NAVIGATE THE WORLD OF OLFACTION

A Design Intervention by DEEPTHA RAMESH

Acknowledgement

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Abstract

Olfactory disorders (OD) are often overlooked among the many healthcare challenges. This project addresses the unmet needs of people with OD in India's unique sociocultural context. OD significantly affects daily life, but it is usually hidden and misunderstood. This initiative combines design thinking principles with healthcare advocacy to take a holistic approach.

The project began with a comprehensive service safari that explored the diagnostic process and post-diagnosis care. By interviewing patients and healthcare professionals, the research uncovered systemic gaps that hinder effective OD management. These range from lack of awareness and information to societal stigmas.

The intervention consists of interactive cards that are more than a design solution. They are a step towards destigmatisation, a plea for acknowledgement, and a catalyst for societal transformation. The cards guide individuals through a four-week neuroplasticity training that combines sensory engagement and emotional connection. The training emphasises habit-building, emotional well-being, and community for those affected by OD.

The project aims to create a future where the Svasa toolkit can be scaled and adapted to meet the needs of a wider audience. This includes expanding its language options, incorporating digital tools for online consultations, and creating informational zines to reach more people. The project aims to improve individual coping mechanisms, bring more attention to hidden disabilities, and encourage changes in societal behaviour towards them. This will help prioritise olfactory disorders in healthcare discussions.

As the project ends, a sense of responsibility and optimism prevails. Svasa is a design intervention and an advocacy initiative that strives to create a compassionate and inclusive healthcare environment for individuals with olfactory disorders in India. With its innovative and human-centric approach, Svasa paves the way for a transformative journey towards health equity and understanding for those with olfactory disorders.

Table of Content

Abbreviation used in the report

OD: Olfactory Disorder

SNOT Test: Sino-Nosal Outcome Test

UPSIT: University of Pennsylvania Smell Identification Test

PHC: Primary Healthcare Centres

01. THE RATIONALE

(1.1) Acknowledging the Perspective

Despite being a vibrant culture with its 1.4 billion population (Worldometers, 2023) from diverse societies, India still fights many silent battles like hidden disabilities (Earnshaw & Quinn, 2011). A hidden disability, also referred to as a non-visible disability or a concealed health condition, encompasses conditions that are not apparent to others but may necessitate additional assistance or accommodations (Invisible Disabilities Association, 2010). This makes them elusive to the casual observer, although profound in their impact on people's lives. These conditions often defy traditional definitions of disability by the governments and medical practitioners and can pose significant challenges for individuals in accessing the support and assistance they require (Singh, 2017). In India, the legal framework for disability primarily recognises visible disabilities defined by medical boards. According to the Rights of Persons with Disability Act of 2016 (Department of Empowerment of Persons with Disability, 2023), disabilities are categorised into physical, intellectual, mental, chronic and multiple disabilities. However, recognising hidden disabilities such as ADHD, Dyslexia, Dyspraxia, Olfactory Disorder (OD), and various other conditions is absent from the legal framework and are not offered the same concessions as those with recognised disabilities.

According to research conducted by Harvard Medical School, individuals shape their life stories based on the collective memories they have created throughout their lifetime (Harvard et al.). Larsson and Willander (2009) discovered that 16% of autobiographical memories are triggered by odour, which helps retrieve personal experiences. Our sense of smell is crucial in evoking and encapsulating memories, as we often associate smells like coffee and freshly baked bread with positive experiences.

The research also shows that smell significantly impacts a person's mood and psychological health (Fifth Sense Blogs, n.d.). However, the loss of this sensory capacity can have severe consequences in various domains, including personal hygiene, safety, dietary habits, social interactions, and fundamental health aspects like the potential for weight gain.

(1.2) Positionality

As a user experience designer, design manager, and researcher, my deep commitment to humanising experiences is rooted in a personal connection to this project. My advocacy for inclusivity in healthcare comes from my brother's diagnosis of Hyposmia, a condition that reduces the sense of smell. This experience offered me profound insight into the shortcomings of the hospital experience in India when dealing with patients and their families affected by illnesses that may not have a cure. During his diagnostic process (Appendix 4.1, PP 64-65), it became evident that the healthcare system and its personnel often lack the necessary sensitivity to support patients and their families. The PHCs also need more tools to aid the patient's need for emotional support post-diagnosis, and the personnel need more awareness of themselves to provide humanised care.

Hence, the primary focus of this research is centred on the humanisation of the healthcare system in India, with the overarching aim of enhancing awareness in society and aiding healthcare centres with tools to provide care delivery to patients with acquired olfactory disorders.

(1.3) Stakeholder Analysis

When researching OD, it was crucial to understand the target audience clearly. A comprehensive stakeholder analysis was conducted to provide a complete overview of all the individuals and organisations involved in addressing the challenges of OD. Image 1 shows two primary stakeholder categories: patients struggling with OD and primary healthcare centres (PHCs) responsible for delivering comprehensive care.

It was critical for policymakers and government organisations to collaborate with patients and PHCs to create effective interventions that address issues and inform policy. Additionally, partnerships with pharmaceutical companies can drive innovations in medications and therapeutic modalities, thus enhancing the spectrum of available treatments.

Strategic partnerships with support groups and NGOs can create a sense of community and ensure that the intervention is patient-centric, catering to the multifaceted needs of those grappling with OD. It is essential to focus the research on patients and PHCs since they are the primary stakeholders. This will help better understand the patient experience while diagnosing, managing, and adapting to OD. However, exploring the potential benefits of involving or establishing support groups is also valuable. Such entities can enrich the research by providing additional support and resources, offering valuable insights, shared experiences, and community-building.

STAKEHOLDERS INVOLVED IN OLFACTORY DISORDER

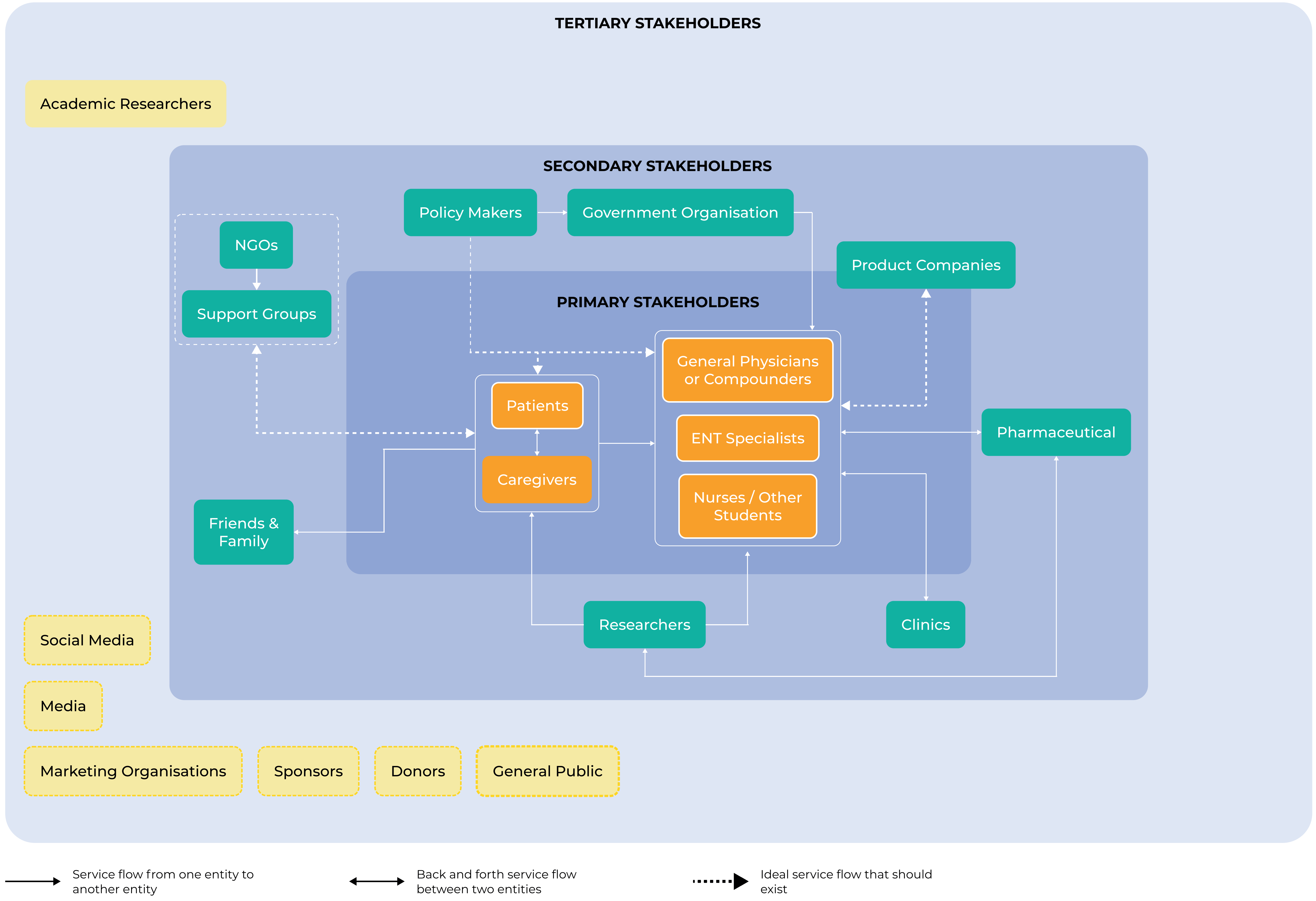


Image 1: Stakeholder Map along with their level of influencer and impact [Self Illustrated]

By integrating primary users, healthcare providers, and auxiliary support groups, the research can be more comprehensive and attuned to the diverse needs and challenges associated with OD.

02. PROBLEM DEFINITION

The Aim

To design a service toolkit for primary healthcare facilities in India to educate and support individuals with olfactory disorders in adapting to lifestyle changes.

The Objectives

Objective 1
Understand the realm of olfaction and identify the factors that impact the diagnostic experience for patients and PHCs.

Objective 2
Explore the interventions provided for OD in the Western world to provide a better customer experience journey.

Objective 3
Identify the potential collaboration and barriers b/w hospitals, Government agencies, and advocacy groups in India.

Objective 4
Explore the detailed problems faced by patients and the PHCs in humanising healthcare services.

Objective 5
Design and develop a service toolkit to help the PHCs support the patients and raise awareness about OD and hidden disabilities.

Research Question

How might we equip primary healthcare centres in India with a service toolkit to educate and support individuals with olfactory disorders in adapting to lifestyle changes?

Problem Statement

Acquired olfactory disorders pose a significant challenge in India, where access to adequate healthcare facilities still needs to be improved. Lack of awareness and knowledge can hinder the ability of individuals with OD to adjust to lifestyle changes and ultimately affect their well-being. Design intervention is necessary to provide patients with the education, guidance, and resources required to improve their quality of life and confidently navigate their daily routines.

(2.1) Research Framework

The project adopted a mixed-methods research framework, integrating theoretical and practical research to collect qualitative data. The double diamond framework (Design Council, 2005) and the Humanisation of Healthcare framework (Todres et al., 2009) provided a structured approach to understand the problem. A top-down methodology was employed for problem comprehension, qualitative data collection, analysis, and solution design.

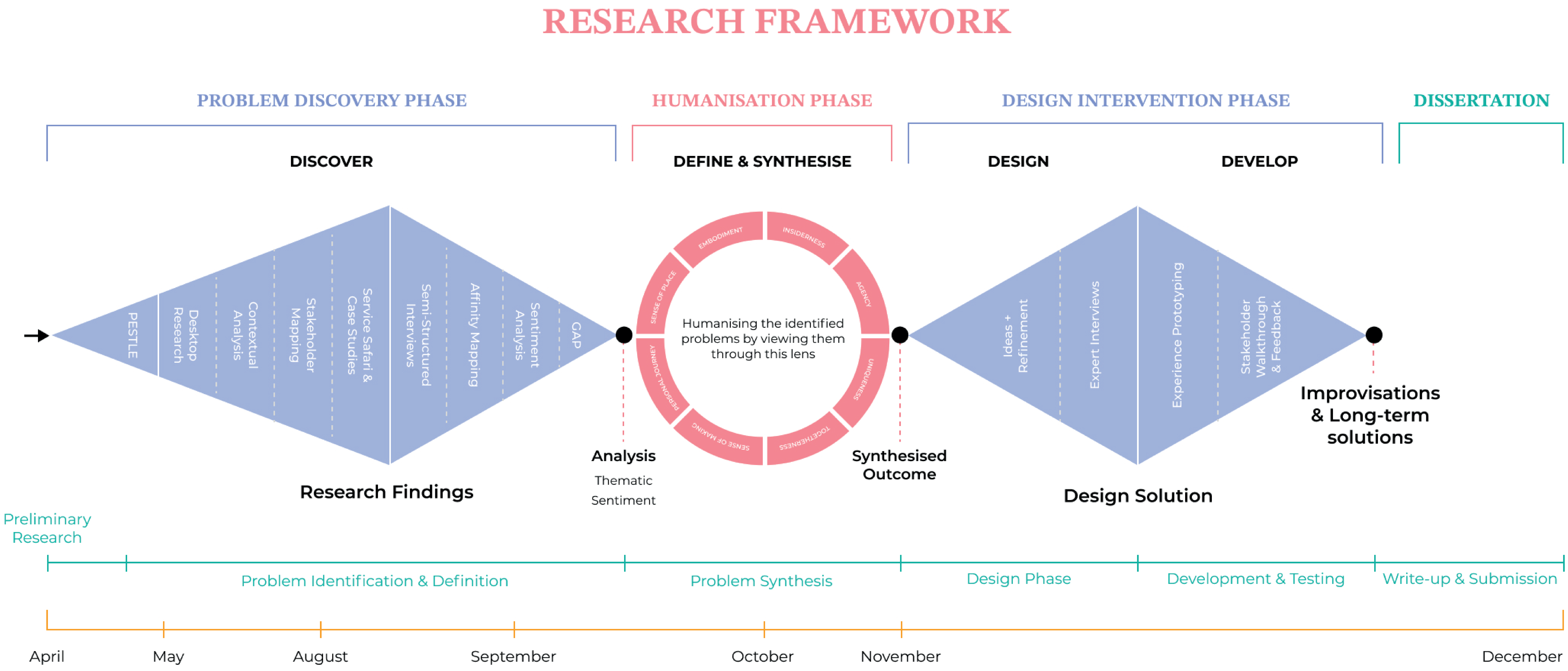


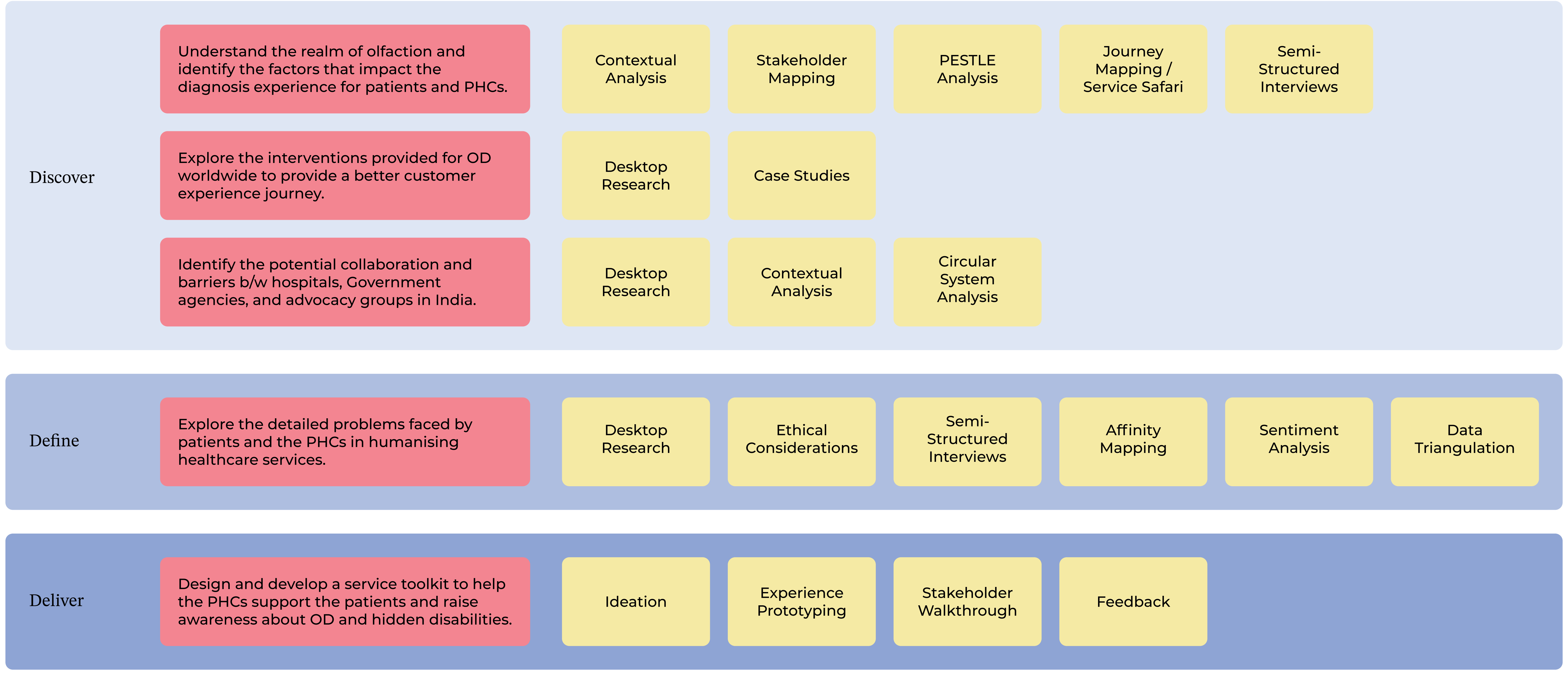
Image 2: Research Framework followed in the Project

Research Framework

A mixed-methods approach ensured a holistic understanding of complexities related to olfactory disorders and the healthcare system’s response. The research timeline encompassed four phases, with the initial phase focusing on problem discovery through in-depth primary and secondary research. The subsequent humanisation process employed eight lenses (Insiderness, Agency, Uniqueness, Togetherness, Sense-Making, Personal Journey, Sense of Place, and Embodiment) for stakeholder-focused problem evaluation.

Applying these lenses facilitated the creation of a solution space for swift user adjustment and improvement in their lives. In the Design Intervention phase, the emphasis was on crafting a service toolkit to aid healthcare facilities in offering optimal support and tools for patients with OD. The humanisation phase thoroughly scrutinised problem areas, fosters creative ideation, and generates prototypes. These prototypes were tested with a healthcare professional, and the iterative feedback loop ensured continuous refinement to deliver a user-friendly solution.

OBJECTIVE MATRIX



Discover	Understand the realm of olfaction and identify the factors that impact the diagnosis experience for patients and PHCs.	Contextual Analysis	Stakeholder Mapping	PESTLE Analysis	Journey Mapping / Service Safari	Semi-Structured Interviews	
	Explore the interventions provided for OD worldwide to provide a better customer experience journey.	Desktop Research	Case Studies				
	Identify the potential collaboration and barriers b/w hospitals, Government agencies, and advocacy groups in India.	Desktop Research	Contextual Analysis	Circular System Analysis			
Define	Explore the detailed problems faced by patients and the PHCs in humanising healthcare services.	Desktop Research	Ethical Considerations	Semi-Structured Interviews	Affinity Mapping	Sentiment Analysis	Data Triangulation
Deliver	Design and develop a service toolkit to help the PHCs support the patients and raise awareness about OD and hidden disabilities.	Ideation	Experience Prototyping	Stakeholder Walkthrough	Feedback		

Image 3: Methods followed to achieve the objectives of the research project [Self Illustrated]

Objectives & Methodology

This research project utilised a lateral thinking methodology (De Bono, 2014) to address the multifaceted objectives. The approach involved a parallel execution of diverse methods across three stages: Discover, Define, and Deliver. Each stage employed specific methodologies tailored to achieve its objectives, encompassing a comprehensive exploration of olfaction, global interventions for OD, and the impact of external factors in the Indian context.

Objective Matrix

Desktop Research

The project commenced with a comprehensive Desktop Research phase to investigate the challenges of OD and hidden disabilities within the Indian healthcare system. This phase encompassed exploring causes, treatment modalities, diagnosis procedures, timelines, prevalence rates, and various interventions related to OD. OD's political, sociocultural, economic, technological, and legal impacts were scrutinised. Primary healthcare centres were analysed concerning their role in OD treatment, governing regulations, distribution across the country, and the impact of tool scarcity on patients' experiences. Drawing from scholarly articles, research papers, journals, books, and government resources, the literature review aimed to pinpoint gaps in the existing system and provide insights into supporting OD-diagnosed patients, a validation subsequently confirmed through primary research.

Contexual Analysis

A crucial Contextual Analysis was conducted to specify the problem within India's defined parameters. This examination aimed to comprehend the intricacies of the healthcare system, legal frameworks, and socio-cultural factors governing the country. This scrutiny was indispensable for evaluating India's strategies in managing hidden disabilities, including policies for OD patients and the tools available in Primary Healthcare Centers (PHCs) for facilitating transitions post-OD diagnosis. The analysis facilitated a nuanced understanding of unique needs, challenges, and opportunities, ensuring culturally sensitive, adaptable interventions tailored to diverse populations affected by OD.

PESTLE Analysis

In India's healthcare system, PESTLE analysis (Appendix 2, PP 59-60) identified stakeholders involved in OD diagnosis and subsequent interventions (Image 1). Considering political, economic, socio-cultural, technological, legal, and environmental factors, this analysis determined their impact on healthcare. Insights into policies and societal attitudes towards OD were gleaned, aiding the identification of potential barriers and areas for enhancement to promote project viability and adoption.

Stakeholder Mapping

Stakeholder Mapping (Image 1) was pivotal for OD management, categorising entities contributing to the problem. A prioritised stakeholder map was created through rigorous analysis of secondary research and PESTLE findings, facilitating a comprehensive view of the workflow and gap identification in the problem space.

Service Safari

Service Safari and Customer Journey Map (Appendix 4.1, PP 64 - 65) employed an auto-ethnographic approach, assuming the researcher's caretaker role. Through observational analysis of patient interactions at a PHC in Bangalore, India, the map delineated pre-diagnosis, diagnosis, and post-diagnosis phases. Emotions of patients and caregivers categorised as Happy, Neutral, and Exhaustive, served as a critical metric. This method revealed first hand patient pain points and gaps in the healthcare system experience.

Case Studies

Case Studies were instrumental in comprehending real-life implementations of interventions for hidden disabilities, such as OD, in other countries. Examining the Sunflower Organisation (Hidden Disabilities Sunflower, 2020) provided valuable insights for understanding diverse interventions and their potential translation to the Indian context.

Semi-Structured Interviews

Semi-structured Interviews were conducted with patients and doctors to acquire qualitative insights into OD Diagnosis in India, particularly in a niche area with limited pre-COVID-19 research. A poster (Appendix 3.1, P: 61) was distributed to five clinics in Bangalore and Chennai, inviting patient participation. Despite QR code sign-up availability, there was no response. Subsequently, a social media post (Appendix 3.2, P:61) was made to engage patients within personal networks, resulting in six individuals participating in virtual interviews via WhatsApp (Appendix 4.5 - 4.10, PP: 67 - 70). Expert interviews with doctors were also conducted through walk-in appointments (Appendix 4.2 - 4.4, PP: 66 - 67). This method was chosen for its efficiency in coding and categorising data. Interviews allowed for a detailed exploration of patients' experiences and emotions while maintaining a consistent standard of service for all participants.

Thematic Analysis

According to Braun and Clarke (2006), Thematic Analysis was employed in this study to facilitate the identification, analysis, and organisation of key findings into five themes (Appendix 5.3, P: 76). The analysis encompasses data from interviews with patients and doctors and observational data to provide a comprehensive understanding of the problem. The resulting themes were then utilised to define problem areas, plot an ideal system map, and identify intervention spaces for achieving the ideal system (Image 14 - 15, P: 35).

Sentiment Analysis

A Sentiment Analysis was employed during the research to address participants' reluctance to express sentiments about their healthcare experiences. This method involved analysing interviewees' tones to discern their emotions toward the healthcare system, providing deeper insights into pain points and opportunities for humanising the research and enhancing healthcare services. MonkeyLearn (2023), an online Sentiment Analysis tool, was utilised to offer insights into each interview's overall positive or negative tone (Appendix 5.1, P: 72).

