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

^{1,2} Dr Mariam A Khokhar- BDS, DDPH RCS (Eng), MDPH, PhD. PhD Student, School of Clinical Dentistry, University of Sheffield and Research Fellow at Department of Health Sciences, University of York, York, UK

³ Dr Muhammad Omar Niaz- BDS, MDPH, DDPH RCS (Eng). Assistant Professor, Department of Community and Preventive Dentistry, Foundation University College of Dentistry, Islamabad, Pakistan.

⁴ Professor Adnan Aslam- BDS, FCPS, FFDRCSI. Professor of Oral and Maxillofacial Surgery, Margalla College of Dentistry, Rawalpindi, Pakistan.

^{5,6} Dr Hassan Aqeel Khan- BSc, MSc, PhD. Assistant Professor, School of Electrical Engineering and Computer Science, National University of Sciences and Technology, Islamabad, Pakistan. Assistant Professor at College of Computer Science and Engineering, University of Jeddah, Saudi Arabia.

⁷ Dr Asif Loya- MBBS, Diplomate American Board of Pathology. Medical Director and Department of Pathology, Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore, Pakistan.

¹ Professor Paul M Speight- BDS, PhD, FDSRCPS, FDSRCS, FRCPath. Emeritus Professor in Oral and Maxillofacial Pathology, School of Clinical Dentistry, University of Sheffield, UK.

¹ Dr Syed Ali Khurram- BDS, MSc, PhD, MFDS-RCS, FDS-RCS, FRCPath. Senior Clinical Lecturer and Consultant Pathologist, School of Clinical Dentistry, University of Sheffield, UK.

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Corresponding Author- Dr Syed Ali Khurram. Senior Lecturer and Consultant Pathology,
Unit of Oral and Maxillofacial Pathology, School of Clinical Dentistry, 19 Claremont Crescent,
University of Sheffield, Sheffield S10 2TA, UK.

Email- s.a.khurram@sheffield.ac.uk

Phone- +44114 2159378

Fax- +44 114 2717894

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

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2 **Pakistan Oral Cancer Collaborative- Analysing barriers and obstacles to oral cancer**
3 **diagnosis, treatment and prevention in Pakistan.**
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7 Conflicts of interest: None.
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13 **Keywords:** Pakistan, oral cancer, mouth cancer, head and neck cancer, prevention,
14 awareness, barriers to diagnosis.
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Abstract

1
2 Oral cancer is a global health problem with increasing cases numbers worldwide and no
3
4 significant improvement in prognosis over the last few decades. It is one of the most
5
6 common cancers and the leading causes of death in Pakistan, although the number reported
7
8 are significantly under-reported due to lack of a national cancer repository and the true
9
10 magnitude of this challenge is not known. Bilateral discussions and workshops funded by the
11
12 Global Challenges Research Fund Workshop brought together a number of like-minded
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14 researchers and clinicians from the UK and Pakistan to analyse the status quo and plan the
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16 future course. This article reviews some of these discussions as well as barriers to oral
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18 cancer diagnosis in Pakistan, and makes recommendations to investigate the magnitude
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20 and develop measures that may help tackle this devastating disease.
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Introduction

1
2 Oral cancer is among the leading causes of death in South Asia (Pakistan, India, Sri Lanka
3 and Taiwan) and has a high prevalence worldwide. It is the 16th most common cancer in the
4 world with 354, 864 new cases in 2018.¹ In the UK, oral cancer is amongst the twenty most
5 common occurring cancers.² However, in low and middle-income countries like Pakistan, it is
6 the second most common cancer after breast cancer with 16,959 new cases (9.5% of all
7 cancers).^{3,4} It is a major public health problem due to its increasing incidence and mortality
8 rates.⁵ The known risk factors include alcohol, smoking, tobacco chewing, old age although
9 oral cancer is on the rise in younger people without these well-known risk factors with a
10 predilection for low socioeconomic groups particularly in the developing countries.
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Pakistan: A myriad of customs, attitudes, socioeconomic standard, patriarchy and beliefs

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

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

1 allowance made only for radio and chemotherapy, as oral cancer is considered a 'dental
2 issue'.
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5 **A 'protective' attitude?** 6

