotional material used via POCC platforms on anti-tobacco day linking it with Eid celebrations.

**Acknowledgements**

The authors would like to acknowledge Professor Barry Gibson (Professor in Medical Sociology, School of Clinical Dentistry, University of Sheffield) for his advice and support.

**Source of funding**

The authors would like to acknowledge a QR-GCRF pump priming grant which allowed bilateral visits between the UK and Pakistan facilitating the discussions and work covered in this paper.

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Figure 1

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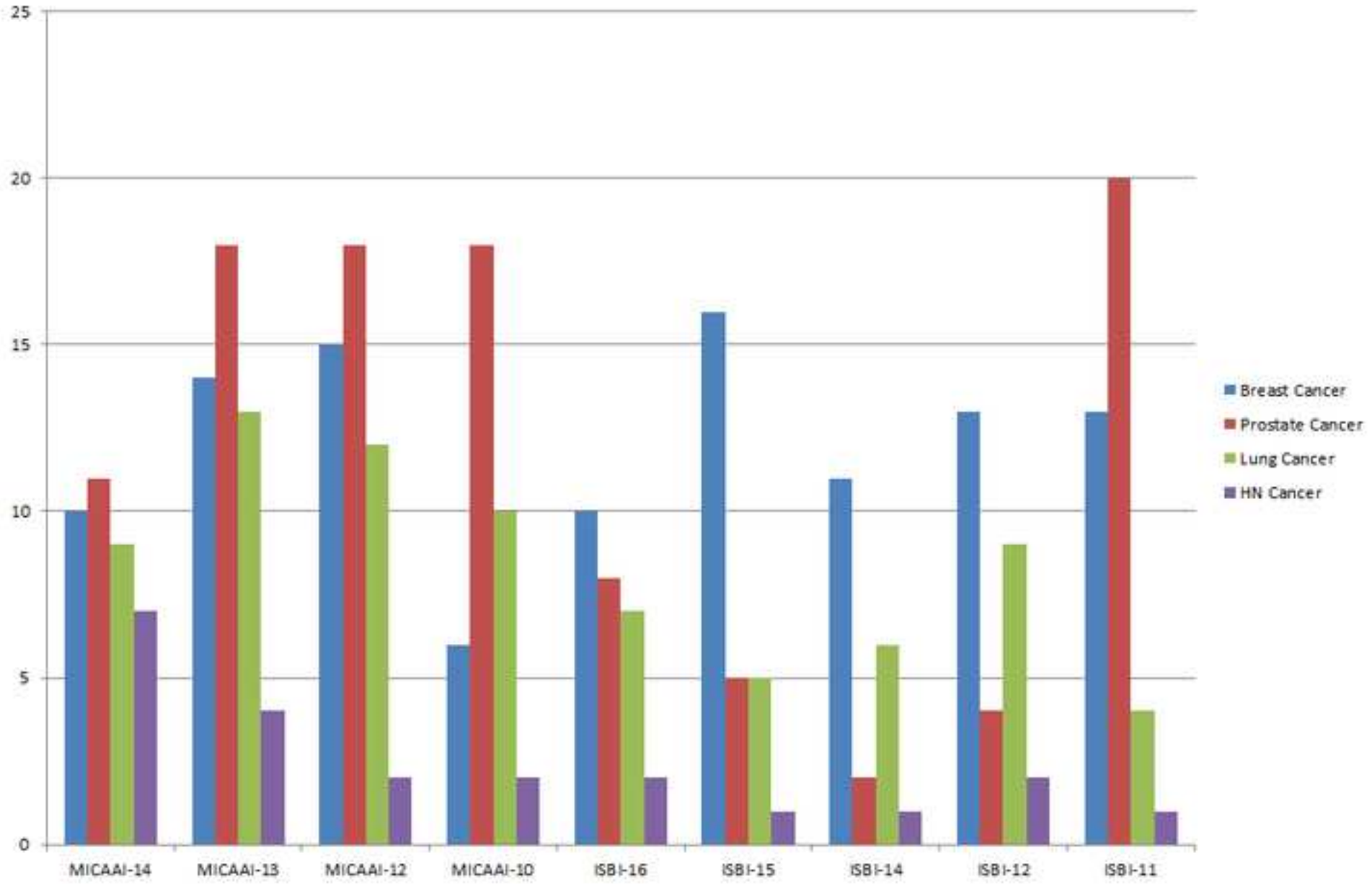

Figure 2

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Figure 3

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