Triangulation & System Maps

Following an examination of primary and secondary research, along with case studies, a Data Triangulation was performed to discern the dynamics of the healthcare service system in India. A Circular System Map visualised the interconnections and relationships among entities involved in the diagnosis process and healthcare (Image 14, P:35). This map, juxtaposed with an ideal systems map created through data triangulation (Image 12, P:31), facilitated the identification of gaps in the current system. These gaps were scrutinised to delineate the intervention space necessary to align the existing system with the ideal state.

For vulnerable participants, including those under 18, persons over 60, or differently-abled individuals, involvement was restricted to interview or workshop sessions accompanied by parents, caretakers, or guardians. Consent forms were obtained from these accompanying figures. Additional assistance and support were provided to participants over 60 for online communication platforms during interviews and feedback workshops. Alternative language support or feedback systems were facilitated if required. Participants with disabilities were only engaged with explicit consent from their caretakers, parents, or guardians.

Video recordings of interviews and workshops were stored on the researcher's laptop, with transcripts incorporated into the report (Appendix 4.2 - 4.10, PP: 66 - 70). Data retention adhered to a one-year time frame until December 31st, 2024, after which all data will be permanently deleted from the researcher's laptop and other sources, except for summarisation in any report. Personal information not consented to by participants will be redacted from the report, and general descriptions will used for those declining to provide personal information (Mathur, 2017, pp. 7-8).

User Testing

As part of User Testing, a collaboration with the Fifth Sense Organisation in the UK was planned to facilitate participant recruitment. Indian OD-diagnosed patients were intended to be invited through the provided sign-up form (Appendix 3.4, P:63), and six participants, based on their availability within a critical timeframe for an online feedback session, were to be selected. Before the session, participants would receive a research brief, and consent forms were to be collected via Google Forms (Appendix 3.3, P: 62).

However, due to a lack of time and sign-ups, the feedback session had to be conducted one-on-one with Dr. Naveen, whom I had connected with during our primary research. A link to the Figma prototype (Appendix 6.1, P: 77), which was simulated to experience the use of cards, was shared with him and the his feedback.

Please view the Literature Review in the next page

03. LITERATURE REVIEW

(3.1) Cultural Impact on the Healthcare in India

The intersection of Disability in India is a multi-faceted concept that is influenced by complex interplays of culture, society, religion and history. According to Barnartt and Altman (2013), in India, disability is seen as a product of cultural hindrances such as beliefs and religion. Many people, even to date, associate disability as a way of paying debts for the sins committed in the previous birth. In a society where culture and religion are so highly intertwined into the fabrics of the society, it's construct also plays a vital role in how disability is perceived. That is, in many underprivileged societies in India, healthcare is not a priority as a prominent aspect of the culture (Roy and Howard, 2007). In the article by Songra (2018), the challenges faced by individuals due to the stigma associated with disabilities resulting in social discrimination and isolation are highlighted as an epitome of the intersectionality of religion, culture and health.

Research conducted by Rohwerder and Thompson (2020) highlights the ineffectiveness of the human rights framework in India. Many religions in India do not allow persons with disabilities (PwD) to participate in the religion by their religious leaders, thus leading to discrimination of the person in the society. Idolatry is seen as a way of viewing god or as a vehicle towards acknowledging the presence of god (Jha, 2018). However, in many cases, the places of worship require the people to access them using stairs and under-maintained routes or paths. This makes it difficult for PwD to access these places; hence, they are marginalised. Many other fellow citizens of the country have expressed their views on this issue of accessibility (Appendix 1, P: 59).

Due to the strong co-relations of culture and religion, people exclude themselves from full participation in society due to the prejudices they had experienced and expected to experience again. Malvika Padin, an Indian freelance journalist based in London and an award-winning writer, shares her personal experience of internalising negative perceptions and the fear of disclosing her disabilities due to the potential for differential treatment (Padin, 2021). A simple example of this is the use of names like "Viklang" for disability, which brings in self-pity and division, as Language plays an essential role in how it makes them feel (Kulkarni, 2017). It is unfortunate to learn that in societies like India, disability is stigmatised and viewed as a topic of taboo due to various reasons.

Image 4: Language used to depict a disability compartment in the IRS (Vashishth, 2012)

In 2016, the country implemented new laws to provide rights and care to disabled people (Department of Empowerment of Persons with Disability, 2016). However, the current definition of disability only recognises visible disabilities, as stated by the National Medical Council. It implies that invisible disabilities such as ADHD, Dyslexia, Dyspraxia, and even Olfactory

Disorder and others are not addressed or recognised by the legal framework. Even the United Nations lacks clarity on the definition of disability in their framework of the Rights of Persons with Disabilities (United Nations, 2006). The lack of clarity in the legal framework and awareness among people regarding the inclusivity of these disorders means that healthcare facilities are not inclusive of people with hidden disabilities. The photo journaling project by Vicky Roy and VR Feros titled ‘Everyone is Good at Something (EGS)’ (Roy & Ferose, n.d.) covers 21 disabilities from the 28 states of India, shedding light on issues like taboo and stigma around disabilities like being disabled is an expensive affair or that disability is contagious or the best of all, disability is the karma from the previous birth (Griffin, 2021). These accounts underscore the need for greater awareness, understanding, and support for individuals with hidden disabilities in India and beyond. This also includes olfactory disorders.

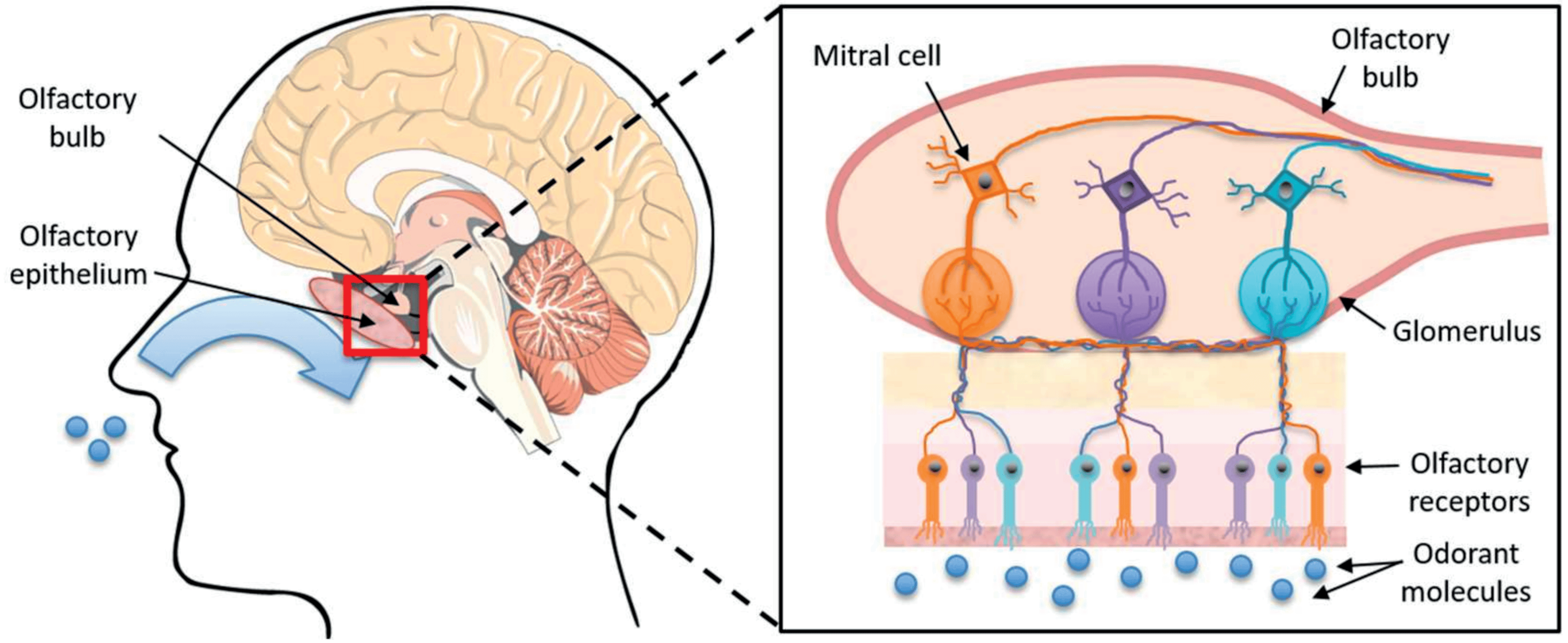


Image 5: Working Principle of the Olfactory Bulbs in a Human Brain (Kotecha et al., 2018)

(3.2) Demystifying Olfaction

What is an Olfactory Disorder?

An olfactory disorder (OD) signifies a condition characterised by the partial or complete loss of an individual’s sense of smell (NIDCS, 2015). The sense of smell, integral to the chemosensory organ or the chemical senses, primarily originates from specialised sensory nerves known as olfactory sensory neurons, which are situated within the upper nasal passages (Fifth Sense, 2011). These sensory neurons house specialised odour receptors that directly connect to the olfactory bulbs in the brain’s frontal lobe (Grujičić, 2022). When substances release minute odour molecules, these odour receptors capture these molecules and subsequently transmit neural signals to the olfactory bulbs, enabling the brain to recognise and interpret the particular scent.

What are the types of OD?

OD can be congenital (born with the condition) or acquired later in life and includes Anosmia, Hyposmia, Parosmia, and Phantosmia (NIDCD, 2023). Individuals can develop this condition for various reasons, primarily classified into pathological, neurological, and functional categories. Pathological factors include respiratory infections, inflammations, physical injuries to the nasal passages, such as those caused by head traumas or infections like COVID-19, and other physical or mental injuries. Neurological factors encompass head injuries resulting in damage to the neurons, congenital conditions where the olfactory bulbs may be absent or where the connections to the nasal receptors are missing, and other conditions affecting the nervous system. Functional factors include nasal polyps, smoking, age-related deterioration, and other factors.

How is OD diagnosed?

Many countries follow different conventions in testing patients for OD. They are also tested for different conditions using different methodologies. According to (Rumeau et al., 2016) and many doctors, a Sniffin' Sticks test (Hummel et al., 1997) which is universally accepted as a European standard test is conducted to diagnose OD and in the USA, the University of Pennsylvania Smell Identification Test (UPSIT) (Doty et al., 1984) is conducted (Johns et al.) (NIDCD, 2023). Similarly, the Sinonasal Outcome Test (SNOT) (Khan et al., 2021) is used in India. It is noteworthy that while OD due to pathological factors may be reversible through corrective surgical interventions, this reversibility is not feasible in cases arising from other factors (Davidson et al.; A. A., 1995).

How does this affect their lifestyle?

Infants are inherently born with an acute olfactory sense, a trait that evolves to facilitate exploration and cognition of the surrounding environment (Elaine, 2020). The pivotal role of the sense of smell in detecting and distinguishing hazardous odours, thus ensuring safety, is paramount (Blomkvist & Hofer, 2021). This study also shows that the influence of olfaction extends significantly to personal, social, and romantic relationships, integral components for emotional and psychological development. The regulation of mood and psychological well-being underscores the importance of the olfactory sense in an individual's life. Instances where odours evoke memories, such as freshly baked bread, extend nostalgic recollections of happy moments. The impairment of the olfactory senses, whether partial or complete, impacts various facets of life. These repercussions affect personal hygiene, safety protocols, dietary patterns, social engagements, and fundamental health considerations, including the potential for alterations in weight (Blomkvist & Hofer, 2021).

Prevalence of Olfactory Disorder in India

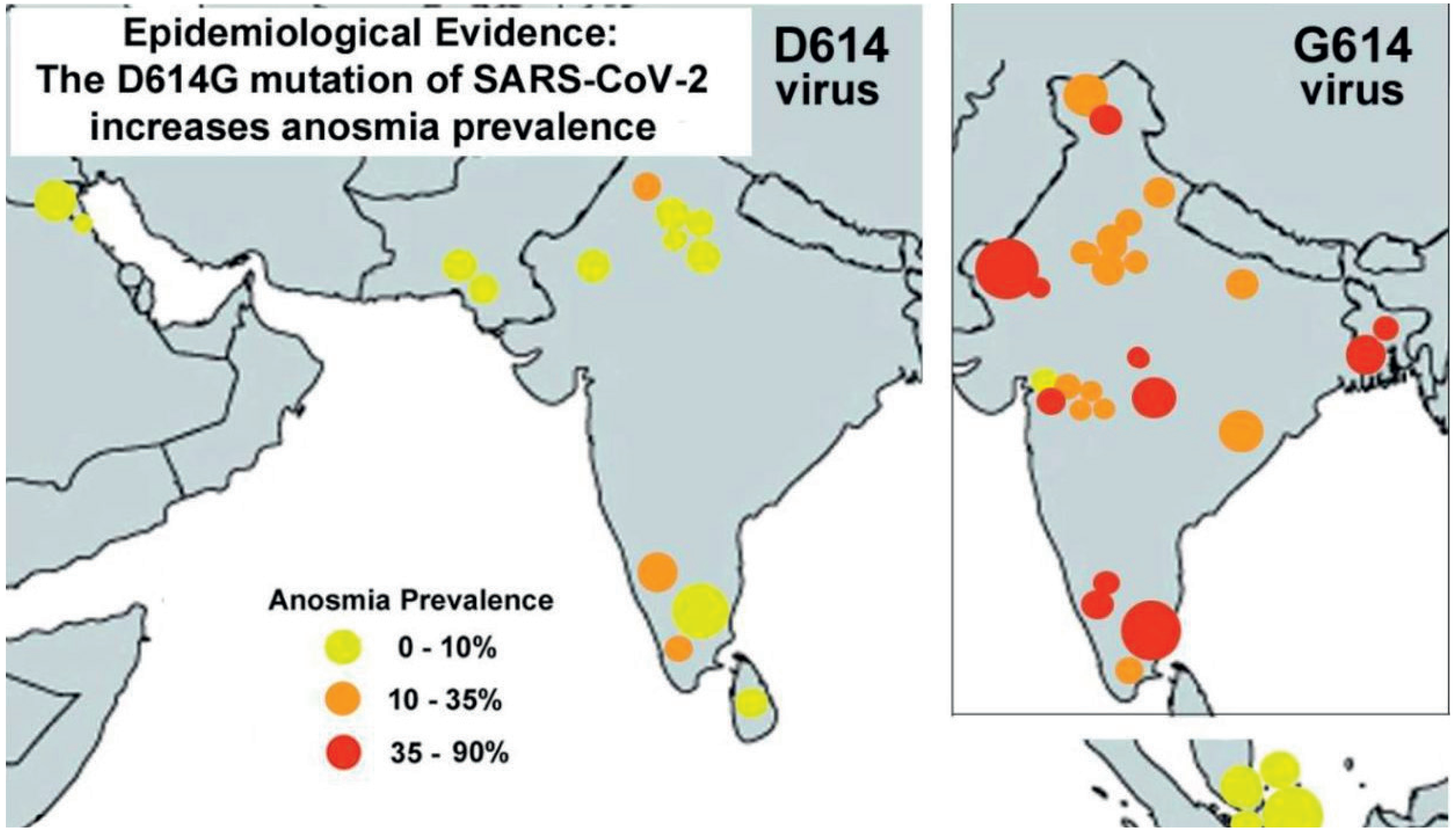


Image 6: Prevalence of OD during COVID Pandemic (Von Bartheld, Hagen and Butowt, 2021)

As discussed before, invisible disorders such as OD have been overlooked by the legal framework in India, resulting in limited research studies. However, following the COVID-19 pandemic breakout in 2020, many studies were conducted on OD, as one of its main symptoms is the loss of sense of smell. A pilot review of 16 studies conducted by Aanand et al. (2021) found that the incidence range of OD varied widely from 9% to 80%, with an average incidence of 30.19% of anosmia. However, the study also revealed that the incidence of OD in India is much lower than the European standard due to negligence and other factors. According to a study by Hura et al. (2020), 5% of the general population had anosmia before the COVID-19 pandemic, and 12% of patients still have complete loss or dysfunction of the sense of smell even after six months of the viral infection.

Due to limited research and geographical constraints, only a small number of articles and journals were covered in this study to understand the incidence of the disorder. However, to ensure the project's long-term success, it is essential to understand the prevalence of OD, which should be determined under the supervision of an ENT specialist.

(3.3) Primary Healthcare Centres and it's problems

Primary Healthcare Centres (PHCs) are crucial in providing public healthcare services in India. They are the first point of contact for people living in rural areas who need medical assistance from qualified healthcare professionals. PHCs provide curative, preventive, and promotive healthcare services to individuals who directly report or are referred from Sub-Centres. The PHCs are expected to offer essential services such as outpatient department (OPD) services, 24-hour emergency services, referral services, and in-patient services. They must have at least six beds available for patients to occupy.

India has made significant progress in the healthcare sector since gaining independence in 1947. The country has established private and public healthcare services to provide basic care and access to all its citizens. However, the public healthcare system has struggled to extend services to those below the poverty line. According to Gupta (2020), the health and welfare sectors were severely underfunded until 2017, with less than 10% of the total budget allocated to healthcare. As a result, public hospitals lacked the necessary facilities and infrastructure to provide quality healthcare services to their citizens. In 2018, the government launched the "Ayushman Bharat Program" to improve access to healthcare services in tier 2 and 3 cities and rural areas

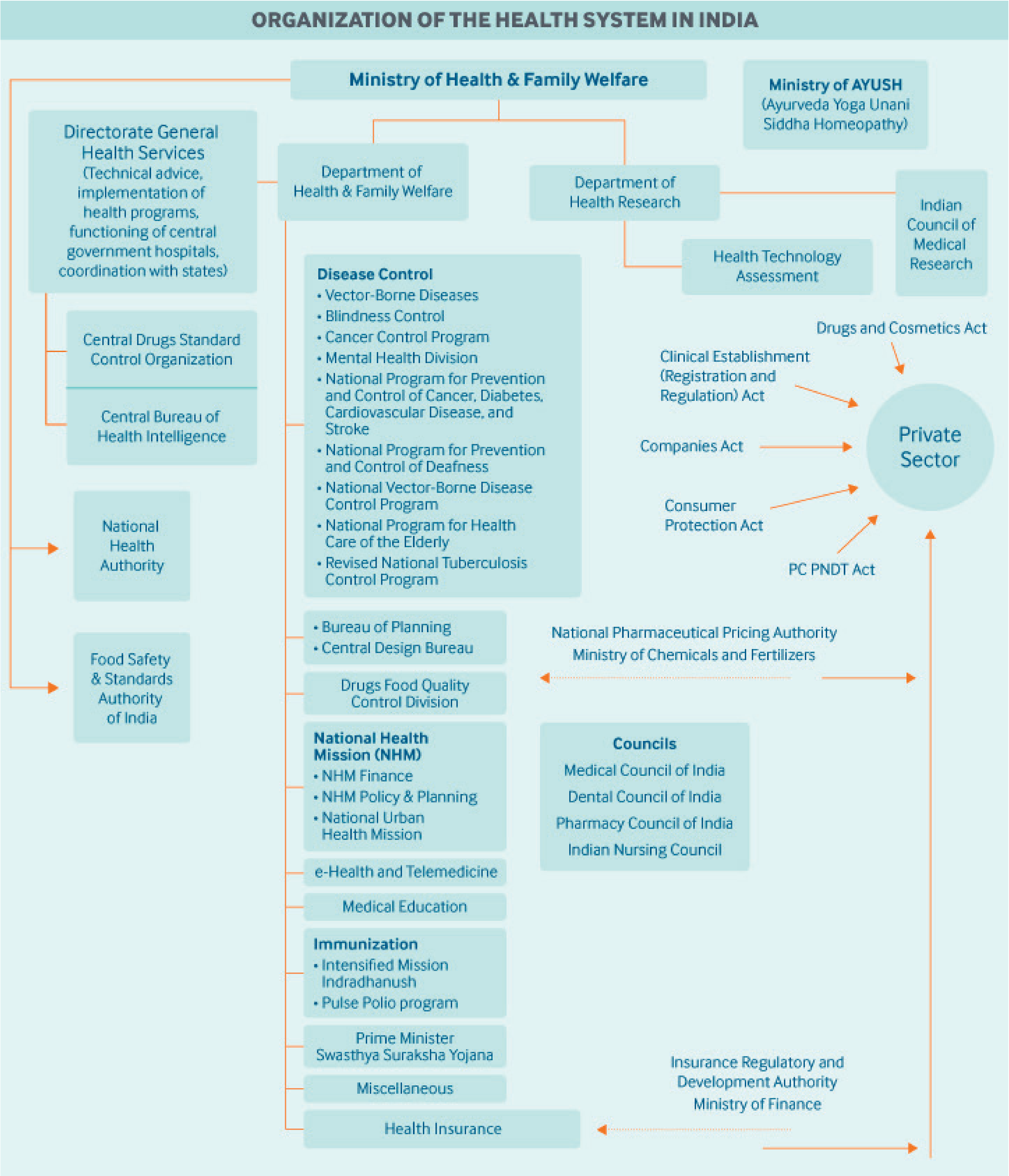
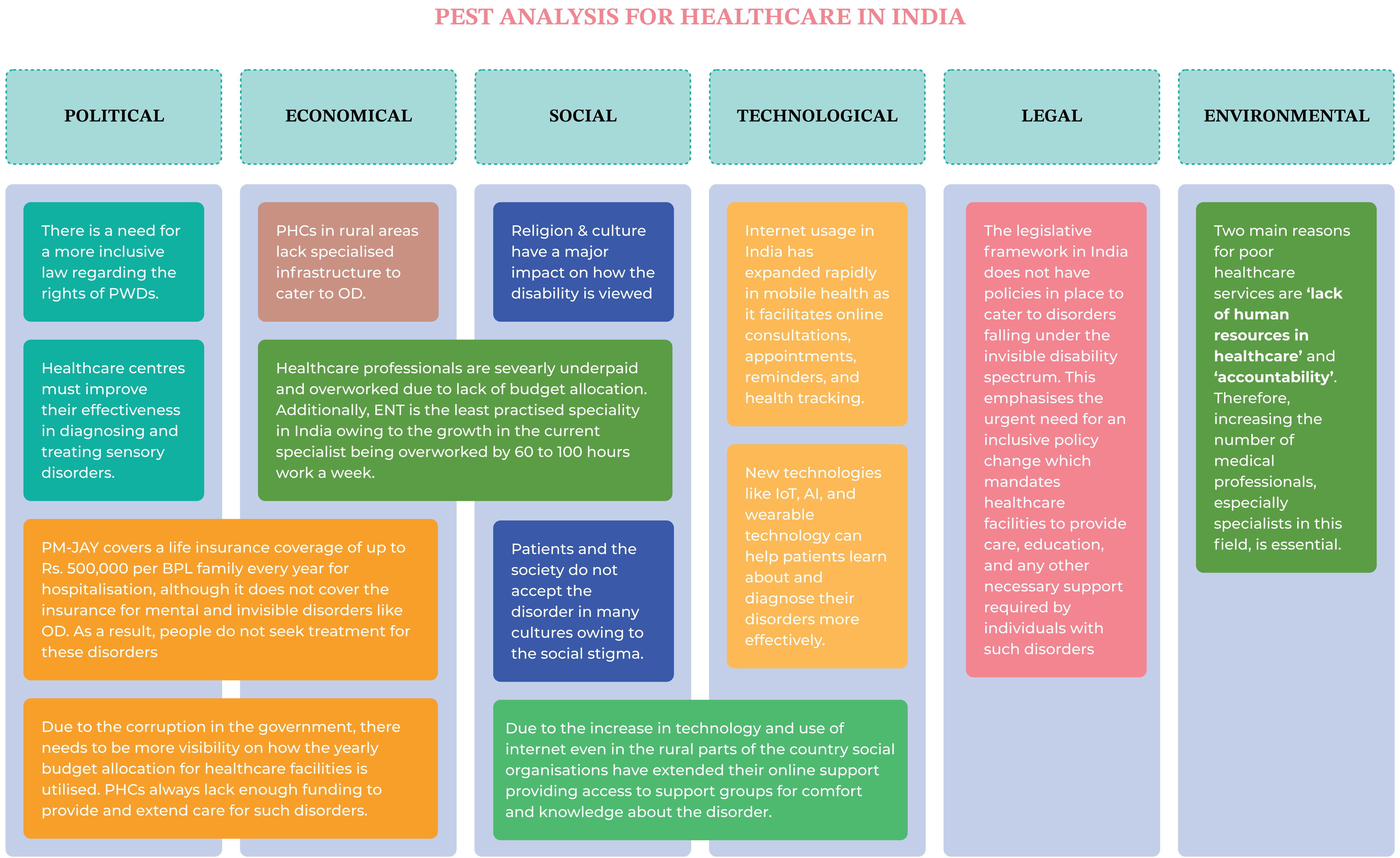


Image 6: Organisation of healthcare system in India (Gupta, 2020)

(National Health Authority, 2018). This program aimed to provide comprehensive healthcare and hospitalisation services for ten crore families by offering insurance coverage of up to 5 lakhs for secondary and tertiary hospitalisation. The government has set a target of establishing 150,000 primary healthcare centres by 2022 to support patients. However, despite these efforts, public healthcare services are underutilised due to factors such as the lack of trust in the skills of the public sector (Niva Health Insurance, 2023). Lahariya (2020) explains that many doctors prefer to work in private hospitals due to higher pay and a lack of fair compensation for their work in government hospitals. This leads to a shortage of service providers and longer wait times for appointments and diagnosis. Government health insurance policies only cover some illnesses due to the need for more inclusivity in the framework. As a result, 36% of people in the country have private health insurance (Gupta, 2020), and many families still do not have any insurance.