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8 The families of the cancer patients may also pose a challenge for physicians. It is very
9 common for a number of family members to 'get involved' in diagnosis and treatment
10 discussions and they may wish to keep some of this information from patients for 'protection'
11 from a negative state of mind (which is a cultural norm). e.g. children may not inform their
12 parents of a cancer diagnosis and similarly parents do not disclose diagnosis to their
13 children.⁸ It is also believed that information about cancer can cause mental trauma to the
14 patient and worsens their quality of life as they are already struggling to deal with their
15 deteriorating health. There is also a strong cultural belief that letting the patient know of their
16 cancer diagnosis will hasten death.¹²
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29 **Delays in presentation and diagnosis** 30

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32 Research reveals that cancer patients in Pakistan tend to hide their health issues for as long
33 as possible and until they become apparent. There could be various reasons for delays in
34 seeking help such as the fear of cancer at large, affordability, lack of diagnosis/treatment
35 availability close by, adverse effects of cancer treatment as well as lack of understanding or
36 mistrust in the medical system and doctors. Patients have also been reported to avoid
37 diagnosis because they wish to avoid becoming a financial or emotional burden on the
38 family.¹²
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49 **Lack of support** 50

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

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

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

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49 Spiritual healing is the second most common method of treatment delivered by presumed
50 spiritual and holy men known as 'Piirs', providing spiritual therapy either personally or
51 through a designee.¹⁶ Low socioeconomic groups in Pakistan do not report to medical
52 services because they take illness as a blessing or punishment from God and instead of
53 availing medical therapies, start planning on 'setting their deed right' and contacting faith
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1 healers.¹⁷ From mental health issues to fertility issues, the first point of contact is faith
2 healers who have a tremendous psychological influence on patients as well as their
3 families.¹⁸ The majority of the clients of these faith healers are uneducated women. This
4 finding is consistent with previous findings reporting that most of the traditional faith healing
5 was employed by the women who were uneducated, under-privileged and vulnerable.¹⁹
6
7 Similarly, a study conducted on 387 mental health patients in Karachi, Pakistan. found that
8 45% of patients had consulted the faith healers as a result of family recommendations, belief
9 in spiritual healing and the belief that medical physicians would be unable to cure them.²⁰
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11 Other studies also suggest that traditional faith healing is the most popular choice for people
12 with mental health problems in Pakistan.²¹
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23 In terms of curing physical ailments like cancer, people in Pakistan (particularly those from a
24 low socioeconomic background and with lack of education) often visit the shrines and tombs
25 of saints and piirs. Most of these people are of the view that cancer is a disease caused by
26 an evil spirit (or jinn), who has cast a shadow on the person. It is believed that only these
27 'piirs' can manage this situation via amulets or by reciting holy verses on the patient. Some
28 cancer patients may even undergo physical torture as treatment (as the piirs believe these
29 patients to be 'possessed' performing exorcisms as treatments). For example, red-hot iron
30 bars have been known to be placed on the patient's chest or abdomen as a part of the
31 treatment in an attempt to hurt or scare the spirit and cure the cancer.¹⁶
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44 People living in the remote areas of Pakistan mostly use spiritual and faith healing instead of
45 conventional medical therapies because of their easy availability, closeness to where they
46 live, family pressure and affordability.²² It can be argued that although a lot of time is wasted
47 in consulting the local healers and homeopathic treatments, (which are comparatively
48 cheaper and affordable), if people living in remote areas of Pakistan are to access proper
49 cancer treatment centres, there need to be more resources with attention paid to awareness
50 campaigns, the infrastructure of the country, and more focus on supporting people who are
51 unable to afford healthcare. At present, all of the high quality cancer hospitals and treatment
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1 centres are within 3-4 main urban areas meaning that patients also have to consider travel
2 and accommodation costs for coming to a city far away from their homes.
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5 Currently, there is only basic data available on the use of alternative practices in terms of
6 oral cancer in Pakistan. None of the existing findings have attempted to explore or
7 understand the underlying decision making process for delays in diagnosis. Also, the
8 effectiveness of traditional and spiritual therapies in oral cancer has not been the subject of
9 research. It may be because there is an underlying reluctance to question or test anything
10 that has spiritual or religious elements.
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19 **The Status Quo- 2019 Workshop and Discussions in Sheffield**