(3.4) PESTLE Analysis

To identify the external factors that impact the issue, the potential barriers and liabilities that contribute to the failure or success of the healthcare system in India, a detailed PESTLE analysis was conducted (Appendix 2, PP: 59 -60).



PEST ANALYSIS FOR HEALTHCARE IN INDIA

POLITICAL

There is a need for a more inclusive law regarding the rights of PWDs.

Healthcare centres must improve their effectiveness in diagnosing and treating sensory disorders.

PM-JAY covers a life insurance coverage of up to Rs. 500,000 per BPL family every year for hospitalisation, although it does not cover the insurance for mental and invisible disorders like OD. As a result, people do not seek treatment for these disorders

Due to the corruption in the government, there needs to be more visibility on how the yearly budget allocation for healthcare facilities is utilised. PHCs always lack enough funding to provide and extend care for such disorders.

ECONOMICAL

PHCs in rural areas lack specialised infrastructure to cater to OD.

Healthcare professionals are severly underpaid and overworked due to lack of budget allocation. Additionally, ENT is the least practised speciality in India owing to the growth in the current specialist being overworked by 60 to 100 hours work a week.

SOCIAL

Religion & culture have a major impact on how the disability is viewed

Patients and the society do not accept the disorder in many cultures owing to the social stigma.

Due to the increase in technology and use of internet even in the rural parts of the country social organisations have extended their online support providing access to support groups for comfort and knowledge about the disorder.

TECHNOLOGICAL

Internet usage in India has expanded rapidly in mobile health as it facilitates online consultations, appointments, reminders, and health tracking.

New technologies like IoT, AI, and wearable technology can help patients learn about and diagnose their disorders more effectively.

LEGAL

The legislative framework in India does not have policies in place to cater to disorders falling under the invisible disability spectrum. This emphasises the urgent need for an inclusive policy change which mandates healthcare facilities to provide care, education, and any other necessary support required by individuals with such disorders

ENVIRONMENTAL

Two main reasons for poor healthcare services are **'lack of human resources in healthcare'** and **'accountability'**. Therefore, increasing the number of medical professionals, especially specialists in this field, is essential.

Image 7: PESTLE Analysis of the PHCs in India

Addressing the healthcare challenges demanded a holistic strategy. It began with advocating for legislative reforms that explicitly address hidden disabilities and foster inclusivity within healthcare policies. Simultaneously, establishing transparency and accountability mechanisms is crucial to ensure that allocated funds effectively reach healthcare centres. Investing in developing the healthcare workforce, particularly in specialised fields like ENT, was essential for delivering quality care. Concurrently, efforts to improve public awareness and destigmatise invisible disorders like OD were imperative. Technology integration has enhanced accessibility and diagnosis. Collaborating with NGOs can amplify support, resources, and advocacy, creating a comprehensive approach to uplifting the healthcare landscape.

(3.5) Humanisation of Healthcare Framework

The PESTLE analysis highlights profound challenges in treating and caring for patients diagnosed with OD within PHCs. The main issue is hospitals' are the lack of adequate intervention strategies, particularly concerning information. Overburdened healthcare professionals need more bandwidth to address patients' emotional needs during the diagnostic phase, leading to an improved human-centric approach to care.

The insufficiency in considering patients' emotional well-being is evident, with healthcare providers failing to measure the emotional states or potential information overload experienced by OD patients. Moreover, the diagnostic procedure, inherently daunting, contributes to patients' reluctance to follow up on treatment courses. Nielsen, Kvande, and Angel (2022) exemplify the transformative impact of humanising healthcare environments, as demonstrated in intensive care units (ICUs). Customised care practices, responsive communication, and facilitating connections with loved ones significantly enhanced patients' human experience. This paradigm shift applies equally to conventional hospital settings, especially in rural areas where patients are confused about prevalent stigmas.

Consequently, a crucial imperative emerges to humanise care across the diagnostic procedure. Adopting practices that acknowledge and address patients' emotional states, provide responsive communication, and foster connections with their support networks can profoundly enhance the overall patient experience in the context of OD diagnosis and treatment. So, how do we achieve humanising the experience in the PHCs for the patients diagnosed with OD? It necessitates the application of a value framework proposed by Todres, Galvin, and Holloway (2009) as a guiding paradigm for infusing humanistic principles into the healthcare system.

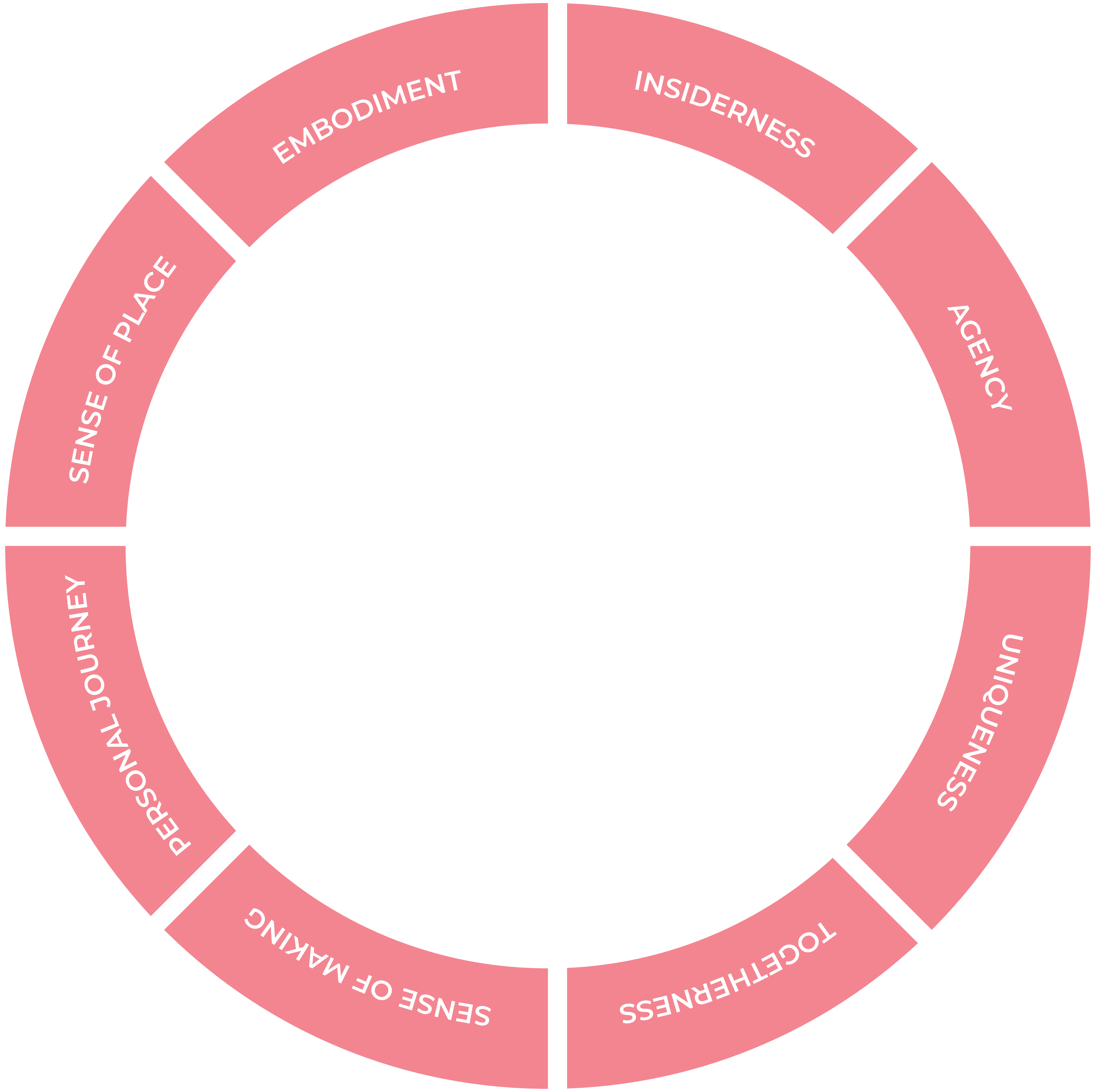


Image 8: Humanisation of Healthcare Value Framework

What sets us apart as humans in this world of AI and technology? It is the ability to feel and emote (Farrar, n.d.). Whereas AI can only try to mimic and fail the emotions we feel. It is this ability that puts us on top of the chart. We must acknowledge this and understand that people are overburdened with various emotions, especially in healthcare.

Humanisation of Healthcare Value Framework

The healthcare landscape is changing, and we are witnessing a shift from the conventional disease-centered approach to a more compassionate and patient-centered model. This transformation is paving the way for a more empathetic, understanding and individualised approach to care beyond treating just the ailment. This movement is guided by a value framework (Todres et al., 2009) meticulously crafted for healthcare professionals and aimed at cultivating a more humane approach to care. The framework is built around eight key principles: Insiderness, Agency, Uniqueness, Togetherness, Sense of Making, Personal Journey, Sense of Place, and Embodiment, which together encapsulate the essence of being human.

Insiderness

In healthcare, it is common for patients to be seen as mere subjects, overshadowed by diagnostic systems. However, it is crucial to remember that patients are human beings with unique stories. Amid complex studies and clinical assessments, it is essential to communicate with patients in a way that is understandable and relatable to their experiences rather than relying solely on clinical jargon. This will help ensure that patients are treated with the dignity and respect they deserve.

Agency

Having a sense of agency, or the ability to make choices and be responsible for one’s actions, is a fundamental aspect of the human experience. This sense of agency is closely intertwined with dignity, and when it is diminished, it can erode one’s sense of personhood. Empowering patients means keeping them informed and actively involved in their healthcare journey, restoring a sense of control and autonomy.

Uniqueness

As humans, we are more than just a list of attributes. It is crucial to recognise the uniqueness of each patient and treat them as individuals. We must understand how they interpret news and navigate their treatment journey by appreciating their distinct essence. A nuanced approach is necessary to achieve this.

Togetherness

The meaning of human existence is found in the community, where our unique characteristics engage in a perpetual dance with shared experiences. Togetherness and uniqueness are interwoven, defining the human experience of solitude and intimacy. Recognising this duality is essential in fostering meaningful connections in healthcare.

Sense of Making

The human ability to make sense of things involves creating stories that connect different pieces of information. Allowing people to form their comprehension of treatments and disorders is crucial. It is not just about providing information but also creating a space where patients can make sense of their health journey.

Personal Journey

Human life is an ongoing process encompassing past experiences and evolving future possibilities. Delving into their history and anticipating future outcomes is essential to comprehend someone in any particular moment fully. Medical professionals must pay close attention to the intricate narratives that shape a person’s life.

Sense of Place

Our sense of identity as humans is closely tied to a particular place beyond a physical location. It encompasses the environment where we feel a sense of belonging and comfort. Creating healthcare spaces that provide privacy, dignity, homeliness, and hope is crucial. These spaces are not just defined by their physical boundaries but also by the practices and interactions within them.

Embodiment

Human existence is fragile and can be affected by both physical and mental well-being. In India's rich holistic health traditions, it is essential to recognise the interconnectedness of the mind and body. A compassionate healthcare system should prioritise holistic healthcare practices that promote mental and physical well-being harmonisation.

As healthcare professionals navigate the complex web of these eight lenses, they embark on a journey of humanisation beyond just following clinical routines. They strive to understand each patient's unique story and identity and provide personalised care that empowers and empathises with them. This narrative is built on the foundations of empathy, empowerment, and individualised care, creating a healthcare paradigm that resonates with the profound depth of the human experience.

04. CASE STUDY

Clothing & Accessories

Gifts & Personal Items

All Wearer Products

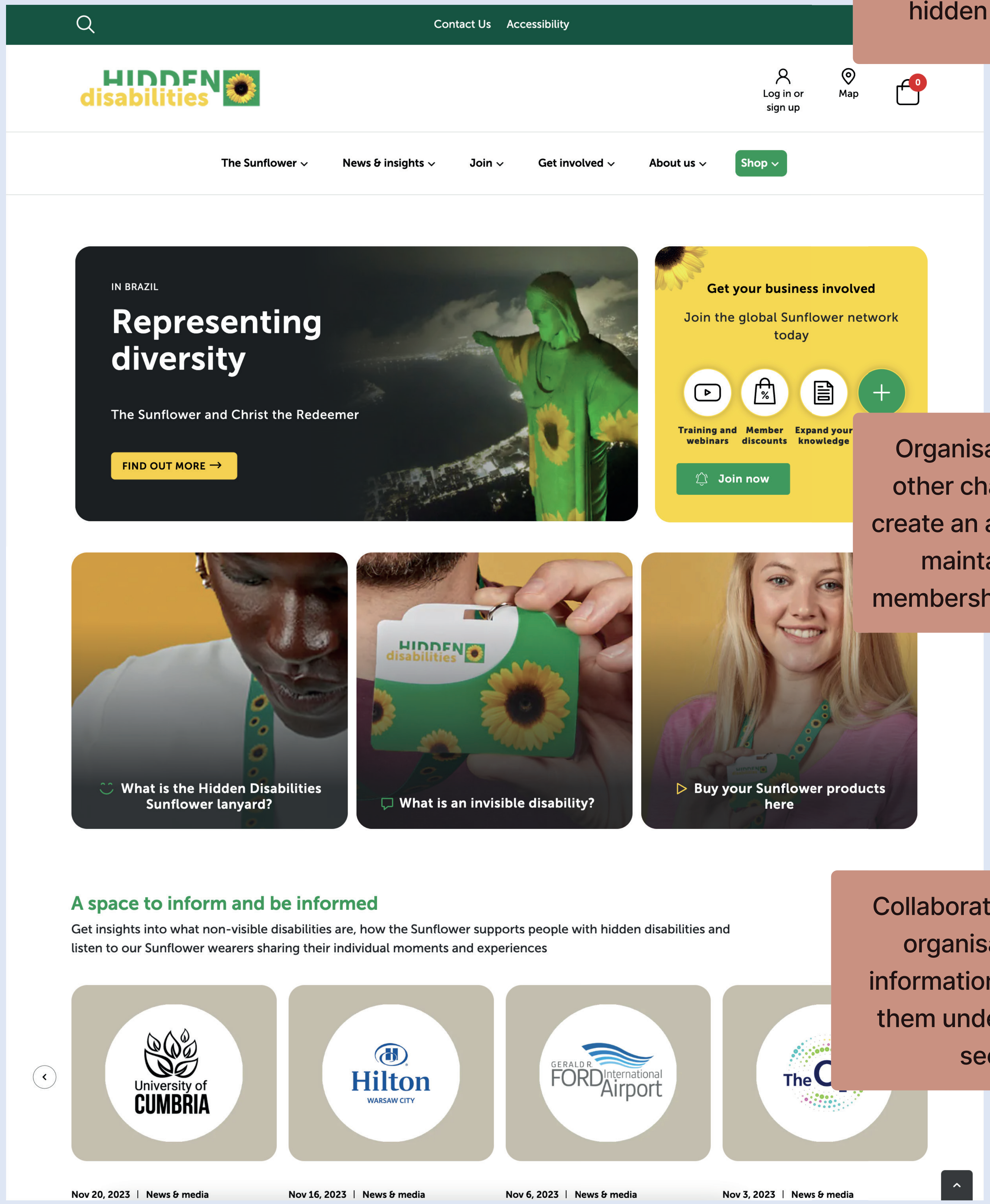
All Supporter Products

Global

All Memberships

All Member Products

An organisation that supports people with hidden disability



IN BRAZIL

Representing diversity

The Sunflower and Christ the Redeemer

Get your business involved

Join the global Sunflower network today

A space to inform and be informed

Get insights into what non-visible disabilities are, how the Sunflower supports people with hidden disabilities and listen to our Sunflower wearers sharing their individual moments and experiences

Nov 20, 2023 | News & media

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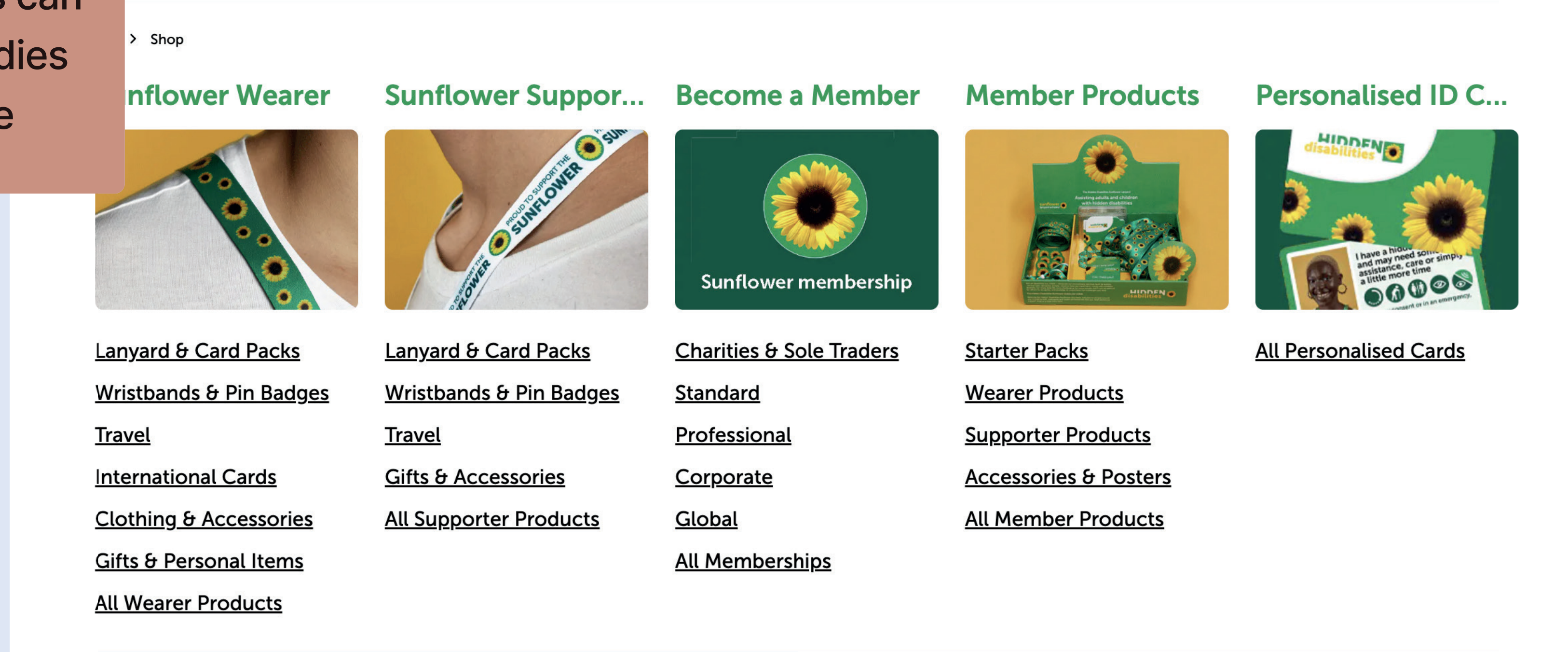
Nov 6, 2023 | News & media

Nov 3, 2023 | News & media

Wearers, Supporters and organisations can buy the goodies from here



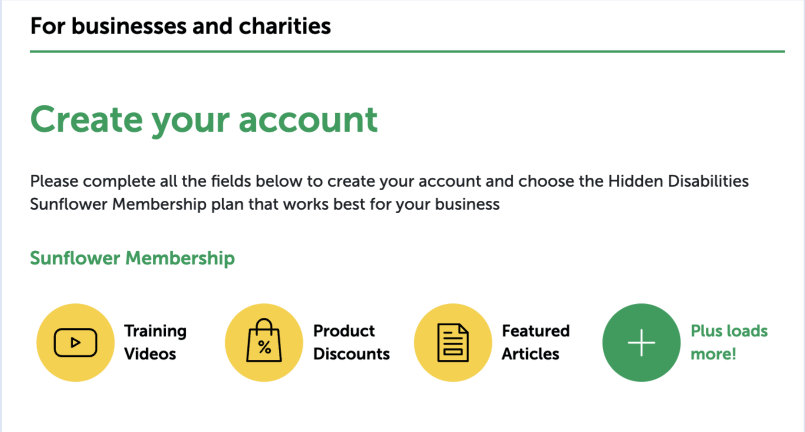
Lanyard & Card Packs
Wristbands & Pin Badges
Travel
International Cards
Clothing & Accessories
Gifts & Personal Items
All Wearer Products

Lanyard & Card Packs
Wristbands & Pin Badges
Travel
Gifts & Accessories
All Supporter Products

Charities & Sole Traders
Standard
Professional
Corporate
Global
All Memberships

Starter Packs
Wearer Products
Supporter Products
Accessories & Posters
All Member Products

All Personalised Cards



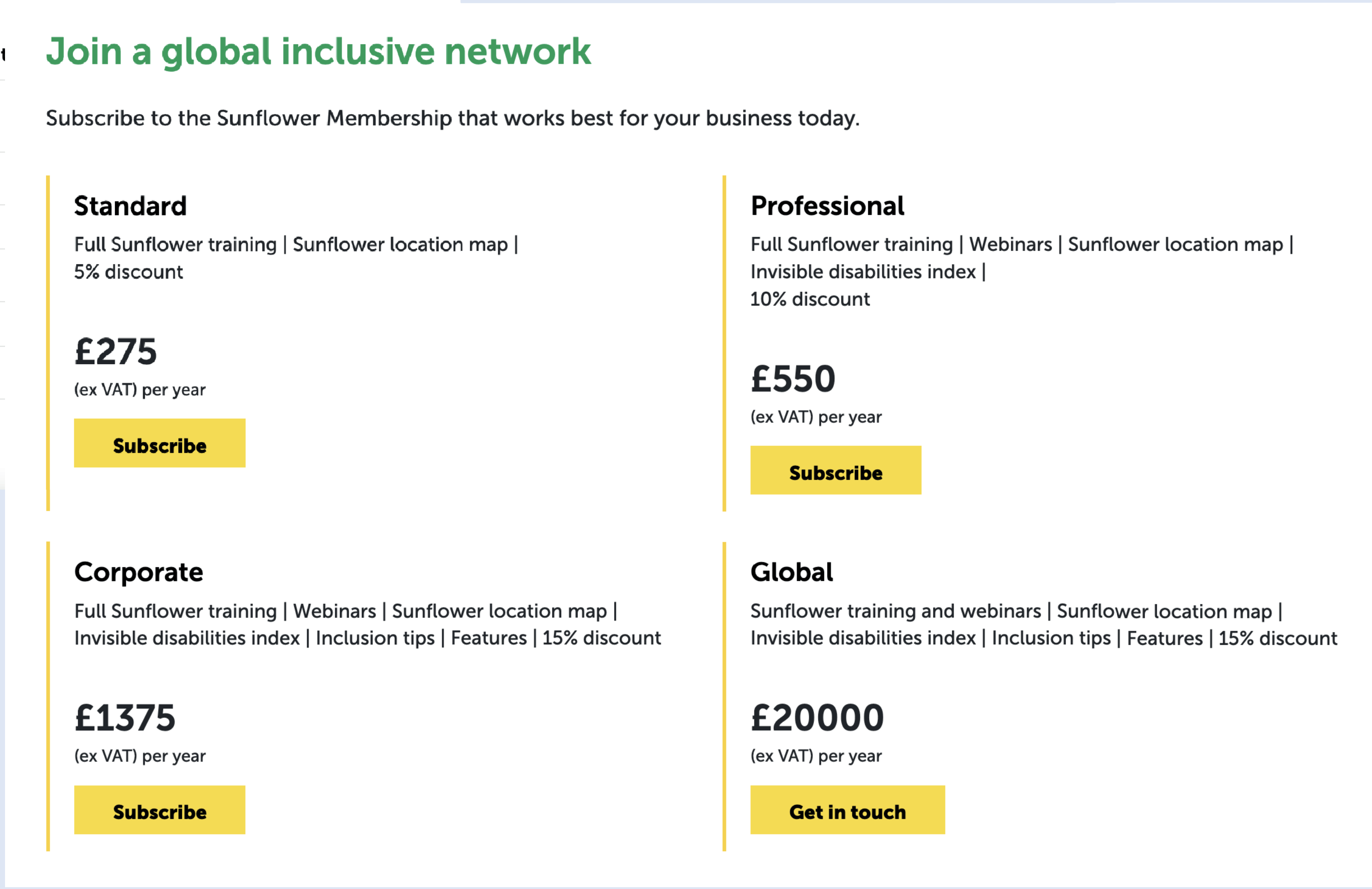
For businesses and charities

Create your account

Please complete all the fields below to create your account and choose the Hidden Disabilities Sunflower Membership plan that works best for your business

Sunflower Membership

Organisations and other charities can create an account and maintain their membership from here



Join a global inclusive network

Subscribe to the Sunflower Membership that works best for your business today.

Standard

Full Sunflower training | Sunflower location map | 5% discount

£275

(ex VAT) per year

Professional

Full Sunflower training | Webinars | Sunflower location map | Invisible disabilities index | 10% discount

£550

(ex VAT) per year

Corporate

Full Sunflower training | Webinars | Sunflower location map | Invisible disabilities index | Inclusion tips | Features | 15% discount

£1375

(ex VAT) per year

Global

Sunflower training and webinars | Sunflower location map | Invisible disabilities index | Inclusion tips | Features | 15% discount

£20000

(ex VAT) per year

Collaboration with the organisation and informations regarding them under the news section

The Sunflower Lanyard Scheme® launches at London Gatwick Airport

The lanyard is designed to identify passengers with a hidden disability who may need additional help while travelling

2016

2017

The Hidden Disabilities Sunflower Lanyard rolls out across all major UK airports

The Co-operative Channel Islands is the first UK supermarket chain to pilot the Hidden Disabilities Sunflower Lanyard

UK rail providers become members of the Hidden Disabilities Sunflower Lanyard Scheme®.

2018

Major UK supermarkets trials take place

NHS trusts and independent GP surgeries trial and launch the Hidden Disabilities Sunflower Lanyard Scheme®

Work with international airports.

Tabbers Limited trademarks the Hidden Disabilities Sunflower Lanyard Scheme®

Cinemas and visitor attractions launch the scheme throughout the UK

2019

Supermarkets:

M&S is the first UK supermarket to roll out the Hidden Disabilities Sunflower Lanyard in all their UK stores;

Sainsbury's and Argos launch throughout their UK stores; and Tesco launch in all of their stores in the UK and Ireland

Banks, hospitals, insurance companies, shopping centres, sports venues, and arenas join across the UK

Global airports launch the Hidden Disabilities Sunflower:

Sydney and Brisbane in Australia Seattle and San Jose in the US Copenhagen, Trieste and Amsterdam in Europe Istanbul in Eurasia and Dubai in the Middle-East

The Hidden Disabilities Sunflower online store opens.

Facebook Page 25,000 likes within a few days - individuals and businesses from all over the world request the Hidden Disabilities Sunflower Lanyard.

Over 2 million lanyards distributed globally

The Hidden Disabilities Sunflower training videos are released for businesses and organisations to train their staff

2020

Nationwide trials the Hidden Disabilities Sunflower becoming the first financial institution to join the scheme

National lockdown starts in the UK - new Sunflower cards released

Sunflower Stories launched

Chelsea Football Club launch

National Express becomes the 1st national road transport business to recognise the Sunflower

Face coverings mandatory on all UK public transport -

Hidden Disabilities Sunflower collaborates with the national rail network to find a way to support those people whose hidden disability means they are unable to wear a face covering.

Hidden in Heritage

Hidden Disabilities Sunflower creates and launches an online festival to shine a light on hidden disabilities in heritage

Students return to university - Hidden Disabilities Sunflower launches its Back to Campus campaign

Australia and New Zealand launch - partnering with Bayley House

North American launch - partnering with The Sourcing Group

Pearson Airport becomes the first airport in Canada to recognise the Sunflower

International Day of Persons with Disabilities

Hidden Disabilities Sunflower releases its 'Hidden Disabilities and me' poetry book, an anthology of poems written by Sunflower wearers and supporters

Borderforce UK launch the Sunflower to ensure everyone travelling into the UK wearing a Sunflower will be provisioned for by Borderforce staff

2021

UK vaccine roll-out - Hidden Disabilities Sunflower launch 'Our Sunflower, Your NHS' campaign to provide free Sunflower products and training to every Covid vaccination centre in the UK

(4.1) Hidden Disability Sunflower Organisation, UK

[Source: Hidden Disabilities Sunflower, 2020]

In 2016, Gatwick Airport witnessed the conception of a groundbreaking initiative, The Hidden Disabilities Sunflower Organisation. Spearheaded by the Airport Advisory Group and led by Ruth Rabet, the foundation sought to address the challenges faced by individuals with hidden disabilities, emphasising inclusivity and understanding. They wanted to create a safe space for individuals to voluntarily express the necessity for additional assistance, understanding, or extended time in various settings such as retail environments, workplaces, public transportation, and communal spaces.

The Founding Team

The core team comprised visionaries such as Tim Wilkins from the Alzheimer's Society, Daniel Williams from Visualise, Daniel Cadey, formerly associated with the National Autistic Society, and Maria Cook from Autism Support Crawley. Maria's connection to autism through her son Ryan added a poignant perspective to the initiative.

Why the Sunflower?

Motivated by a shared commitment to creating a more inclusive society, the team embarked on discussions that would shape the future of hidden disability acknowledgement. Evaluating various symbols, they decided on a lanyard adorned with sunflowers on a green background (Hidden Disabilities Sunflower, 2020). The sunflowers symbolised confidence, growth, and strength, injecting happiness and positivity into the narrative and being gender-neutral (University of Birmingham, n.d.).

Implicit Communication

The Sunflower merchandise comprising lanyards, pins, scarfs, and more emerged as an implicit mode of communication. When adorned, these items conveyed a discreet message to the public. It was a voluntary disclosure, signalling the wearer's need for additional assistance, understanding, or more time. The unobtrusive nature of the Sunflower allowed individuals to navigate various settings, including retail spaces, workplaces, public transportation, and communal areas, with greater ease.

Positive Impact

Since its inception, the Hidden Disabilities Sunflower has garnered widespread recognition and adoption. It has become a symbol of a safe space and a call for empathy. Individuals with hidden disabilities have found a voice through the Sunflower, fostering a more supportive environment in various societal contexts.

The Challenges

- Lack of Awareness

Initially, the organisation faced challenges in garnering awareness. Convincing airports and governments to align with the cause proved to be a hurdle, highlighting the initial struggle for acknowledgement (Hidden Disabilities Sunflower, 2022).

- Proliferation of Sunflower Symbols

With international recognition, variations of the sunflower lanyard and ribbons emerged worldwide. This led to difficulties for international travellers receiving consistent recognition for hidden disabilities.

- Misuse During COVID-19

The COVID-19 pandemic brought a new challenge as people began misusing the sunflower lanyard. Instances were reported where individuals exploited it to evade mask mandates, creating difficulties for authorities to distinguish between genuine cases and misuse (Luke, 2021).

The Intervention

The team addressed the challenges by initiating awareness campaigns on social media and podcasts to educate airports, governments, and the public about the purpose and significance of the sunflower symbol. This educational effort was crucial in gaining support and widespread adoption. By encouraging organisations in different countries to collaborate with the organisation, they overcame the challenge of maintaining a consistent design and standardisation. This commitment to a recognisable symbol helped create a cohesive, globally identifiable representation of hidden disabilities. The organisation further implemented strategies such as increased public awareness about the proper use of the sunflower symbol and collaboration with authorities to overcome the issues of misusing symbols during the pandemic.

Discussion in term of Indian Healthcare System

Recognising and supporting PWD is crucial, especially for those whose disabilities may not be immediately apparent. However, in countries like India, social stigma and taboos surrounding disabilities remain high. A possible solution could be the implementation of badges or lanyards, which discreetly inform others that the wearer has a disability. This would be a voluntary disclosure, allowing the wearer to indicate that they have a disability and would appreciate any help or support. Such a practice would help break down social stigmas and taboos, creating a paradigm shift in the country.

This approach would also help raise awareness and educate people about hidden disabilities and how to be supportive and sensitive towards people with disabilities. Healthcare providers and facilities would be better equipped to provide more subtle and compassionate care and support and work collaboratively with the government to create a more inclusive definition of disability. This would ultimately empower PWDs to navigate the world more confidently and efficiently while improving their quality of life.

05. PRIMARY RESEARCH

(5.1) Problem Identification

Based on secondary research and case studies, it is evident that OD is a relatively niche area of study in the Indian healthcare system. By triangulating data from these two sources, as seen in Image 10, several issues were identified, including the lack of inclusion rights for hidden disabilities in the legal system, social and cultural impacts leading to social stigma and taboo, lack of information on diagnosis and post-diagnosis care, economic impact on treatment, and most importantly, the lack of humanisation of healthcare among medical professionals in PHCs.

However, some gaps still required further information. Therefore, primary research was conducted to understand the patient's journey through the diagnosis process. This analytical research provided further insights into the customer journey, the pain points, and the emotional journey of patients throughout the diagnosis process. It also highlighted medical professionals' pain points due to a lack of resources to communicate the diagnosis and post-diagnosis care to patients.

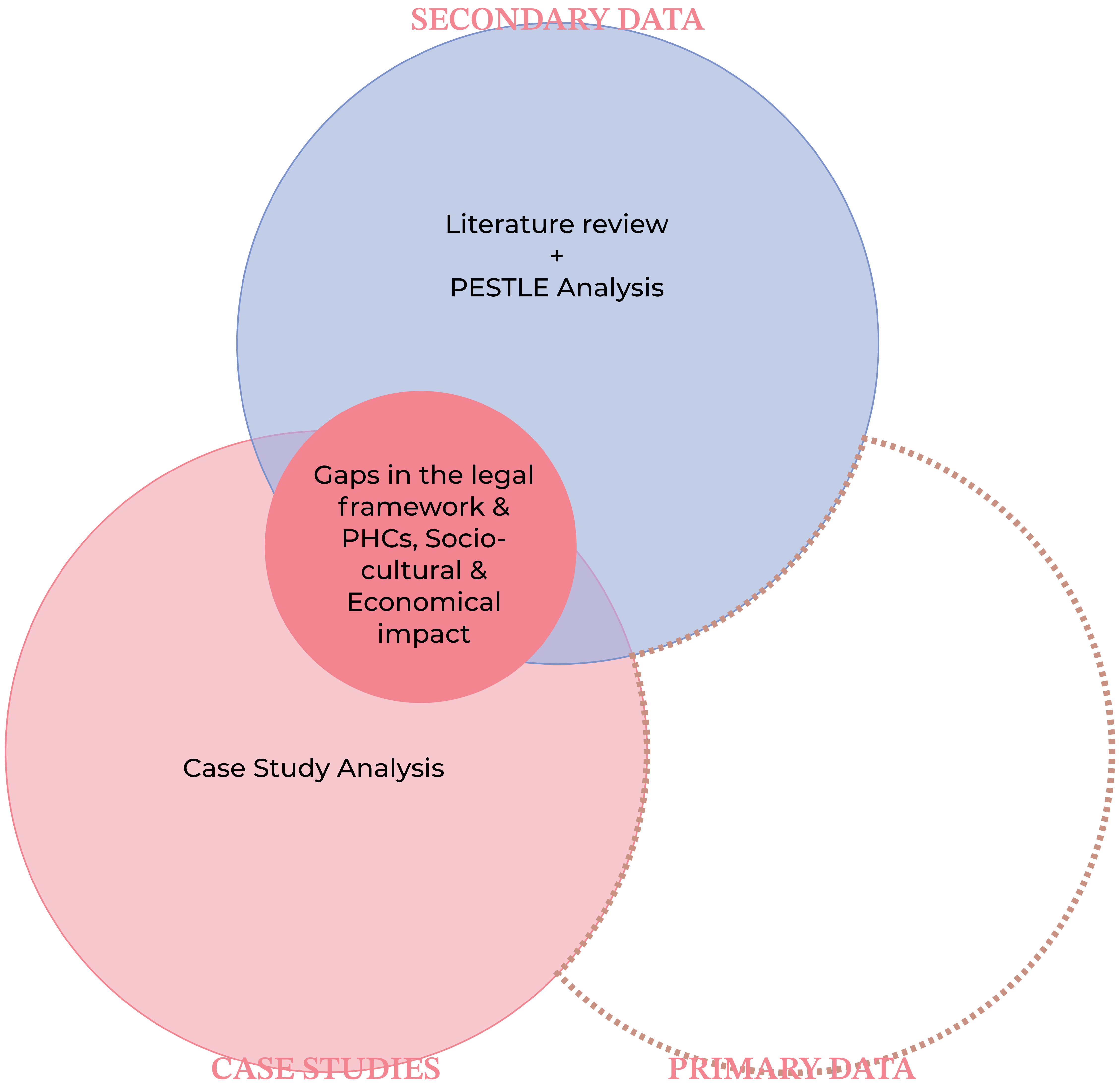


Image 10: Data triangulation and need for a primary research

(5.2) Summary and analysis of the primary research

The project began with a service safari, providing first hand insights into pre-diagnosis, diagnosis, and post-diagnosis care (Appendix 4.1, PP: 64 - 65). Primary research, comprising patient interviews (Appendix 4.5 - 4.10, PP: 67-70), doctor interviews (Appendix 4.2 - 4.4, PP: 66-67), and hospital observations (Appendix 4.11, P:70), uncovered insights.

Despite assertions that Primary Health Centres lack ENT amenities (Appendix 4.11, Image 32, P: 70) showed dedicated ENT departments at government hospitals like Victoria Hospital and Kauvery Hospital in tier 1 cities. These hospitals, often government-aided with attached medical colleges, serve diverse patients. However, doctors juggling faculty roles and residents balancing studies impact patient communication. Hospital environments, illustrated in (Appendix 4.11, Image 32, P: 70), reveal waiting area disorganisation due to walk-in appointments. Flexibility is beneficial, but scheduling systems may be needed. Senior residents, particularly master’s students, were observed as non-responsive, posing a problem. Additional challenges include tests needing private clinic visits, adding financial burden, and the hospitals lacked designated grief rooms for emotional processing.

Semi-structured interviews with three doctors and six patients revealed critical insights into problems within the healthcare ecosystem. Dr Naveen G (Appendix 4.4, P:67) emphasised the under-recognition of the sense of smell among patients when there is a deviation from the normal ability to smell. This pattern can also observed in the interviews with Prathiba, Patient A, Arnav, and Deeksha (Appendix 4.5, P:67 , 4.6, P: 68, 4.7, P; 68, 4.9, P: 69) who took more than six weeks to notice their loss of smell. Dr Naveen also noted that 90% of ENT clinic visitors experience a complete loss of smell, 5% have changed sense of smell, and 5% have partial loss of smell.

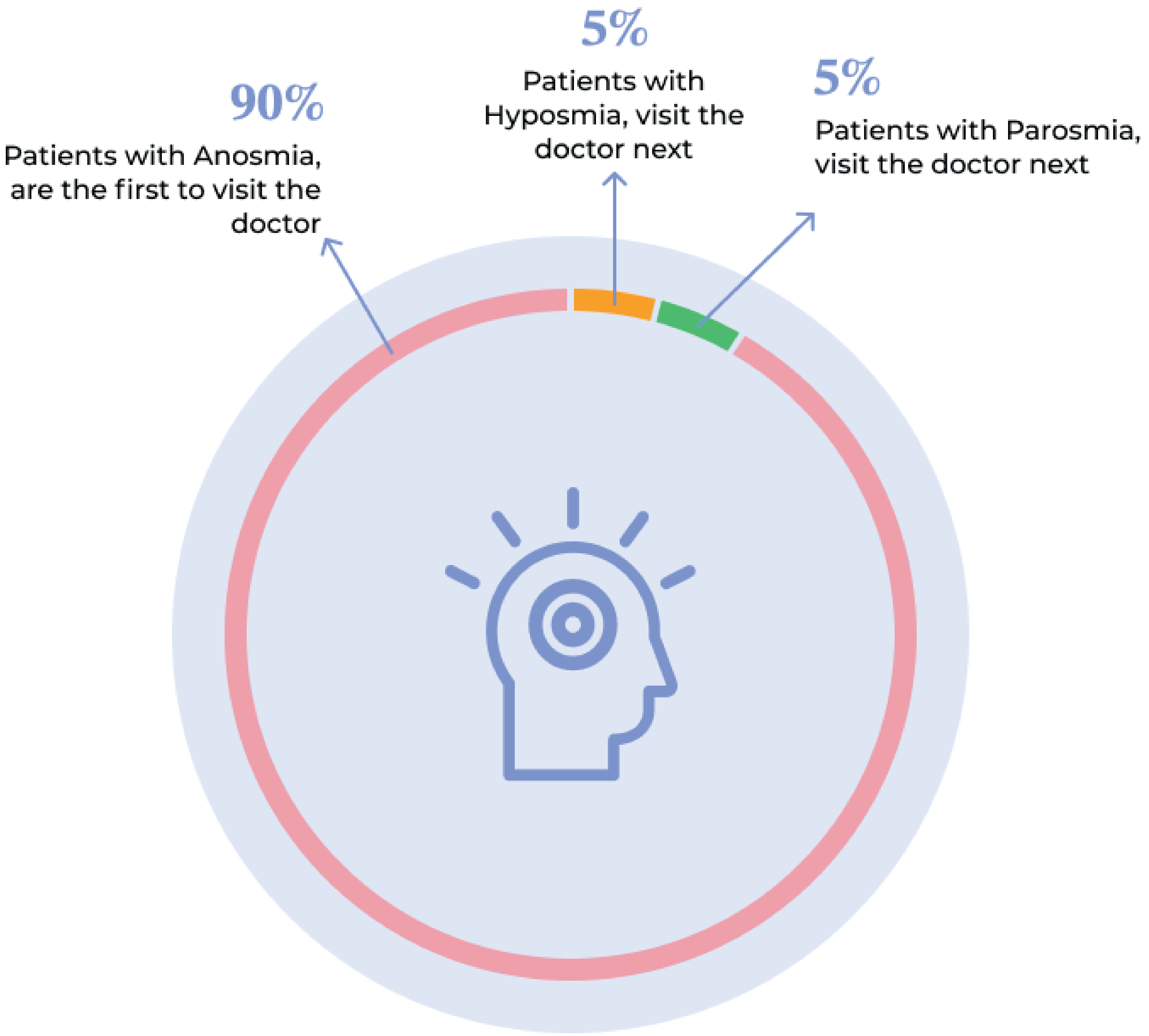


Image 11: Analysis of the patients visiting the doctor based on the Severity of their disorder according to the interview with Dr. Naveen

It is essential to note that the diagnostic process described by Dr Aravind (Appendix 4.2, P: 66) was tedious due to a lack of information brochures, information in the hospital or other support websites. The interview with Arnav and Prathiba also revealed that the patients were usually overwhelmed by the medical terms and process information provided by the medical professionals. However, medical professionals tried to simplify explanations for patients by explaining in local languages with examples and easing the process by providing information printouts from the internet. Language nuances were addressed by Dr. Naveen, who communicates in the local language with the help of nurses. However, the interview with Arnav revealed a further need for assistance in this area to improve the process experience. The service safari and the interviews with Prathiba, Patient A, Arnav, and Deeksha exposed that medical professionals do not extend emotional care during post-diagnosis.

Additionally, there were no grief centres or mental healthcare interventions to provide the patients who had been diagnosed with assistance to accept the disorder. This lack of intervention, coupled with patients' reluctance to return for follow-up sessions due to various reasons like social stigma, economic constraints, and the coexistence of other disorders, as seen in the literature review, contributed to difficulties in maintaining the health records of the patients. Moreover, there was a lack of a centralised database in the hospitals or with the government, creating challenges in patient follow-up.

By conducting this primary research, all the stakeholders in the problem space were analysed, and the current flow of service (Image 12) was highlighted, revealing the gaps in involvement and a need for thematic analysis to inform interventions.

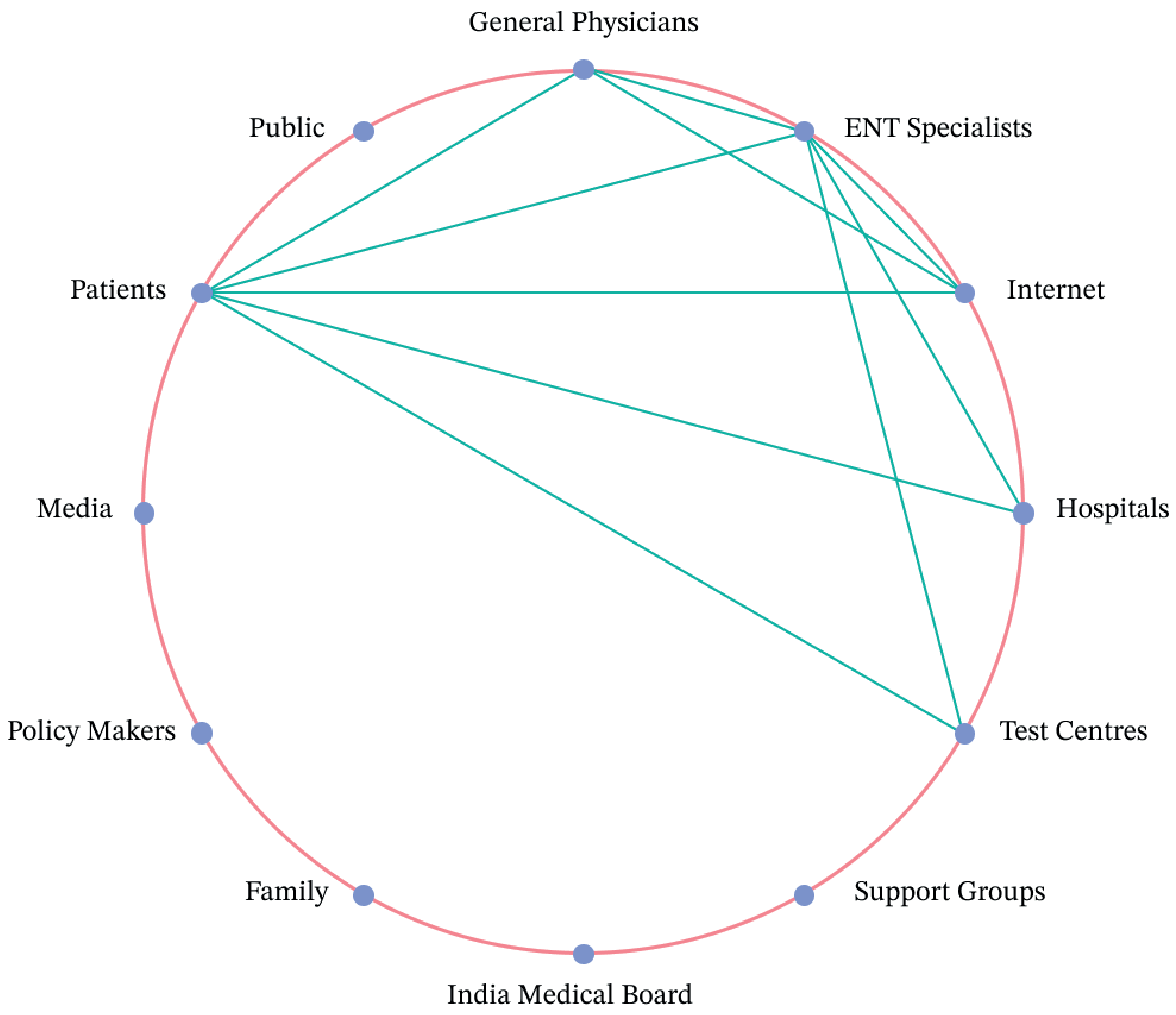


Image 12: System Map of the current Healthcare system in India

(5.3) Sentiment Analysis

As mentioned earlier, the patients, as well as other participants, were hesitant to share their detailed emotional experiences related to the disorder due to limited interaction time and various social factors. In India, expressing one's emotions and sharing one's emotional journey is often considered a sign of weakness, which may have contributed to the patients not sharing their emotional experiences entirely. Instead, they used general terms like "frustrating," "confusing," and "overwhelming". Sentiment analysis was conducted to gain deeper insights into the emotions and attitudes expressed in the collected data (Appendix 5.1, P:72). This analysis helped identify the overall sentiment or tone of the text, whether positive, negative, or neutral. It provided a better understanding of the impact and implications of the topics discussed. It also helped identify patterns and trends in the data, providing a deeper understanding of the subject matter and helping to inform decision-making processes.