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21 Based on funding received from the Global Challenges Research Fund (GCRF;
22 <https://www.ukri.org/research/global-challenges-research-fund>), a three-day workshop was
23 organised at the University of Sheffield in April 2019 to provide a discussion platform with
24 regards to oral cancer diagnosis, treatment and challenges in Pakistan as well as brainstorm
25 for solutions to overcome these hurdles. GCRF is a £1.5 billion UK Government initiative
26 and forms a part of the UK's official development assistance (ODA) to maximise the potential
27 and impact of ground breaking research to address everyday challenges faced by low and
28 middle income countries and improve lives.
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42 The workshop was called 'Pakistan Oral Cancer Collaborative' and aimed to bring like-
43 minded researchers and clinicians from the UK and Pakistan together to tackle the challenge
44 of rising oral cancer numbers and delayed diagnosis as well as developing ideas and
45 networks for future work. The workshop started with a welcome address from Dr Syed Ali
46 Khurram and an introduction to the GCRF initiative followed by plenary presentations. These
47 included: an update on cancer (and oral cancer) diagnosis, on-going research and
48 challenges in the biggest cancer hospital in Pakistan (Dr Asif Loya, Medical Director,
49 Shaukat Khanum Memorial Cancer Hospital and Research Centre. SKMCH&RC, Lahore,
50 Pakistan), a real world experience of management of head and neck cancer patients in
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1 limited resource settings (Professor Adnan Aslam, Consultant Oral and Maxillofacial
2 Surgeon, Margalla College of Dentistry, University of Health Sciences, Rawalpindi,
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4 Pakistan). The complex healthcare system in Pakistan and issues surrounding access to
5
6 and awareness of oral health and oral cancer, and the potential for public health strategies
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8 for its prevention were also highlighted (Dr Omar Niaz, Dental Public Health Specialist,
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10 Foundation University College of Dentistry, Islamabad). Importantly, the role of social
11
12 determinants in Pakistani patients seeking treatment were also discussed by Dr Mariam
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14 Khokhar (University of Sheffield/University of York, UK) who undertook her PhD field work in
15
16 Pakistan. The state of the art mechanisms was shared in the form of National Health Service
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18 cancer care and ideal referral pathways, as well as the potential for screening as a tool for
19
20 early identification of oral cancer (Professor Paul Speight, University of Sheffield). The
21
22 potential for digital technologies and artificial intelligence (AI) for oral cancer diagnosis and
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24 triaging was also discussed (Dr Hassan Aqeel Khan, SEECs, National University of Science
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26 and Technology, Pakistan). These presentations provided a springboard for the identification
27
28 of key themes and issues for further discussion during the workshop.
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35 Discussions from the first day highlighted that oral health as well as oral cancer awareness
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37 unfortunately were not high on the national agenda despite a prescribed National Health
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39 Vision (2016-2025) from the Government of Pakistan which mentions key points; including
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41 establishment of early detection or surveillance programmes for early treatment of patients,
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43 improvement of care pathways, development of health information systems, improving
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45 governance and linking of surveillance programmes, public health measures and community
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47 outreach and consideration of electronic and digital health technologies.²³ However, it does
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49 stop short of specifically highlighting oral health or a national dental vision. There is lack of a
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51 national cancer registry although some regional registries exist, the knowledge is not
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53 assimilated or shared at a national level. The delegates also learnt that the Pakistan Health
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55 Research Council has had the mandate to create a national registry for a little while but only
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1 collects data from eight hospitals which do not include the two big cancer centres in
2 Pakistan.

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6 It was discussed how the biggest cancer hospital in Pakistan, SKMCH&RC caters for the
7 majority of cancer cases in Pakistan. There is a complete lack of referral pathways and most
8 of the patients presenting to SKMCH&RC do it through the walk-in clinics of this hospital on
9 a self-referral basis. The hospital has four walk-in clinics and 200 plus laboratory collection
10 centres across the country. Despite relying on charity, this hospital offers free treatment to
11 75% of patients with over 237,289 outpatient visits, 12,635 admissions, 53,567
12 chemotherapy sessions, 15,497 surgical procedures, 65,165 radiotherapy session, 160,987
13 imaging studies and 5,109,465 pathology tests indicating the magnitude of the workload.

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Despite this huge workload, SKMCH&RC runs 77 medical education programmes as well as breast cancer and anti-tobacco campaigns. Oral cancer is the 2nd 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.