The sentiment analysis used an online toolkit provided by MonkeyLearn (2023). When the interview transcript without the interviewee's name was uploaded to the toolkit ran through an algorithm, it provided the overall sentiment (Appendix 8.1) of the interview using the Neuro-Linguistic Program (NLP) and machine learning techniques. Based on the observations in (Image 13), it is evident that the patients experience negative emotions during and after the diagnosis process. Therefore, there is a need to implement interventions that can provide a more humanised experience to the patients and change the overall process. Firstly, the pain points and overarching issues would have to be identified.

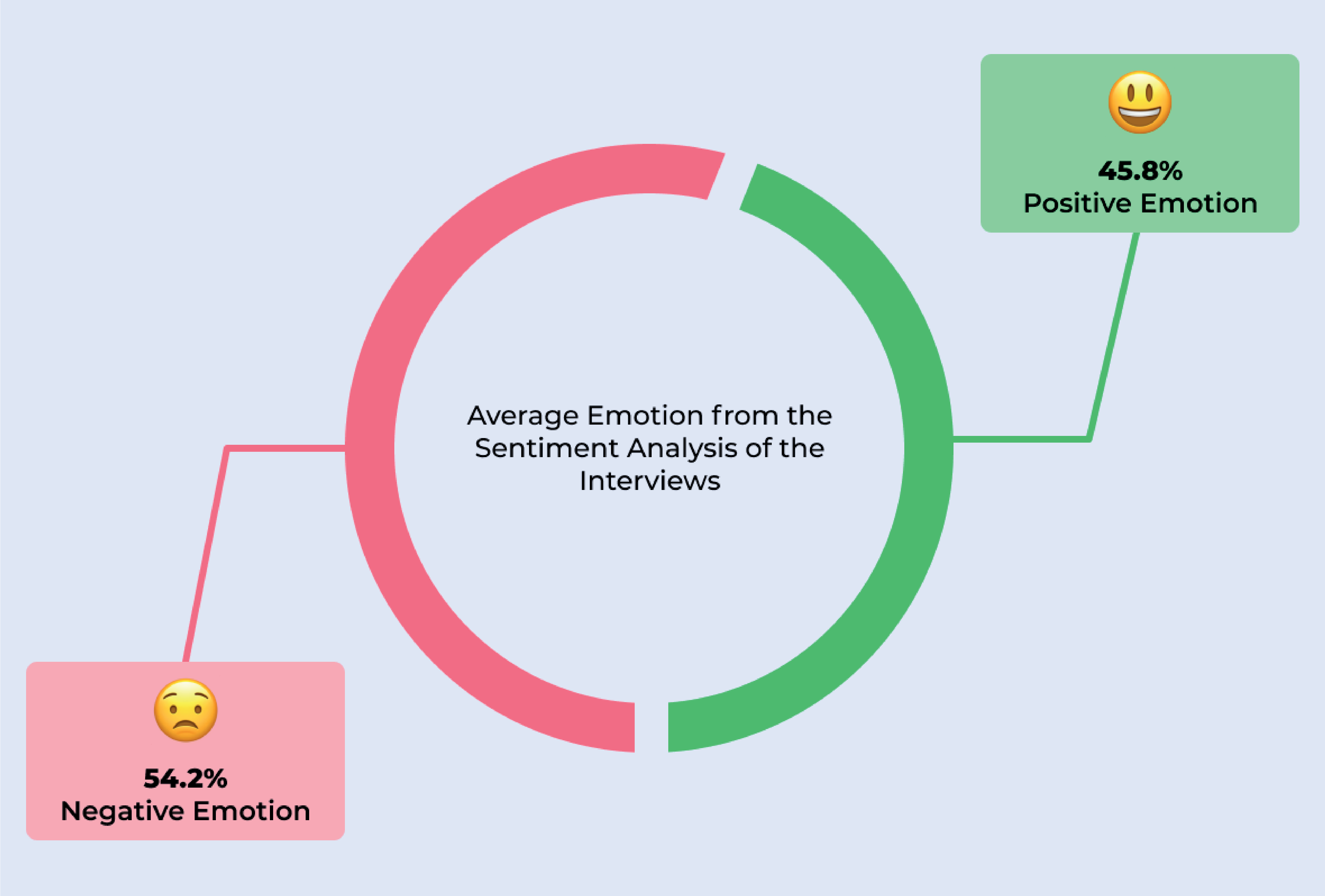


Image 13: Sentiment Analysis from the interview with the 6 patients

(5.4) Thematic Analysis

The interviews, although few, provided valuable insights and evidence for the intervention (Appendix 5.2, PP: 73 - 75). The data from the interviews were then coded and translated into the overarching themes of the problem area (Appendix 5.3, P: 76).

Initially, all the interviews with the doctors and patients and the hospital observations were critically analysed for any potential data to understand the interviewer's tone and intentions. The analysis data were then grouped into similar and overarching themes that defined the problems from various perspectives. The five overarching themes are:

Lack of Information

Patients often received limited or overly technical information about their condition from doctors, which made it difficult for them to understand their disorder. In order to provide clarity, doctors sometimes explained medical concepts in layperson's terms, but this could still be confusing for patients. As a result, some patients hesitated to undergo necessary treatment due to a lack of understanding. In addition, patients did not have access to pictorial brochures or online resources to help them learn more about their condition. This lack of information prevented patients from becoming educated about olfactory disorders and hindered their ability to seek treatment. It was clear that there was a need for healthcare settings to provide more accessible, understandable, and approved informational materials to patients.

Lack of Strong Policies

In India, the policies that catered to the rights of people with hidden disabilities were very fragile. Unfortunately, hidden disabilities were not recognised as disabilities. OD, being a hidden disability, did not receive enough attention from the government. Unlike other disabilities, less support was available to raise awareness about it. We needed to address this issue to ensure that OD patients received the support they needed. Hospitals should have focused on OD as a disorder, and government policies should have helped in increasing the involvement of OD patients.

Lack of care and support

After being diagnosed with OD, the patient faced significant gaps in care and information on how to adapt to life with their condition. The lack of guidance and support left the patient feeling frustrated and anxious. They received very little assistance in coping with lifestyle changes, had limited access to relevant local resources, and struggled to find credible and tailored information. The absence of support groups and informational brochures compounded their difficulties. The patient preferred access to local and multilingual tools, pictorial brochures, and internet-based resources. They expressed interest in participating in focus groups and research efforts to find the necessary support for dealing with everyday activities affected by OD, such as identifying gas leaks or spoiled food.

It was not very common for people to consider acceptance and smell therapy as a potential cure for OD. Patients had to first acknowledge the disorder, which could only be done by seeking the help of a therapist. However, in India, this was hindered by societal taboos. Therefore, this crucial aspect had to be incorporated into the intervention to address the issue effectively.

Lack of awareness

Patients with OD encountered varied experiences within the healthcare system. Many initially approached their family doctors, who often failed to recognize the condition or considered it a temporary consequence of other health issues such as COVID-19 or smoking. Patients faced challenges when physicians overlooked the severity of the olfactory disorder, assuming it was a common issue or a side effect that would resolve naturally. Additionally, some expressed frustration when doctors provided limited information or classified their condition as rare, resulting in delayed diagnosis and management of their olfactory disorder. The fear of disclosure and concern about societal perceptions were evident, leading to delays in seeking help and support.

Language Barrier

One of the significant challenges faced by the healthcare system was the language barrier, especially when it came to diagnosing and treating OD. It became difficult to communicate important information about OD and treatment options when patients and healthcare providers did not share a common language. This led to confusion and frustration, resulting in poor patient health outcomes. Additionally, healthcare information needed to be available in multiple languages due to the diverse linguistic landscape of the country. This made it challenging to ensure that critical details were preserved in translation. Therefore, it was essential to establish a comprehensive system that prioritised language as a primary consideration in addressing this issue.

Creating a more inclusive, informed, and supportive healthcare ecosystem was crucial to addressing individuals' challenges with OD. A multifaceted approach was necessary for bridging the gaps identified in this thematic analysis, which ranged from enhancing informational resources to strengthening policies. Moreover, a humanized healthcare ecosystem was essential, where patients received support and care from all the systems to make their transition to a changed lifestyle better.

(5.5) System Analysis

After mapping out the current system, along with the thematic analysis and sentiment analysis, a data triangulation was conducted to plot the desired flow of support and service among the stakeholders in the system, as seen in (Image 14).

Everyone involved in the healthcare system in India must work together to support those with OD. Patients, healthcare providers, government entities, and support groups should all collaborate and share information to ensure that those with OD receive the best possible care. Policies that recognise hidden disabilities, including OD, can make a big difference in the effectiveness of the healthcare system. It is essential to keep patients at the centre of everything and to provide them with emotional support and resources to help them navigate their condition. The system map can serve as a helpful guide to ensure that everyone takes a holistic and patient-focused approach to OD.

The required interventions in the healthcare system were identified by overlaying the current system flow with the desired flow, as shown in (Image 15).

Images in the next page

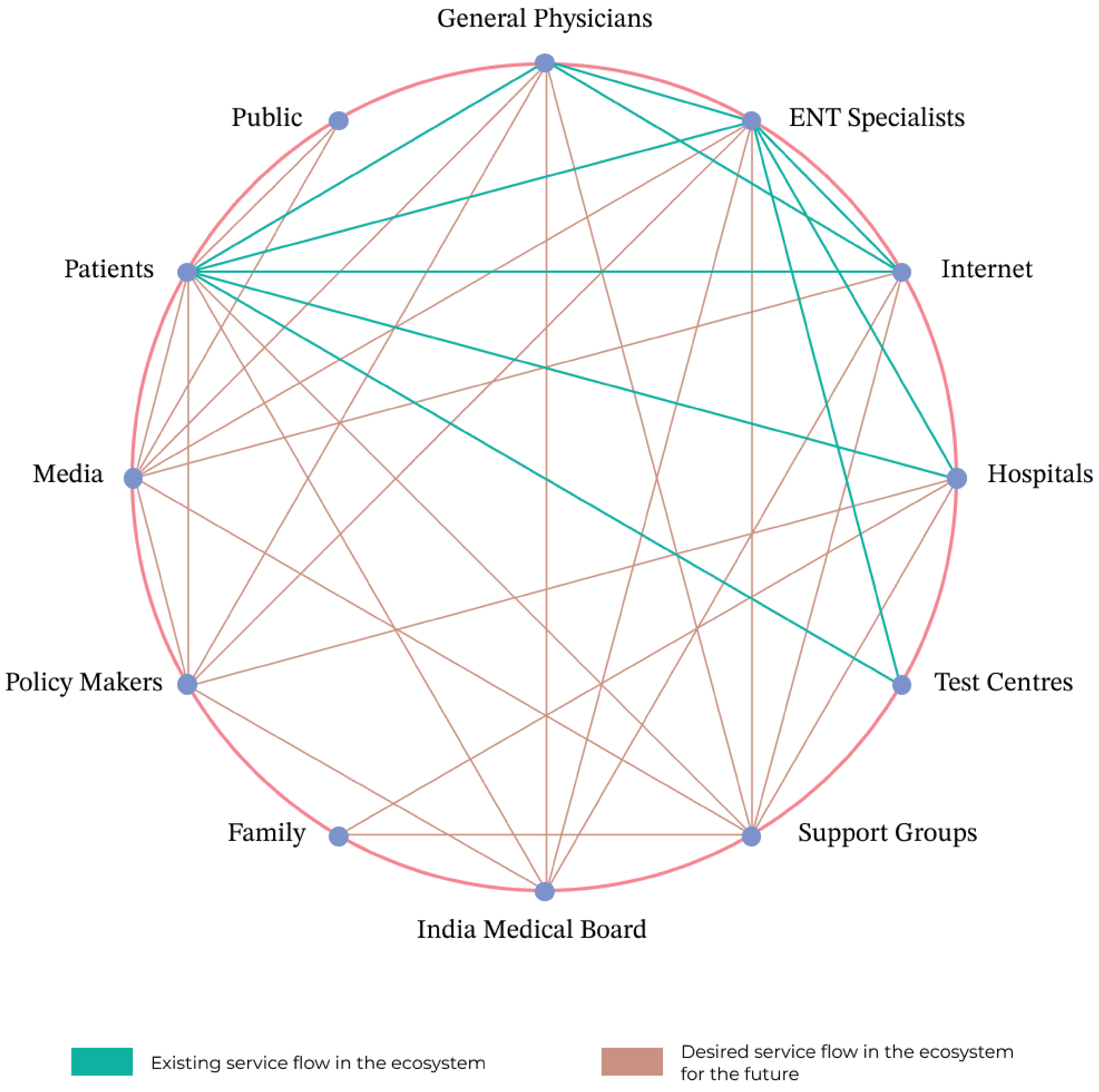


Image 14: Desired System Flow

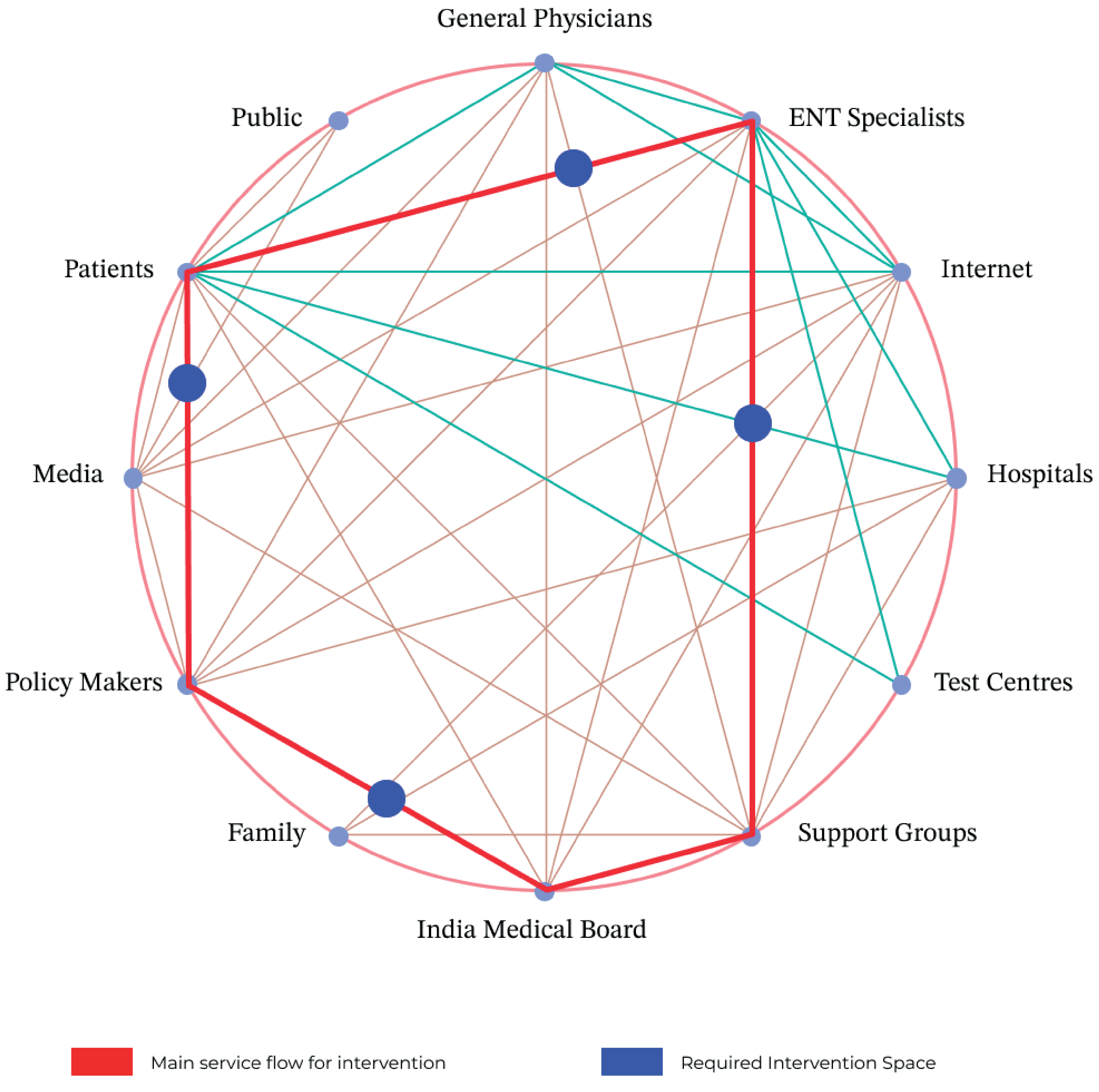


Image 15: The areas of Design Intervention

Redefined Problem Statement

Acquired olfactory disorders poses a significant challenge in India, where access to adequate healthcare facilities still needs to be improved. Lack of awareness and knowledge can hinder the ability of individuals with OD to adjust to lifestyle changes and ultimately affect their well-being. Design intervention is necessary to provide patients with the education, guidance, and resources required to improve their quality of life and confidently navigate their daily routines.

06. SOLUTION SPACE

(6.1) Data Triangulation between Secondary Research Data, Case Study and Primary Research Data

The data triangulation analysis between the secondary research, case studies and primary research helped in identifying the areas of improvement in the space of healthcare. As seen the image 16, the areas of improvement would focus on a systemic change where the legal entities in the country needs to be on boarded regarding the lack of inclusivity towards hidden disability in the disability framework. It is high time for a country like India to consider redesigning it's framework to be more people-centric rather than process centric approach.

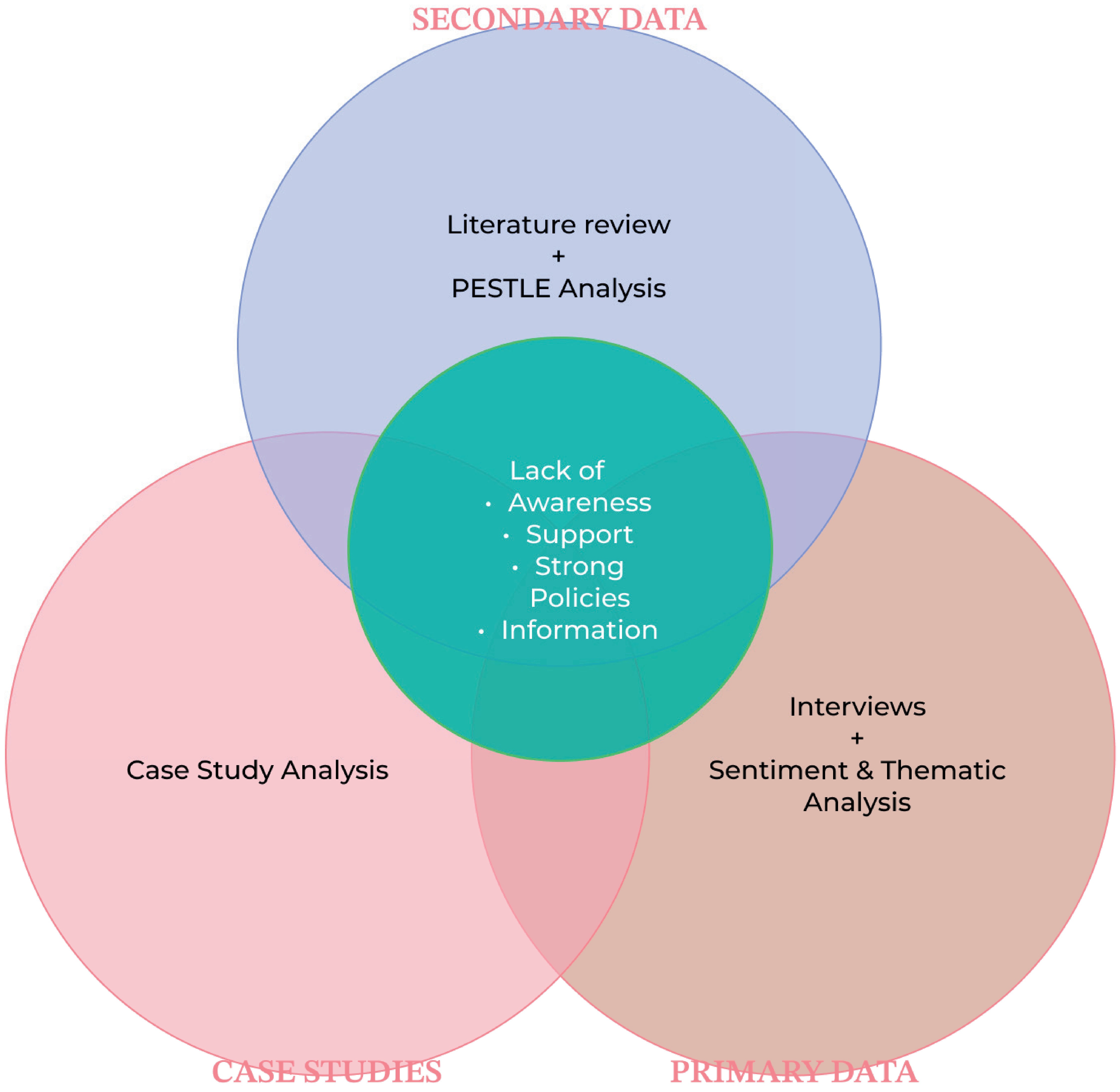


Image 16: Problem space identified through data triangulation

(6.2) Interview with the psychologist

To provide better support and care for patients suffering from OD and to overcome the stigmatization of disability, it was essential to involve the government and change people's attitudes towards disability. This was achieved by creating an intervention that raised awareness about the disorder among the general public and encouraged them to rethink the way they viewed disability. Changing the perception of disability in a society where culture and religion were tightly woven into everyday life required a behaviour change model. However, achieving this goal was a long-term process as it involved getting governmental bodies and other organisations to change their strategies and laws of the country.

The focus was finding an intervention to help patients accept, process and learn how to handle a changed lifestyle. During an interaction with Dr. Naveen, it was discovered that smell therapy is a possible intervention that could achieve this goal. *Smell therapy* is a process used in olfactory training where therapists help patients retrain their brains to enable other senses to activate when a scent is inhaled, simulating a similar effect of smell in a human (Nguyen & Patel, 2018). Following further discussions with an Occupational therapist, Dr Ramya Karthik, the use of Neuroplasticity as a behaviour change model in therapy was highlighted. Neuroplasticity is the change in the behaviour of the nervous system in response to intrinsic or extrinsic stimuli by reorganising its structure, functions, or connections (Puderbaugh & Emmady, 2022). She also highlighted that the first step of therapy is for the patient to accept their disorder. Acceptance and Commitment Therapy (ACT) encourages patients to embrace their thoughts and feelings rather than fighting or feeling guilty for them. ACT is a form of behavioural therapy that combines mindfulness skills with the practice of self-acceptance, developing psychological flexibility (Ackerman, 2017). During the therapy session, therapists use Neuroplasticity to help patients reorganise how they perceive emotions that were once triggered by the sense of smell, linking back to our initial observation of smell and its effect on humans. However, Dr Ramya highlighted that many people in India are not very open about the concept of therapy due to the stigma surrounding mental health. Therefore, an intervention that addresses all these issues would be the ideal solution.

Meet SVASA!

svasa

What is SVASA?

Svasa is a toolkit designed to aid healthcare facilities in providing care and support to patients diagnosed with olfactory disorders, both during and after diagnosis. It also aims to empower society at large by creating a fostering environment for people who have been diagnosed with OD, helping them navigate their everyday lives by educating society about the disorder and fostering care and empathy in the community.

The toolkit currently aims to assist hospitals and medical practitioners in providing patients with tools like therapy cards, which can help them cope with their journey. The four-week program of cards is intended to assist individuals with OD in a comprehensive process of acclimatisation, identification, emotional connection, and long-term resilience based on the principles of Neuroplasticity. The cards aim to equip participants with the tools to redefine their narrative, gain empowerment, and embrace the diversity of living with an OD.

Why the name SVASA?

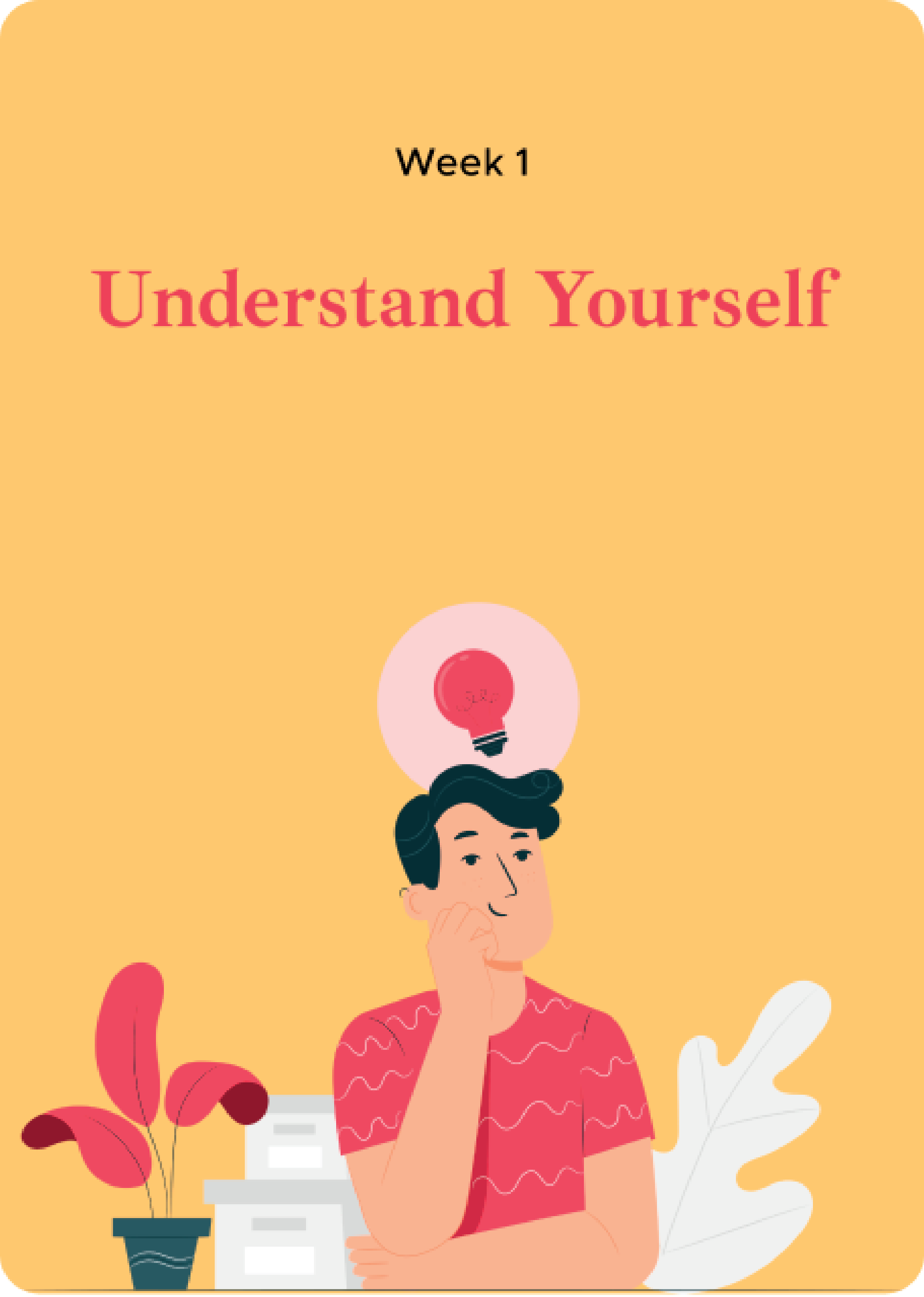
Svasa is derived from the Sanskrit root word ‘Svas’, meaning ‘to breathe’ (Wisdom Library, 2015). Sanskrit was originally known as the language of the Gods in Hindu scripture (Kakwani, 2023) and seemed like the perfect choice for the name. The name was chosen because breathing is the key to life, and it is also key to overcoming difficult situations. When faced with adversity, taking a moment for ourselves and taking a deep breath is essential. This helps to calm the nervous system and clear the mind, allowing us to think better. The name Svasa reminds us to take time for ourselves and focus on breathing, even during stressful times.

What does the toolkit consist of?

The toolkit comprises ‘Therapy Cards’ (Appendix 6.1, P: 77), which are the first step in breaking the stigma around mental health, as research shows that therapy is often seen as taboo. ENT specialists can give therapy cards before suggesting smell therapy to remove apprehensions and give them confidence in therapy.

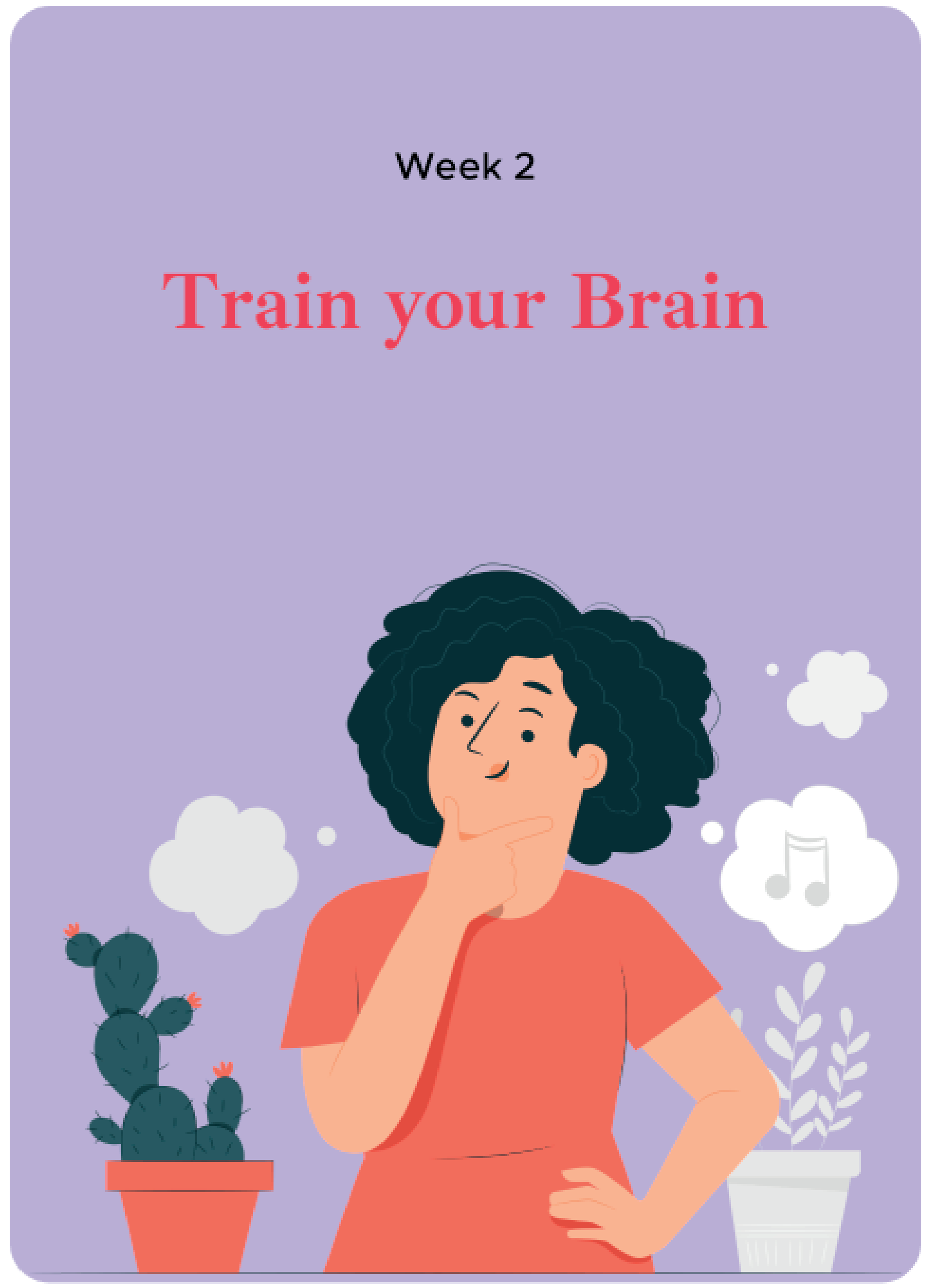
The set of 27 cards is organised into four weeks, with seven information cards and 20 action cards. The action cards have two sides, ‘learn’ and ‘reflect’. The ‘Learn’ side helps patients understand and practice neuroplasticity activities to cope with life. In contrast, the ‘Reflect’ side helps them process their emotions safely without hurting themselves or others.

4 Weeks Therapy Cards



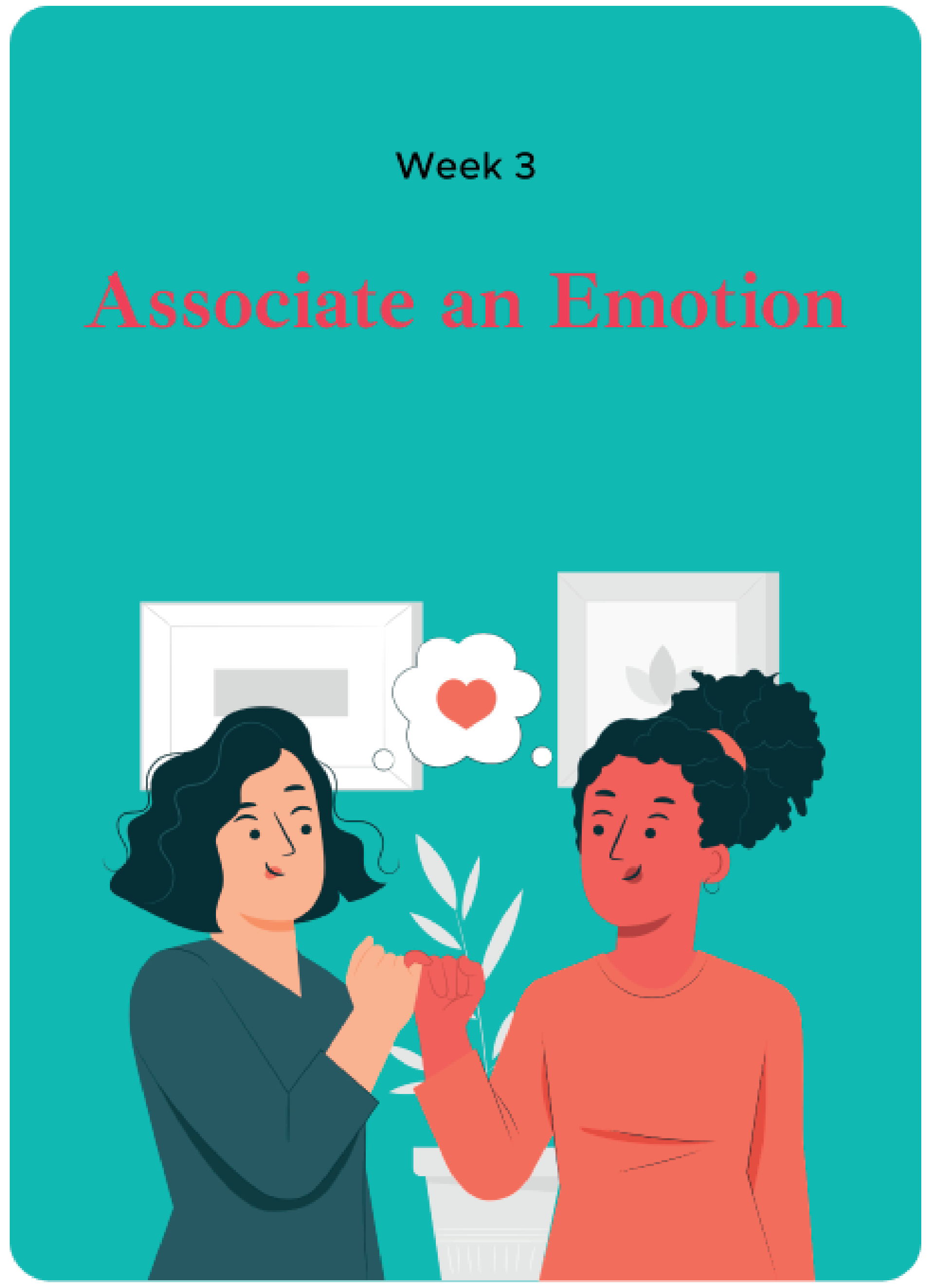
Understanding Yourself

empowers you to understand the disorder and navigate the challenges more effectively, facilitating a holistic approach to your well-being.



Train Your Brain

Repetitive smelling fosters neuroplasticity, encouraging the brain to adapt and potentially recover from the condition.



Associate an Emotion

Associating emotions with smells helps you create a deeper, more personal connection, aiding in emotional processing and memory recall.

Keep Going

Persist in your smell training journey, embracing progress and staying committed to reclaiming your olfactory experiences.

Image 17: SVASA, Therapy Cards

(6.3) SVASA: Navigating the World of Olfaction

Week 1 - Understand Yourself

During the first week of the journey, the cards are designed to provide a supportive and gradual introduction to olfactory disorder. The objective is to help individuals ease into the process by starting slowly and creating a compassionate environment essential for them to embark on their journey with a positive mindset. The cards are tailored to progressively guide participants through activities that align with the overarching themes of explaining the disorder, acclimatising the environment, normalising the experience, and fostering acceptance. The ultimate goal is to create a reassuring and accepting environment that encourages participants to embrace their journey confidently.

Week 3 - Associate an Emotion

This week’s focus is on the powerful connection between smell and emotion. The designed cards for this week will guide participants in associating an emotion with a particular scent, thereby rediscovering the emotional connection with their past experiences. The aim is to explore how different smells impact emotions and to create a personalised emotional smell palette. Participants will be encouraged to look beyond the physical aspect of smelling and instead focus on the emotional essence of scents. By examining and exploring the emotional aspects of smells, participants can start a journey of self-discovery and emotional enrichment. The cards have been thoughtfully created to facilitate this exploration, urging participants to embrace the emotional dimensions of their olfactory world.

Week 2 - Train Your Brain

This week’s primary focus is to deepen the understanding of olfactory perception. The cards designed for this week are intended to help identify the potential smells and create a smell inventory to discover the limits and embrace personal growth. The overarching theme emphasises exploring through olfactory experiences, encouraging us to become more attuned to the sense of smell, recognise the boundaries and embark on a journey of self-discovery. The cards are thoughtfully curated to facilitate this exploration, creating a transformative and empowering experience for anyone participating in the training.

Week 4 - Keep Going

As we approach the end, the focus in this concluding week shifts towards fostering long-term olfactory resilience and self-discovery. The objective is to guide participants in building olfactory habits that will last. The cards for this week provide affirmations and positive reinforcements to help them defy olfactory stereotypes and cultivate mindful reflections and re-discovery. The central theme of this week revolves around instilling habits for ongoing olfactory engagement, reinforcing a positive self-perception, and embracing the unique journey of developing olfactory resilience. The cards provide tools for participants to build resilience, redefine their narrative, and celebrate the richness of navigating life with an olfactory disorder.

(6.4) Feedback Intervention

As previously mentioned, this project focused on involving the stakeholders throughout the process to gain a deeper understanding of the experience with the intervention. In order to test the Svasa Cards with users in India, a connection was established with the Fifth Sense organisation, which has Indian participants enrolled. After sharing the complete study report with the organisation, they agreed to contact the participants enrolled with them along with the consent form (Appendix 3.3, P: 62) and sign-up links (Appendix 3.4, P: 62) to help them sign up for the workshop.

A virtual workshop (Appendix 6.2, P: 78) was planned to test the prototype of the cards using the Figma Link (Appendix 6.1, P:77) sent to them before the workshop. The testers were to use the simulated prototype to mimic the cards during the virtual workshop. However, the feedback session could not be conducted due to the lack of sign-ups for the workshop and time constraints. Nonetheless, the link was shared with Dr Naveen for his feedback. He provided valuable feedback regarding the intervention and product. According to his feedback, any new trial or intervention must be approved by the Central Drugs Standard Control Organisation in accordance with their laws from 2019 (Central Drugs Standard Control Organization, 2019) before being used in practice as a course of treatment. Therefore, to add the cards as an intervention in treatment, we must first onboard all the specialists and therapists onto the product and then raise a proposal.

Dr Naveen was also excited about the opportunity to use the cards in his practice and onboard his patients to gain further feedback from real-time users.

(6.5) Impact of the Intervention

Svasa is a solution that aims to tackle a larger problem beyond just a lack of intervention. The bigger issue involves a need for behaviour change in society's attitude towards disability, which would then force the legislature to become more inclusive in their laws related to disability. Although it is a complex problem, the therapy cards are a positive step in the right direction.

The therapy cards are intended to assist individuals with OD in a comprehensive process of acclimatisation, identification, emotional connection, and long-term resilience based on the principles of Neuroplasticity. The aim is to provide participants with the tools to redefine their narrative and gain empowerment, allowing them to embrace the diversity of living with an OD. It would enhance the experience of an individual suffering from OD and make their life easier. The cards would also help break the stigma towards disability and encourage individuals to reflect on their attitude towards therapy.

Therefore, the solution's impact is to achieve a significant societal mindset change, one individual at a time.

07. CONCLUSION

This project on OD has been a journey of exploration, empathy, and design innovation. Reflecting on this process, it is evident that the initial ambiguity surrounding the complex challenges faced by individuals with OD in India has evolved into a structured and purposeful intervention – 'SVASA'. The journey also highlighted the broader societal issues related to hidden disabilities and the urgent need for a cultural shift. Breaking social stigmas and fostering inclusivity became integral to the project's ethos. 'Svasa', therefore, is not merely a toolkit but a catalyst for change, advocating for policy adjustments and societal acceptance.

(7.1) Scalability of Svasa

The future of the SVASA project holds immense promise. The project can be expanded to multilingual resources, making it more inclusive and covering more bases. This will make it easier for people to get emotional support and reflect in a comfortable language. The emphasis on habit-building and emotional connection aims to cultivate long-term changes in how individuals with OD perceive and navigate their world.

Incorporating digital tools, including online consultations, allows scalability and adaptation to evolving healthcare landscapes. From interviews with Tanya, Deeksha and Rishabh, it was observed that the country is also moving towards the digital era of mobile tech, where the medical field is slowly expanding its limits with accessibility. This is a potential direction for scalability.

Expanding the intervention to include information zines and bi-monthly resources is a promising step towards increasing awareness about OD. This initiative can serve hospitals, clinics, and subscribers and can be achieved by distributing pictorial brochures designed for easy understanding and with multilingual capabilities. Furthermore, there is a possibility to create support groups and organise workshops, events, and activities that engage individuals diagnosed with OD. This step is vital in establishing a sense of community and ecosystem and provides a platform for shared experiences and mutual support.

In summary, the scalability ideas for SVASA go beyond the initial toolkit. SVASA envisions a holistic approach to addressing OD.

(7.2) The future of OD Management in India

This project goes beyond simply being a design solution for SVASA; it is also an advocacy initiative, a call for recognition, and a step towards empowering individuals with Hidden Disabilities. It represents a movement to start a chain reaction to change societal attitudes towards hidden disabilities. This effort highlights the transformative potential of design thinking, not only in solving practical issues but also in driving social change.

As I conclude this project, I am filled with a sense of responsibility and optimism, hopeful that SVASA will contribute to a more compassionate and inclusive healthcare landscape for those with olfactory disorders in India.

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10. APPENDICES

Appendix 1

People's take on accessibility in to Society

1. Prateek Gujjar, Age 27, Lawyer

"A fellow lawyer's take on the inter-twining of Religion in the accessibility of "Religions which believe in idol worship pose unique challenges to visually impaired persons. On the one hand, religions ask believers to "feel" Gods and divine beings in themselves, but on the other hand requires believers to visit places of worship like temples to "see" their Gods and the associated rituals. I wonder if this leaves visually impaired believers with partial spiritual fulfilment"."

Appendix 2 - PESTLE Analysis

Political

- The laws regarding the rights of individuals with disabilities need to be more inclusive. Additionally, healthcare policies must improve their effectiveness in diagnosing and treating sensory disorders and allocating resources.

- The Pradhan Mantri Jan Arogya Yojana (PM-JAY), previously known as the National Health Protection Scheme (NHPS), provides life insurance coverage of up to Rs. 500,000 per year for secondary and tertiary care hospitalisation to 120 million families belonging to the bottom 40% of the country's population (Below Poverty Level). However, it is essential to note that these insurance plans do not cover mental health and hidden disabilities like ADHD, OD, Dyspraxia, and others. As a result, many people do not seek treatment for these disorders as the cost of treatment is often high.

- Despite allocating funds for the extension of life insurance for individuals and improving primary healthcare centres, corruption within the government and political parties has created a lack of transparency regarding whether these funds are reaching the intended families and healthcare facilities (Singh, 2023). As a result, there is insufficient financing to improve the infrastructure of hospitals, regardless of healthcare policies.

Economical

- In tier three cities, rural areas are mainly equipped with basic healthcare infrastructure and do not have specialised resources to cater to invisible disabilities. Unfortunately, the lack of strong policies focused on invisible disabilities by the Department of Empowerment of Persons with Disability (2016) has led to a limited budget allocation to Primary Health Centers (PHCs), which hinders their ability to provide proper care and interventions for invisible disorders.

- The economic standards of a country are typically classified into two main categories: Above Poverty Level (APL) and Below Poverty Level (BPL). The PM-JAY scheme provides health insurance for BPL individuals but does not cover mental and invisible disorders.

- The doctors working in government hospitals face the serious issue of being underpaid and overworked due to the insufficient budget allocation for caregivers and government hospitals. They handle various critical cases in these hospitals, which makes their job even more challenging. Despite their hard work and efforts, they are not paid enough, which is a significant concern.

Social

- Religion and culture have a significant impact on how illness and disorders are perceived in a country like India. Unfortunately, disability is still not widely accepted as a condition that requires support and assistance. Instead, many people in India view it as a punishment for past sins.

- There is still a social stigma surrounding disability in the country, according to Griffin (2021). As a result, many people may feel hesitant to share their disability with healthcare providers, making it difficult for medical facilities to identify patients with OD. This lack of disclosure leads to a lack of awareness about the disorder. Furthermore, some medical professionals claim patients do not follow up with additional tests and treatment after their preliminary consultation.

- Due to the vast population in the country and the limited number of medical professionals specialising in ENT (Sharma, 2021), there is a meagre doctor-to-patient ratio in the country. Doctors work between 63 and 100 hours a week, which is not advisable from a human perspective, and they are always overworked (Radhakrishnan, 2015).

- Many organisations, such as Anupryaas and Fifthsense, have extended their online support to Indian communities, providing access to support groups for comfort and knowledge about the disorder.

Technology

- Internet usage in India has expanded rapidly, increasing connectivity by 48% in urban and rural areas (Basuroy, 2022).

- Mobile health is an emerging concept in India that facilitates online medical consultations, appointment scheduling, medication reminders, and health tracking, among other services. Introducing apps like Practo and others has significantly contributed to this trend (Ganjoo, 2023). New technologies like IoT and AI can help patients learn about and diagnose their disorders more effectively.

- The emergence of wearable technology, such as smartwatches and fitness trackers, can aid individuals in recognising areas with potent and unpleasant odours, which can be avoided in the future. With Apple's recent effort to incorporate odour sensors in their smartwatches (Purcher, 2019), this technology is moving closer to becoming a reality.

Legal

The legislative framework in India does not have policies in place to cater to healthcare facilities that oversee disorders falling under the invisible disability spectrum, as per the Rights of Persons with Disabilities (Department of Empowerment of Persons with Disability, 2016). This emphasises the urgent need for an inclusive policy change in the legal framework, which mandates healthcare facilities to provide care, education, and any other necessary support required by individuals with such disorders.

Environmental

In India, there is a shortage of ENT specialists (Sharma, 2021), resulting in doctors being overworked and unable to provide personalised treatment to each patient. Kasthuri (2018) identifies the two main reasons for poor healthcare services in India as the lack of human resources in healthcare and accountability. Therefore, increasing the number of medical professionals, especially specialists in this field, is essential.

Despite the legislature's changes and renewal of disability laws, India still needs more inclusivity, especially in healthcare policies. The PM-JAY scheme was introduced to offer health coverage and essential medical benefits to the economically weaker sections of society and to improve healthcare standards. However, the scheme does not recognise mental and other hidden disabilities (National Health Authority, 2018). Less than 2% of funds are allocated to the healthcare industry (Kasthuri, 2018), and corruption in political parties ensures that the entire amount does not reach the respective centres, hampering transparency and impeding hospital infrastructure improvement (Singh, 2023). Doctors in government hospitals are grappling with inadequate budgets and are underpaid and overworked, making it challenging to handle critical cases. This situation poses a significant concern for healthcare professionals (Sharma, 2021). Kasthuri (2018) attributes India's healthcare challenges to a scarcity of human resources and accountability. Limited coverage for hidden disabilities deters people from seeking treatment due to high costs. To worsen this, the social stigma surrounding disabilities still exists, contributing to patients hesitating to disclose their conditions to healthcare providers, impeding the identification of disorders like OD. Luckily, the rapid expansion of internet usage in urban and rural areas signifies enhanced connectivity (Basuroy, 2022). The rise of mobile health, exemplified by apps like Practo, enables online medical consultations, appointment scheduling, and health tracking, helping many patients be more vocal about their disorders. Many organisations like Anupryaas and Fifthsense provide crucial online support, fostering comfort and knowledge about disorders in Indian communities.