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

1 as well as supportive and palliative care options which severely compromise treatment and
2 contribute to the poor prognosis and quality of life. It also became apparent that tumour
3 boards or multidisciplinary team meetings (MDTM) are not the norm even in most specialist
4 hospitals resulting in lack of standardised treatments and evidence based care.
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10 Numerous challenges and shortcomings related to access to healthcare facilities in Pakistan
11 also became apparent during the discussions. Some of the determinants of health and oral
12 health include the low GDP, poor literacy and unemployment with a large proportion of the
13 public living below the poverty line.²⁴ Another interesting point of discussion was how despite
14 the large number of oral cancer cases, the cost of a pack of cigarettes was the lowest in the
15 region in Pakistan whereas smokeless tobacco is almost entirely untracked and unpoliced
16 further aggravating the situation.²⁵ The complex and mixed healthcare system comprises
17 public, para-state and private facilities with the latter including quacks and hakeems (herbal
18 healers). The oral cancer situation in Pakistan is rapidly worsening due to unaffordability,
19 redundant primary care centres and lack of availability of specialist services as well as
20 cultural barriers. However, it was encouraging to know that some institutes are trying to run
21 pilot outreach programmes with undergraduate dental students to promote oral health in the
22 rural areas of Rawalpindi. The social and cultural deterrents appeared to be a recurring point
23 of discussion with some of the work from the group members highlighting the importance of
24 a lay perspective both for the prevention and treatment of oral cancer. There are several
25 social determinants such as gender, socioeconomic status, religious beliefs and beliefs in
26 complementary and alternative medicine that influence patient presentation and contribute to
27 delayed diagnosis and high mortality associated with oral cancer.
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53 The potential for oral cancer screening was also discussed at length. A number of studies
54 have been reported in the literature and at present it appears that there is inadequate
55 evidence that a national level screening programme would result in a decrease in mortality
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2 from oral cancer.²⁶⁻²⁸ However, results from one of the largest studies carried out in Kerala,
3 India, suggests that targeted screening in high risk groups may have some benefit.
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6 However, patient identification is just the tip of the iceberg and appropriate referral pathways
7 need to be in place, as well as capacity for surgical and oncological treatments for all
8 patients identified through such screening programmes, standardised treatments, evidence
9 based and multidisciplinary tumour board decisions and a central national cancer registry so
10 that the patients can be followed up. In this regard, the potential for digital pathology, remote
11 diagnosis, electronic solutions and artificial intelligence (AI) were also discussed to maximise
12 output and reduce pressure on existing resources. Recent advancements show near human
13 performance for AI algorithms that can enhance efficiency and performance, potentially
14 making them ideal for under-served communities. This is supported by the huge abundance
15 of AI talent in Pakistan and the recent establishment of a National Centre for AI. However,
16 the application of AI to pathology and cancer (in particular oral/head and neck cancer) has
17 been very limited even in developed countries and it remains an understudied and neglected
18 area of research despite significantly worse prognosis than breast, lung and prostate cancer
19 (Figure 1).
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40 Discussions continued on the third day and the overarching emerging themes towards the
41 end of the discussion included early detection and prevention, raising awareness of mouth
42 cancer amongst the masses, better use and linking of existing resources, as well as
43 utilisation of AI and digital solutions to develop referral networks and a central
44 cancer/pathology resource or registry.
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53 **Workshops in Rawalpindi and Lahore, Pakistan**

54 Some members of the POCC visited Pakistan in May/June 2019 to find out more about the
55 situation on the ground and take the discussions forward. As part of this visit, a workshop
56 was arranged in Rawalpindi to allow networking with like-minded clinicians. The discussions
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1 and work to date was shared including plans for potential pilot projects involving referral
2 pathways initially run by volunteer clinicians. The group also visited SKMCH&RC to meet the
3 research and surgical teams and to learn about the impressive national breast cancer and
4 tobacco awareness programmes run by the centre which includes school and public
5 outreach health camps, walk in clinics, promotion through electronic, print and social media
6 (Figure 2).
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15 POCC members also approached the Tobacco Control Cell (TCC), Ministry of Health,
16 Pakistan. The objective of TCC is to reduce prevalence of tobacco use in Pakistan by taking
17 administrative, legislative and coordination measures for implementation of the Framework
18 Convention of Tobacco Control (FCTC) Articles. Members of the group met with the Director
19 of Tobacco Control Cell (TCC), Dr Ziauddin Islam who is a health economist and is
20 extremely passionate about reduction of tobacco use (in particular smokeless tobacco). The
21 discussions were very promising and encouraging and plans were made for collaborative
22 working in future pending further funding.
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35 **FUTURE PRIORITIES AND DIRECTIONS**