Appendix 3

(3.1) Poster provided to the Doctor's Clinic

CAN'T SMELL?

Did you lose your smell during COVID or before? Did you gain it back?

Share your experience of the diagnosis process with me and provide feedback on my output to help me define a design intervention of the healthcare in India.

Hello 👋

My name is Deeptha Ramesh. An MA Design Management Student at UAL, London. As a part of my final major project for my Master's course, I am working on designing an intervention for primary healthcare facilities in India to help and provide care for patients with Olfactory Disorder (Reduced or inability to smell)

Scan this QR Code and sign up for to be a part of the Feedback workshop

ವಾಸನೆ ಬರುತ್ತಿಲ್ಲವೇ?

ನೀವು COVID ಸಮಯದಲ್ಲಿ ಅಥವಾ ಅದರ ಮೊದಲೇ ನಿಮ್ಮ ವಾಸನೆಯನ್ನು ಕಳೆದುಕೊಂಡಿದ್ದೀರಾ?

ನಿಮ್ಮ ಅನುಭವವನ್ನು ನನ್ನೊಂದಿಗೆ ಹಂಚಿಕೊಂಡು, ಭಾರತದಲ್ಲಿ ಆರೋಗ್ಯ ಕೇಂದ್ರಗಳನ್ನು ಅಭಿವೃದ್ಧಿಪಡಿಸಲು ನನಗೆ ಸಹಾಯ ಮಾಡಿ.

ಹಲೋ 👋

ನನ್ನ ಹೆಸರು ದೀಪ್ತಾ ರಮೇಶ್. ಲಂಡನ್‌ನ UAL ನಲ್ಲಿ MA ಡಿಸೈನ್ ಮ್ಯಾನೇಜ್‌ಮೆಂಟ್ ವಿದ್ಯಾರ್ಥಿ. ನನ್ನ ಅಂತಿಮ ಪ್ರಾಜೆಕ್ಟಿನ ಭಾಗವಾಗಿ, ಕಡಿಮೆ ಅಥವಾ ವಾಸನೆಯ ಅಸಮರ್ಥತೆ ರೋಗಿಗಳಿಗೆ ಸಹಾಯ ಮಾಡಲು ಮತ್ತು ಆರೈಕೆಯನ್ನು ಒದಗಿಸಲು ಭಾರತದಲ್ಲಿ ಪ್ರಾಥಮಿಕ ಆರೋಗ್ಯ ಸೌಲಭ್ಯಗಳಿಗಾಗಿ ಮಧ್ಯಸ್ಥಿಕೆಯನ್ನು ವಿನ್ಯಾಸಗೊಳಿಸಲು ನಾನು ಕೆಲಸ ಮಾಡುತ್ತಿದ್ದೇನೆ.

ಈ QR ಕೋಡ್ ಅನ್ನು ಸ್ಕ್ಯಾನ್ ಮಾಡಿ ಮತ್ತು ನಿಮ್ಮ ಅನುಭವವನ್ನು ಹಂಚಿಕೊಳ್ಳಿ.

வாசனை வரவில்லையா?

COVID சமயத்தில் அல்லது அதற்கு முன் உங்கள் வாசனையை இழந்தீர்களா?

உங்கள் அனுபவத்தை என்னுடன் பகிர்ந்துகொண்டு, இந்தியாவில் சுகாதார வசதிகளுக்கான வடிவமைப்பு தலையீட்டை உருவாக்க எனக்கு உதவுங்கள்.

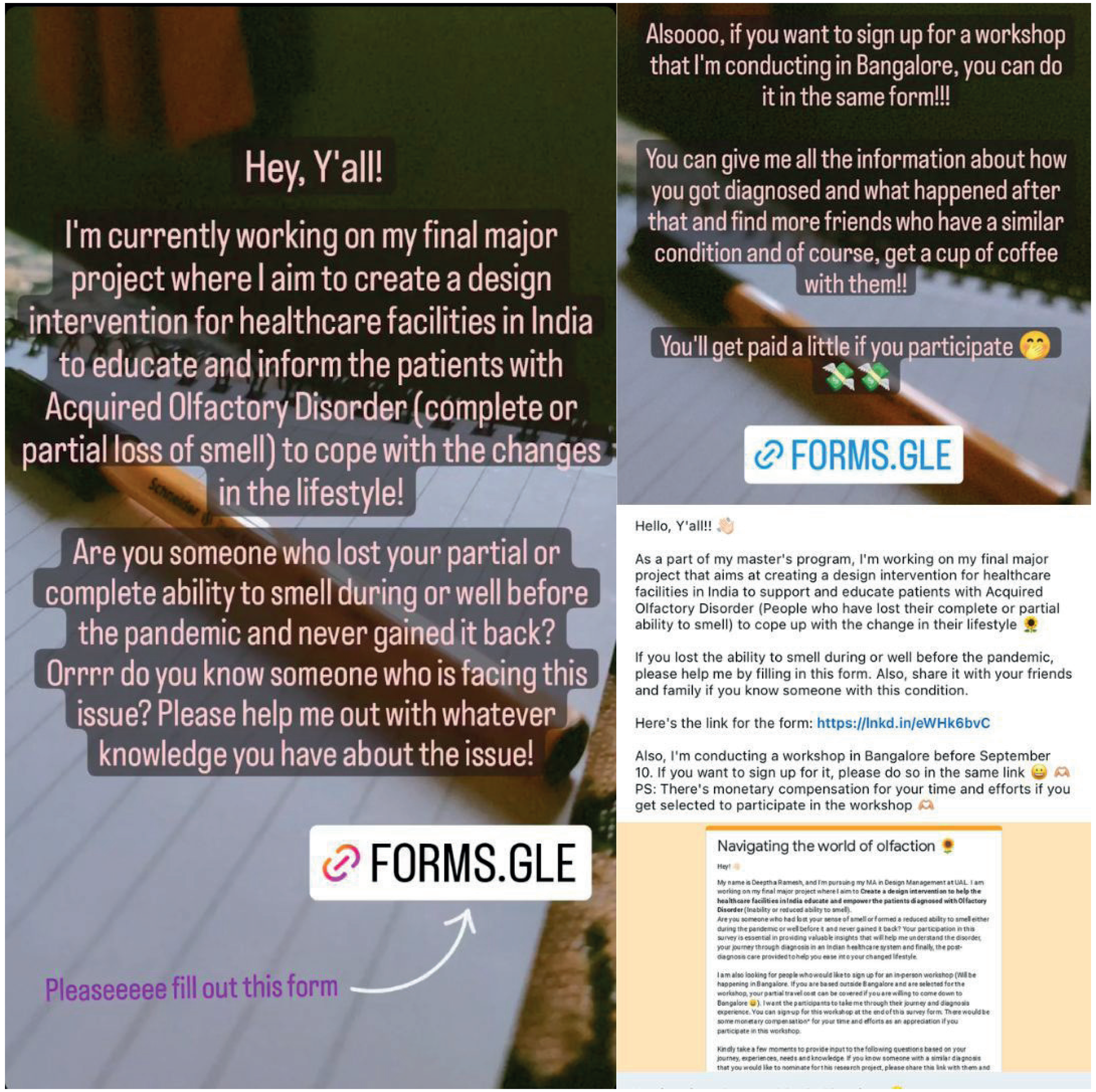
ஹலோ 👋

என் பெயர் தீப்தா ரமேஷ். லண்டனில் உள்ள UAL இல் MA டிஸைன் மேனேஜ்மென்ட் மாணவி. எனது இறுதி ப்ராஜெக்ட்டின் ஒரு பகுதியாக, வாசனை கோளாறு உள்ள நோயாளிகளுக்கு ஆதரவாக இந்தியாவில் உள்ள ஆரம்ப சுகாதார நிலையங்களுக்கான தலையீட்டை வடிவமைப்பதில் நான் பணியாற்றி வருகிறேன்.

இந்த QR குறியீட்டை ஸ்கேன் செய்து, உங்கள் அனுபவத்தைப் பகிர்ந்துகொள்ள பதிவு செய்யவும்.

Image 18: Poster shared with the clinics in Bangalore and Chennai. The poster was made in multiple languages to cater to the majority of the audience in the cities.

(3.2) Screenshots of the Social Media Posts



Hey, Y'all!

I'm currently working on my final major project where I aim to create a design intervention for healthcare facilities in India to educate and inform the patients with Acquired Olfactory Disorder (complete or partial loss of smell) to cope with the changes in the lifestyle!

Are you someone who lost your partial or complete ability to smell during or well before the pandemic and never gained it back? Orrrr do you know someone who is facing this issue? Please help me out with whatever knowledge you have about the issue!

Pleaseeeee fill out this form

Alsoooo, if you want to sign up for a workshop that I'm conducting in Bangalore, you can do it in the same form!!!

You can give me all the information about how you got diagnosed and what happened after that and find more friends who have a similar condition and of course, get a cup of coffee with them!!

You'll get paid a little if you participate 🤭 💸💸

Hello, Y'all!! 👋

As a part of my master's program, I'm working on my final major project that aims at creating a design intervention for healthcare facilities in India to support and educate patients with Acquired Olfactory Disorder (People who have lost their complete or partial ability to smell) to cope up with the change in their lifestyle 🌻

If you lost the ability to smell during or well before the pandemic, please help me by filling in this form. Also, share it with your friends and family if you know someone with this condition.

Here's the link for the form: https://lnkd.in/eWHk6bvC

Also, I'm conducting a workshop in Bangalore before September 10. If you want to sign up for it, please do so in the same link 😀 🫶
PS: There's monetary compensation for your time and efforts if you get selected to participate in the workshop 🫶

Navigating the world of olfaction 🌻

Hey! 👋

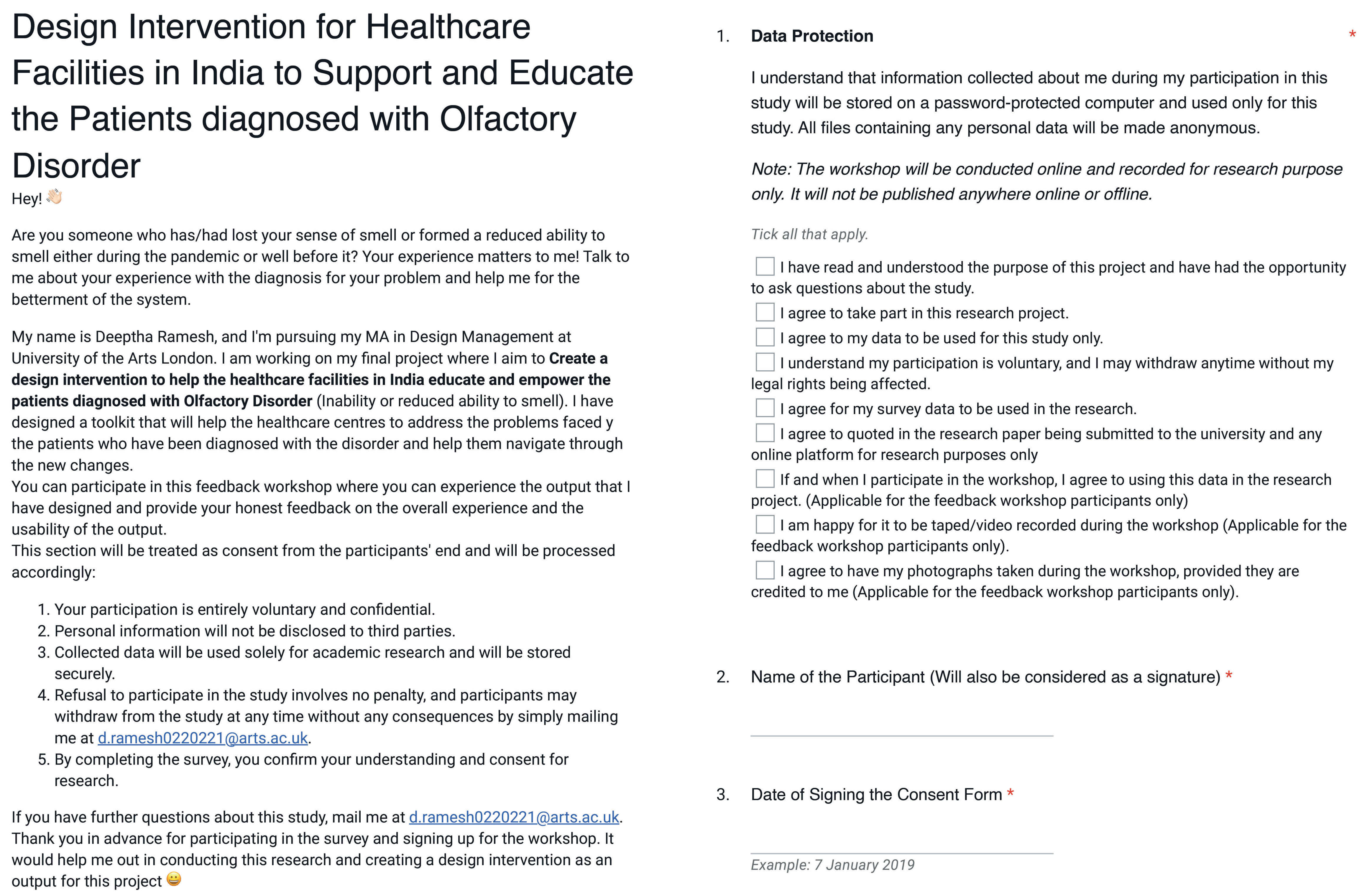
My name is Deeptha Ramesh, and I'm pursuing my MA in Design Management at UAL. I am working on my final major project where I aim to **Create a design intervention to help the healthcare facilities in India educate and empower the patients diagnosed with Olfactory Disorder** (Inability or reduced ability to smell).
Are you someone who had lost your sense of smell or formed a reduced ability to smell either during the pandemic or well before it and never gained it back? Your participation in this survey is essential in providing valuable insights that will help me understand the disorder, your journey through diagnosis in an Indian healthcare system and finally, the post-diagnosis care provided to help you ease into your changed lifestyle.

I am also looking for people who would like to sign up for an in-person workshop (Will be happening in Bangalore. If you are based outside Bangalore and are selected for the workshop, your partial travel cost can be covered if you are willing to come down to Bangalore 😀). I want the participants to take me through their journey and diagnosis experience. You can sign-up for this workshop at the end of this survey form. There would be some monetary compensation* for your time and efforts as an appreciation if you participate in this workshop.

Kindly take a few moments to provide input to the following questions based on your journey, experiences, needs and knowledge. If you know someone with a similar diagnosis that you would like to nominate for this research project, please share this link with them and

Image 19: Screenshots of the posts on the researcher's Social Media to contact the patients diagnosed with OD in the network.

(3.3) Consent Form



Design Intervention for Healthcare Facilities in India to Support and Educate the Patients diagnosed with Olfactory Disorder

Hey! 👋

Are you someone who has/had lost your sense of smell or formed a reduced ability to smell either during the pandemic or well before it? Your experience matters to me! Talk to me about your experience with the diagnosis for your problem and help me for the betterment of the system.

My name is Deeptha Ramesh, and I'm pursuing my MA in Design Management at University of the Arts London. I am working on my final project where I aim to **Create a design intervention to help the healthcare facilities in India educate and empower the patients diagnosed with Olfactory Disorder** (Inability or reduced ability to smell). I have designed a toolkit that will help the healthcare centres to address the problems faced y the patients who have been diagnosed with the disorder and help them navigate through the new changes.
You can participate in this feedback workshop where you can experience the output that I have designed and provide your honest feedback on the overall experience and the usability of the output.
This section will be treated as consent from the participants' end and will be processed accordingly:

1. Your participation is entirely voluntary and confidential.
2. Personal information will not be disclosed to third parties.
3. Collected data will be used solely for academic research and will be stored securely.
4. Refusal to participate in the study involves no penalty, and participants may withdraw from the study at any time without any consequences by simply mailing me at d.ramesh0220221@arts.ac.uk.
5. By completing the survey, you confirm your understanding and consent for research.

If you have further questions about this study, mail me at d.ramesh0220221@arts.ac.uk. Thank you in advance for participating in the survey and signing up for the workshop. It would help me out in conducting this research and creating a design intervention as an output for this project 😀

1. **Data Protection** *

I understand that information collected about me during my participation in this study will be stored on a password-protected computer and used only for this study. All files containing any personal data will be made anonymous.

Note: The workshop will be conducted online and recorded for research purpose only. It will not be published anywhere online or offline.

Tick all that apply.

☐ I have read and understood the purpose of this project and have had the opportunity to ask questions about the study.
☐ I agree to take part in this research project.
☐ I agree to my data to be used for this study only.
☐ I understand my participation is voluntary, and I may withdraw anytime without my legal rights being affected.
☐ I agree for my survey data to be used in the research.
☐ I agree to quoted in the research paper being submitted to the university and any online platform for research purposes only
☐ If and when I participate in the workshop, I agree to using this data in the research project. (Applicable for the feedback workshop participants only)
☐ I am happy for it to be taped/video recorded during the workshop (Applicable for the feedback workshop participants only).
☐ I agree to have my photographs taken during the workshop, provided they are credited to me (Applicable for the feedback workshop participants only).

2. Name of the Participant (Will also be considered as a signature) *

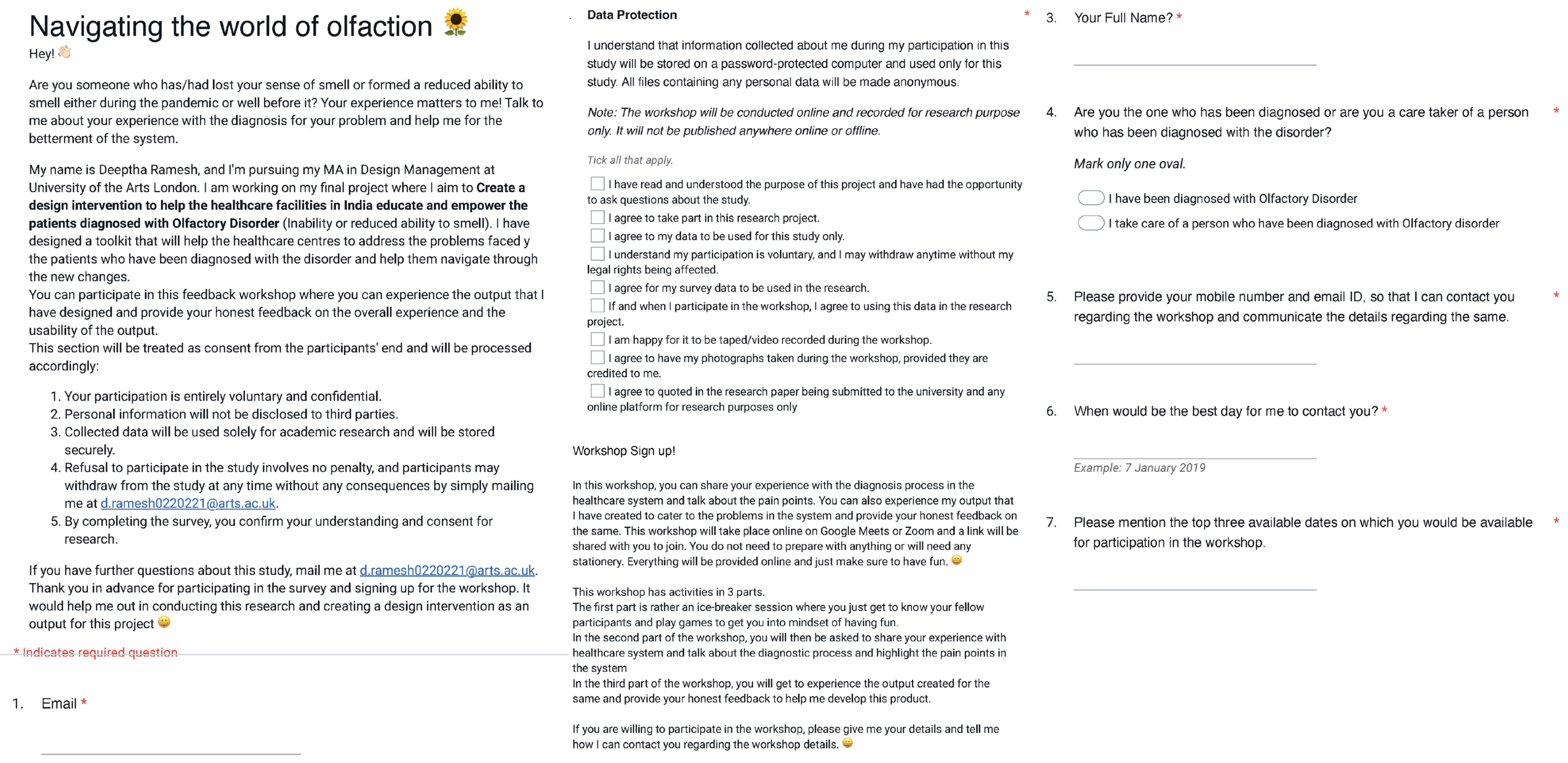
3. Date of Signing the Consent Form *

Example: 7 January 2019

Image 20: Consent Form provided to the Participants to participate in the research project and workshops

An online consent form created on Google Forms was shared with the participants as seen below in the Image. An online format was chosen to simplify the process of signing and making it quicker. Please click on the link to view the Consent form **https://forms.gle/ig229XyXTj9BRLc3A**

(3.4) Sign Up Form



Navigating the world of olfaction 🌻

Hey! 👋

Are you someone who has/had lost your sense of smell or formed a reduced ability to smell either during the pandemic or well before it? Your experience matters to me! Talk to me about your experience with the diagnosis for your problem and help me for the betterment of the system.

My name is Deeptha Ramesh, and I'm pursuing my MA in Design Management at University of the Arts London. I am working on my final project where I aim to **Create a design intervention to help the healthcare facilities in India educate and empower the patients diagnosed with Olfactory Disorder** (Inability or reduced ability to smell). I have designed a toolkit that will help the healthcare centres to address the problems faced y the patients who have been diagnosed with the disorder and help them navigate through the new changes.
You can participate in this feedback workshop where you can experience the output that I have designed and provide your honest feedback on the overall experience and the usability of the output.
This section will be treated as consent from the participants' end and will be processed accordingly:

1. Your participation is entirely voluntary and confidential.
2. Personal information will not be disclosed to third parties.
3. Collected data will be used solely for academic research and will be stored securely.
4. Refusal to participate in the study involves no penalty, and participants may withdraw from the study at any time without any consequences by simply mailing me at d.ramesh0220221@arts.ac.uk.
5. By completing the survey, you confirm your understanding and consent for research.

If you have further questions about this study, mail me at d.ramesh0220221@arts.ac.uk. Thank you in advance for participating in the survey and signing up for the workshop. It would help me out in conducting this research and creating a design intervention as an output for this project 😀

* Indicates required question

1. Email *

Data Protection *

I understand that information collected about me during my participation in this study will be stored on a password-protected computer and used only for this study. All files containing any personal data will be made anonymous.

Note: The workshop will be conducted online and recorded for research purpose only. It will not be published anywhere online or offline.

Tick all that apply.

☐ I have read and understood the purpose of this project and have had the opportunity to ask questions about the study.
☐ I agree to take part in this research project.
☐ I agree to my data to be used for this study only.
☐ I understand my participation is voluntary, and I may withdraw anytime without my legal rights being affected.
☐ I agree for my survey data to be used in the research.
☐ If and when I participate in the workshop, I agree to using this data in the research project.
☐ I am happy for it to be taped/video recorded during the workshop.
☐ I agree to have my photographs taken during the workshop, provided they are credited to me.
☐ I agree to quoted in the research paper being submitted to the university and any online platform for research purposes only

Workshop Sign up!

In this workshop, you can share your experience with the diagnosis process in the healthcare system and talk about the pain points. You can also experience my output that I have created to cater to the problems in the system and provide your honest feedback on the same. This workshop will take place online on Google Meets or Zoom and a link will be shared with you to join. You do not need to prepare with anything or will need any stationery. Everything will be provided online and just make sure to have fun. 😀

This workshop has activities in 3 parts.
The first part is rather an ice-breaker session where you just get to know your fellow participants and play games to get you into mindset of having fun.
In the second part of the workshop, you will then be asked to share your experience with healthcare system and talk about the diagnostic process and highlight the pain points in the system
In the third part of the workshop, you will get to experience the output created for the same and provide your honest feedback to help me develop this product.

If you are willing to participate in the workshop, please give me your details and tell me how I can contact you regarding the workshop details. 😀

3. Your Full Name? *

4. Are you the one who has been diagnosed or are you a care taker of a person who has been diagnosed with the disorder? *

Mark only one oval.