36 It was identified that oral cancer is a significant clinical and public health problem in Pakistan
37 with its incidence and associated mortality on the rise highlighting the need for early
38 detection, effective treatment and sustainable prevention strategies. There also appears to
39 be a dire need for an awareness campaign for oral cancer and oral health through print,
40 electronic and social media. As part of that, POCC members have been actively using social
41 media with numerous awareness messages posted to highlight the devastating nature of
42 oral cancer as a disease on the international anti-tobacco day (Figure 3). Plans were made
43 to either join hands with the national anti-tobacco campaign of SKMCH&RC or plan events in
44 November (mouth cancer action month).
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1 All delegates agreed that there was a need for more robust research, examining the
2 evidence for late presentation, referral pathways as well as barriers and obstacles to
3 diagnosis. Social determinants and delayed cancer treatment in Pakistan appear to be
4 interconnected and need to be considered when planning preventive programmes and
5 treatment. Areas with low socioeconomic status and low literacy rate appear to have higher
6 rates of oral cancer in Pakistan and a delayed presentation leading to poor prognosis.
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9 Although research and advancement of diagnostic and therapeutic techniques would be
10 beneficial, a clear need exists for a proper health care system like the NHS and maximising
11 the resources available. Use and linkage with existing resources such as outreach and
12 community health workers is also an avenue worth exploring. Furthermore, despite the
13 'illegal and non-medical/dental status' of spiritual/faith and other alternative healers, they are
14 unfortunately embedded deep within the society (particularly rural) and it would be prudent to
15 reach out and engage with them for awareness and to allow oral cancer referrals in rural
16 areas in a culturally sensitive way.
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33 The consensus opinion was that prevention and oral health promotion should be the key
34 initial focus to tackle oral cancer in Pakistan. The group decided that a systematic review is
35 required to evaluate the existing literature in low and middle income countries to evaluate the
36 importance of barriers to diagnosis, referral pathways and their correlation to delayed
37 presentation. This review will also evaluate evidence regarding success of interventional
38 measures such as involving the community, setting up outreach health camps, involvement
39 of undergraduate dental and medical students as well as community Health Workers for
40 initial and early identification of oral lesions.
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53 Engagement with other like-minded initiatives such as the GICR (Global Initiative for Cancer
54 Registry Development) at IARC (the International Agency for Research on Cancer,
55 HEADSpAcE (conducting translation studies of head and neck cancer in South America and
56 Europe) and ASTRA (Addressing Smokeless Tobacco and Building Research Capacity in
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1 South Asia) will be very beneficial allowing expansion of the research and knowledge
2 network and learning from their experience. Discussions with existing patient groups (such
3 as The Swallows Head and Neck Cancer Charity) to generate relevant awareness materials
4 in local languages is another avenue worth exploring.
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10 The group also made plans to obtain further funding for Involvement of stakeholders at
11 community, regional and national levels to highlight the seriousness of the situation and to
12 facilitate future policy development and establishment of a cancer registry as well as
13 diagnostic and referral pathways. Collaborative postgraduate research projects and
14 fellowships for Pakistani researchers and clinicians will be a key component for future skill
15 development and sustainable change.
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26 **Conclusions**

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

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2 Figure 1. Analysis of papers presented at the leading medical imaging, computer vision,
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4 machine learning and deep learning conferences over the last few years highlighting limited
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6 attention to head and neck cancers.
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11 Figure 2. Members of POCC visiting Shaukat Khanum Memorial Cancer Hospital and
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13 Research Centre, Lahore, Pakistan in May 2019.
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18 Figure 3. Example of social media promotional material used via POCC platforms on anti-
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20 tobacco day linking it with Eid celebrations.
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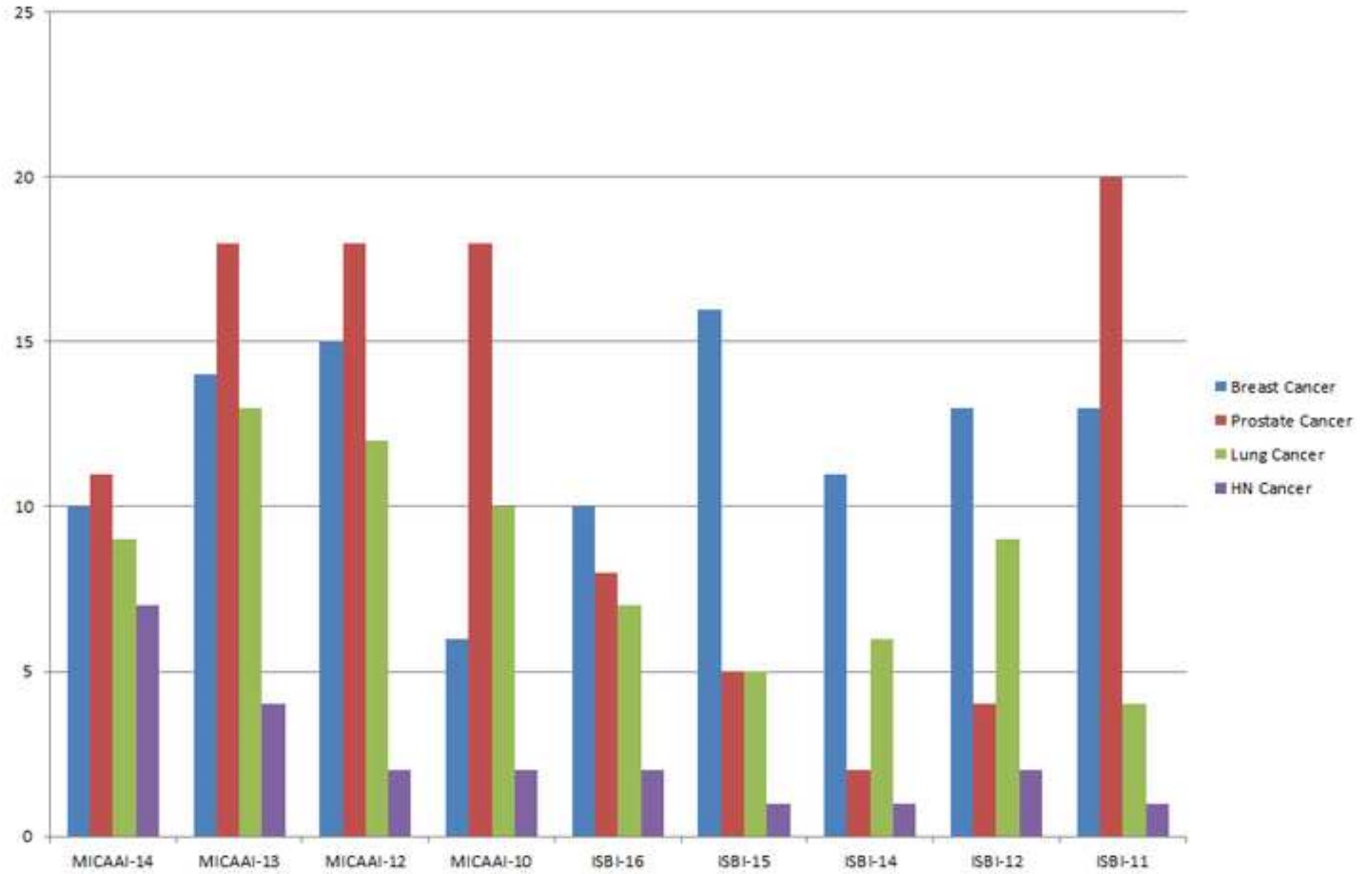
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Figure 1







PERMISSION

The authors give permission of use of the photograph with their recognizable faces.

CrediT author statement

Mariam Khokhar- Conceptualization, writing- original draft, writing- review and editing, investigation, analysis

Muhammad Omar Niaz- Resources, writing- review and editing

Adnan Aslam- Resources, investigation, writing- review and editing

Asif Loya- Resources, investigation writing- review and editing

Hassan Aqeel Khan- Resources, investigation, writing- review and editing

Asif Loya- Resources, supervision, writing- review and editing

Paul M Speight- Resources, supervision, writing- review and editing

Syed Ali Khurram- Conceptualization, funding acquisition, supervision, writing- review & editing, investigation, resources, project administration