○ I have been diagnosed with Olfactory Disorder
○ I take care of a person who have been diagnosed with Olfactory disorder

5. Please provide your mobile number and email ID, so that I can contact you regarding the workshop and communicate the details regarding the same. *

6. When would be the best day for me to contact you? *

Example: 7 January 2019

7. Please mention the top three available dates on which you would be available for participation in the workshop. *

Image 21: Sign up sheet provided to the participants to participate in the Feedback Workshop

An online sign up form using Google forms were created to onboard the participants onto the research project and to enable the researcher to acquire the participant details to contact the participants who are willing for the feedback workshop for the prototype. This form was shared with the participants who were interested to participate in the interview alone as a part of the primary research as well. Please click on the link to view the Sign Up form **https://forms.gle/P8Zv669A3qKFhuwE6**

(3.5) Interview Questions for the Patients

1. When did you lose your sense of smell?

2. How long did it last? (If they gained their sense of smell back)

3. Did you get it diagnosed by a doctor when you lost your sense of smell?

4. If yes, what was the process that the doctors followed to diagnose you?

5. How long did it take for you to initially get the doctor's appointment?

6. Did the doctors brief you about the process before in hand?

7. What did you feel when you were going through the entire process of diagnosis?

8. Did it cost a lot to go through the diagnosis?

9. Did the doctors brief you how much it might cost?

10. When you got diagnosed with the disorder, what care did the doctors give to help you understand the disorder and it's side effects?

11. Were the doctors responsive to you?

12. Were you given any brochures to help you understand?

13. How did losing your sense of smell affect your life?

14. If there is a service that will help you ease into the lifestyle, what would you like to see in them?

(3.6) Interview Questions for the Doctors

1. What is an Olfactory disorder? What are the types of Olfactory disorder?

2. Who can acquire it? Is there an age limit for the disorder to be acquired?

3. What is the course of diagnosis? What tests are prescribed for patients with olfactory disorder?

4. What happens after diagnosis?

5. What type of patients usually come the hospital here? Are they all from the cities or from tier 2 and tier 3 towns?

6. Are the patients usually worried about the treatment or the course of action?

7. Do you brief them during the process about the procedure and why it is being done?

8. Are there any materials that you use to provide information to the patients? Are there any pamphlets that they are provided with?

9. In the case of OD where it cannot be cured via medication or surgery, what do you usually suggest to the patients?

10. What care are the patients provided with? Does smell training work?

11. Do you have an in-house smell training centre in your hospital/clinic?

12. Have the patients given you any feedback on the changes in the system before?

13. Most patients have mentioned that they do not receive all the information and process before in hand. Do you brief them before in hand?

14. Does the hospital also have a grief centre or support groups for the patients to participate in?

15. They also mention that they do not receive any brochures or pamphlets or even information website. Are there no brochures or information website available exclusively for an Indian audience?

16. Are there any programs that you are aware of that acts as a support group for people who have been diagnosed with OD in India?

17. How are hidden disabilities perceived in India?

18. What are some of the challenges faced by primary healthcare facilities in providing comprehensive support to patients with Olfactory Disorder?

19. If we had to create an intervention, what do you think we should include as a part of the toolkit that would help you in helping the patients.

20. As a designer, can I just create a brochure and hand it over to you doctors or is there a system in place that I will have to use?

Appendix 4

The project's foundation was laid with a service safari through the diagnostic process, providing a firsthand experience of pre-diagnosis, diagnosis, and post-diagnosis care. This marked the commencement of primary research, which unfolded in three stages: interviews with patients from India, interviews with doctors working at hospitals in Bangalore and Chennai, India, and observations at these hospitals.

During primary research, observations, coupled with patient and doctor interviews, revealed that despite theoretical assertions that Primary Health Centres (PHCs) lack amenities for the Ear, Nose, and Throat (ENT) department, images (refer to Image X) depict dedicated ENT departments at government hospitals like Victoria Hospital and Kauvery Hospital in tier 1 cities. These hospitals, government or government-aided with attached medical colleges, serve patients from various cities and rural areas. However, the doctors, often doubling as faculty members and students working as residents, must work on their schedules, impacting patient communication and emotional care. Examining the hospital environment, illustrated in Image X, reveals disorganization in waiting areas due to walk-in appointments without strict scheduling policies. While this flexibility is beneficial, a system to organise appointments may be necessary. Moreover, senior residents, particularly master's students, were observed as non-responsive and rude when approached with questions. This represents a problematic aspect.

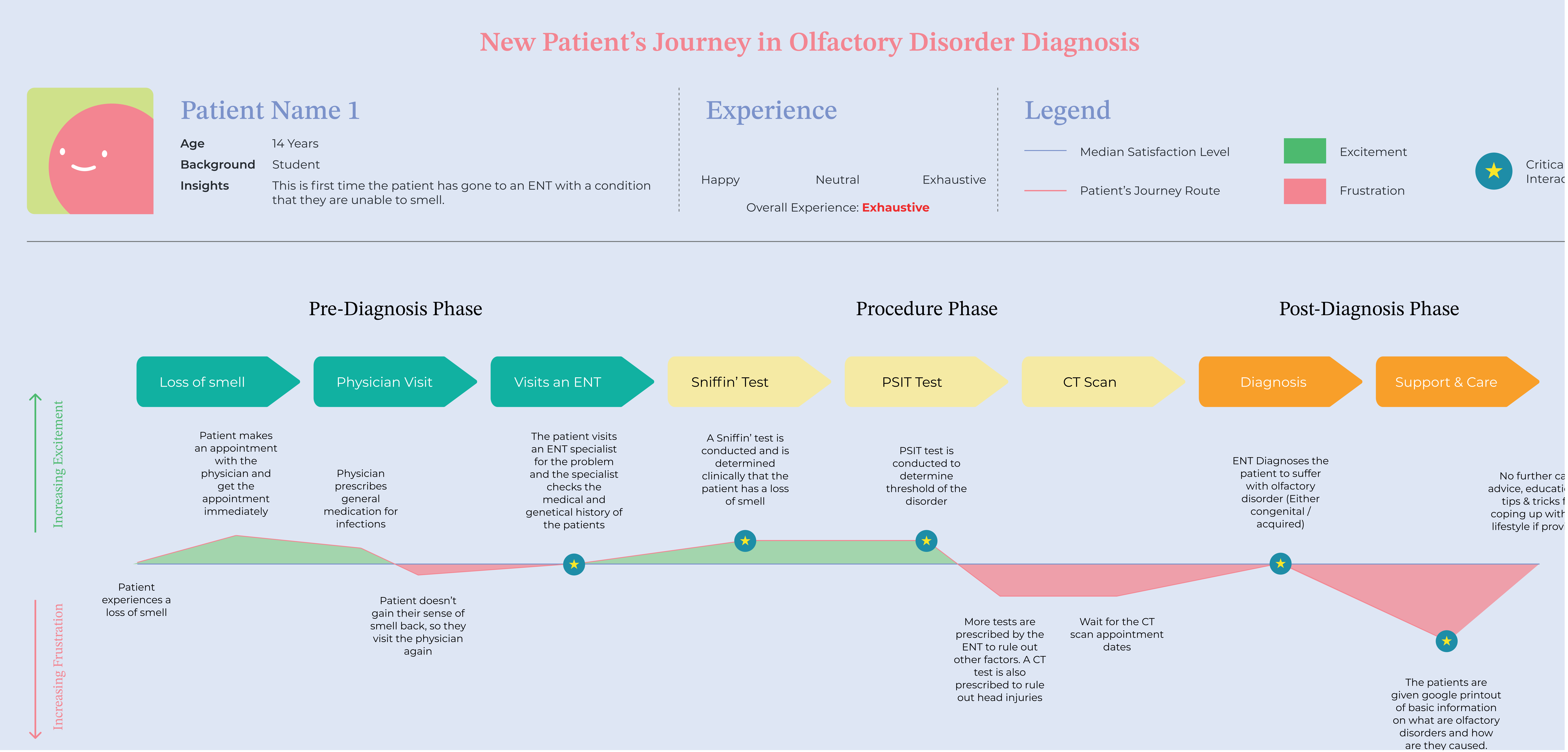
Further issues include requiring specific tests suggested by doctors to be conducted outside the hospitals in private clinics, posing an additional financial burden on patients. This was noted during the service safari preceding the project. Additionally, there is a lack of designated grief rooms for individuals to sit and process their emotions with a therapist, hindering their understanding of their disorders.

(4.1) Customer Journey of an individual with olfactory disorder by birth

This journey was of the researcher's brother and all the information furnished below are first hand information by the family and the patient themselves. (No consent form was collected as it is an observational study).

A couple of years ago, prior to the outbreak of the COVID-19 pandemic, we experienced a gas leak at our home, which got us all bothered except for my brother, who could not detect the smell of the gas. Seeking medical guidance, we consulted a general physician who initially diagnosed his condition with a possible infection or allergy that would clear up in a few days. However, as his symptoms persisted beyond a week, we eventually consulted an ENT specialist who diagnosed that he had been experiencing olfactory issues without realising that he could not smell everyday objects after conducting a preliminary Sniffin' Sticks Test. He then underwent a series of diagnostic tests, including the Olfactory Threshold Test, Discrimination Test, and Odour Identification Test, to determine the extent of his olfactory impairment, leading to a confirmed diagnosis of Hyposmia according to medical standards.

Please view the Journey map image in the next page



New Patient's Journey in Olfactory Disorder Diagnosis

Patient Name 1

Age 14 Years
Background Student
Insights This is first time the patient has gone to an ENT with a condition that they are unable to smell.

Experience

Happy Neutral Exhaustive

Overall Experience: **Exhaustive**

Legend

Median Satisfaction Level
Patient's Journey Route
🟩 Excitement
🟥 Frustration
★ Critica Interac

Increasing Excitement
Increasing Frustration

Pre-Diagnosis Phase

Loss of smell
Physician Visit
Visits an ENT

Procedure Phase

Sniffin' Test
PSIT Test
CT Scan

Post-Diagnosis Phase

Diagnosis
Support & Care

Patient experiences a loss of smell

Patient makes an appointment with the physician and get the appointment immediately

Physician prescribes general medication for infections

Patient doesn't gain their sense of smell back, so they visit the physician again

The patient visits an ENT specialist for the problem and the specialist checks the medical and genetical history of the patients

A Sniffin' test is conducted and is determined clinically that the patient has a loss of smell

PSIT test is conducted to determine threshold of the disorder

More tests are prescribed by the ENT to rule out other factors. A CT test is also prescribed to rule out head injuries

Wait for the CT scan appointment dates

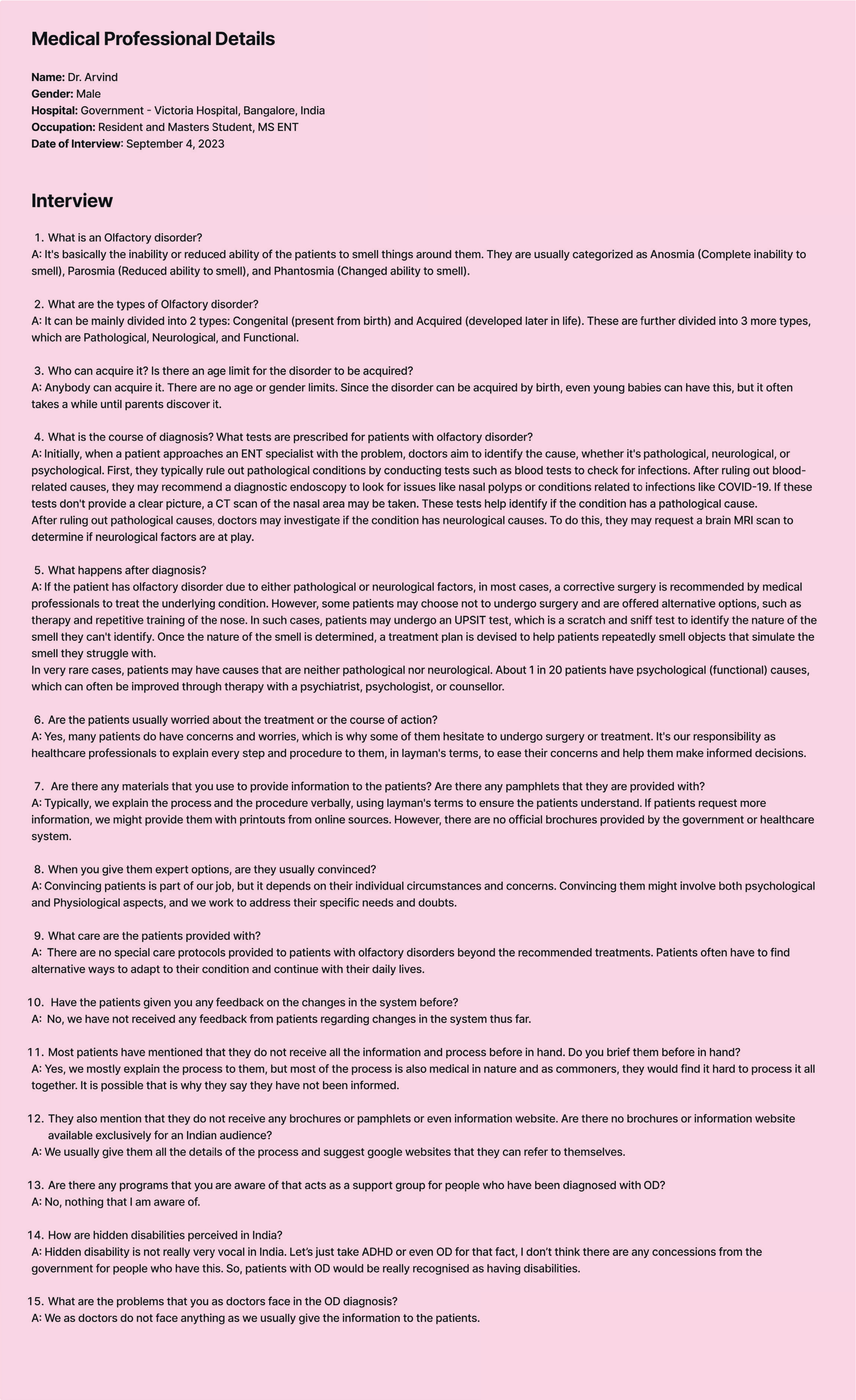
ENT Diagnoses the patient to suffer with olfactory disorder (Either congenital / acquired)

The patients are given google printout of basic information on what are olfactory disorders and how are they caused.

No further ca advice, educati tips & tricks f coping up with lifestyle if prov

Image 22: Customer Journey Map plotted as a part of the Service Safari

(4.2) Interview with Dr Arvind



Medical Professional Details

Name: Dr. Arvind
Gender: Male
Hospital: Government - Victoria Hospital, Bangalore, India
Occupation: Resident and Masters Student, MS ENT
Date of Interview: September 4, 2023

Interview

1. What is an Olfactory disorder?

A: It's basically the inability or reduced ability of the patients to smell things around them. They are usually categorized as Anosmia (Complete inability to smell), Parosmia (Reduced ability to smell), and Phantosmia (Changed ability to smell).

2. What are the types of Olfactory disorder?

A: It can be mainly divided into 2 types: Congenital (present from birth) and Acquired (developed later in life). These are further divided into 3 more types, which are Pathological, Neurological, and Functional.

3. Who can acquire it? Is there an age limit for the disorder to be acquired?

A: Anybody can acquire it. There are no age or gender limits. Since the disorder can be acquired by birth, even young babies can have this, but it often takes a while until parents discover it.

4. What is the course of diagnosis? What tests are prescribed for patients with olfactory disorder?

A: Initially, when a patient approaches an ENT specialist with the problem, doctors aim to identify the cause, whether it's pathological, neurological, or psychological. First, they typically rule out pathological conditions by conducting tests such as blood tests to check for infections. After ruling out blood-related causes, they may recommend a diagnostic endoscopy to look for issues like nasal polyps or conditions related to infections like COVID-19. If these tests don't provide a clear picture, a CT scan of the nasal area may be taken. These tests help identify if the condition has a pathological cause.
After ruling out pathological causes, doctors may investigate if the condition has neurological causes. To do this, they may request a brain MRI scan to determine if neurological factors are at play.

5. What happens after diagnosis?

A: If the patient has olfactory disorder due to either pathological or neurological factors, in most cases, a corrective surgery is recommended by medical professionals to treat the underlying condition. However, some patients may choose not to undergo surgery and are offered alternative options, such as therapy and repetitive training of the nose. In such cases, patients may undergo an UPSIT test, which is a scratch and sniff test to identify the nature of the smell they can't identify. Once the nature of the smell is determined, a treatment plan is devised to help patients repeatedly smell objects that simulate the smell they struggle with.
In very rare cases, patients may have causes that are neither pathological nor neurological. About 1 in 20 patients have psychological (functional) causes, which can often be improved through therapy with a psychiatrist, psychologist, or counsellor.

6. Are the patients usually worried about the treatment or the course of action?

A: Yes, many patients do have concerns and worries, which is why some of them hesitate to undergo surgery or treatment. It's our responsibility as healthcare professionals to explain every step and procedure to them, in layman's terms, to ease their concerns and help them make informed decisions.

7. Are there any materials that you use to provide information to the patients? Are there any pamphlets that they are provided with?

A: Typically, we explain the process and the procedure verbally, using layman's terms to ensure the patients understand. If patients request more information, we might provide them with printouts from online sources. However, there are no official brochures provided by the government or healthcare system.

8. When you give them expert options, are they usually convinced?

A: Convincing patients is part of our job, but it depends on their individual circumstances and concerns. Convincing them might involve both psychological and Physiological aspects, and we work to address their specific needs and doubts.

9. What care are the patients provided with?

A: There are no special care protocols provided to patients with olfactory disorders beyond the recommended treatments. Patients often have to find alternative ways to adapt to their condition and continue with their daily lives.

10. Have the patients given you any feedback on the changes in the system before?

A: No, we have not received any feedback from patients regarding changes in the system thus far.

11. Most patients have mentioned that they do not receive all the information and process before in hand. Do you brief them before in hand?

A: Yes, we mostly explain the process to them, but most of the process is also medical in nature and as commoners, they would find it hard to process it all together. It is possible that is why they say they have not been informed.

12. They also mention that they do not receive any brochures or pamphlets or even information website. Are there no brochures or information website available exclusively for an Indian audience?

A: We usually give them all the details of the process and suggest google websites that they can refer to themselves.

13. Are there any programs that you are aware of that acts as a support group for people who have been diagnosed with OD?

A: No, nothing that I am aware of.

14. How are hidden disabilities perceived in India?

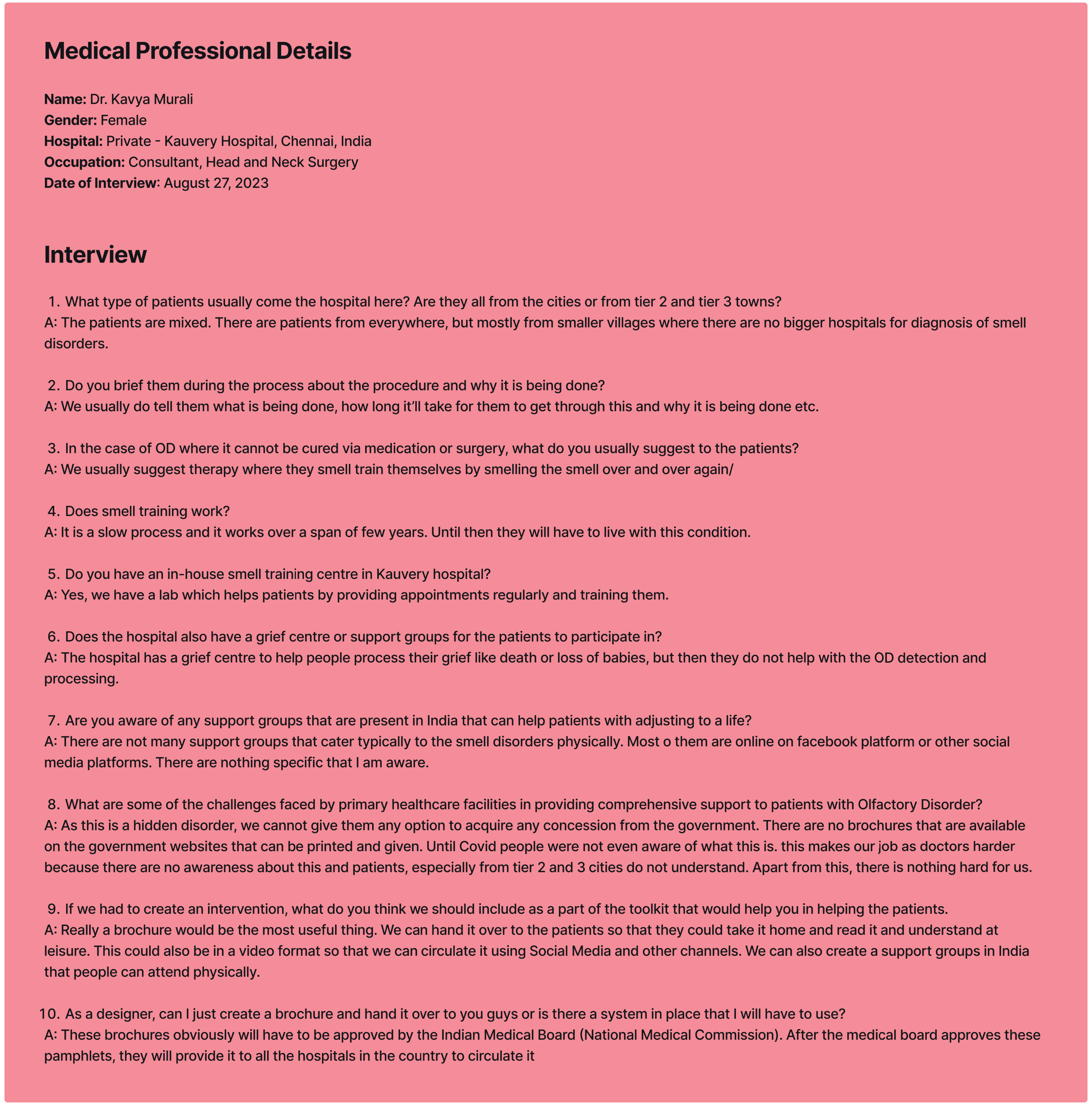
A: Hidden disability is not really very vocal in India. Let's just take ADHD or even OD for that fact, I don't think there are any concessions from the government for people who have this. So, patients with OD would be really recognised as having disabilities.

15. What are the problems that you as doctors face in the OD diagnosis?

A: We as doctors do not face anything as we usually give the information to the patients.

Image 23: Interview Transcript of Dr Arvind

(4.3) Interview with Dr Kavya



Medical Professional Details

Name: Dr. Kavya Murali
Gender: Female
Hospital: Private - Kauvery Hospital, Chennai, India
Occupation: Consultant, Head and Neck Surgery
Date of Interview: August 27, 2023

Interview

1. What type of patients usually come the hospital here? Are they all from the cities or from tier 2 and tier 3 towns?

A: The patients are mixed. There are patients from everywhere, but mostly from smaller villages where there are no bigger hospitals for diagnosis of smell disorders.

2. Do you brief them during the process about the procedure and why it is being done?

A: We usually do tell them what is being done, how long it'll take for them to get through this and why it is being done etc.

3. In the case of OD where it cannot be cured via medication or surgery, what do you usually suggest to the patients?

A: We usually suggest therapy where they smell train themselves by smelling the smell over and over again/

4. Does smell training work?

A: It is a slow process and it works over a span of few years. Until then they will have to live with this condition.

5. Do you have an in-house smell training centre in Kauvery hospital?

A: Yes, we have a lab which helps patients by providing appointments regularly and training them.

6. Does the hospital also have a grief centre or support groups for the patients to participate in?

A: The hospital has a grief centre to help people process their grief like death or loss of babies, but then they do not help with the OD detection and processing.

7. Are you aware of any support groups that are present in India that can help patients with adjusting to a life?

A: There are not many support groups that cater typically to the smell disorders physically. Most o them are online on facebook platform or other social media platforms. There are nothing specific that I am aware.

8. What are some of the challenges faced by primary healthcare facilities in providing comprehensive support to patients with Olfactory Disorder?

A: As this is a hidden disorder, we cannot give them any option to acquire any concession from the government. There are no brochures that are available on the government websites that can be printed and given. Until Covid people were not even aware of what this is. this makes our job as doctors harder because there are no awareness about this and patients, especially from tier 2 and 3 cities do not understand. Apart from this, there is nothing hard for us.

9. If we had to create an intervention, what do you think we should include as a part of the toolkit that would help you in helping the patients.

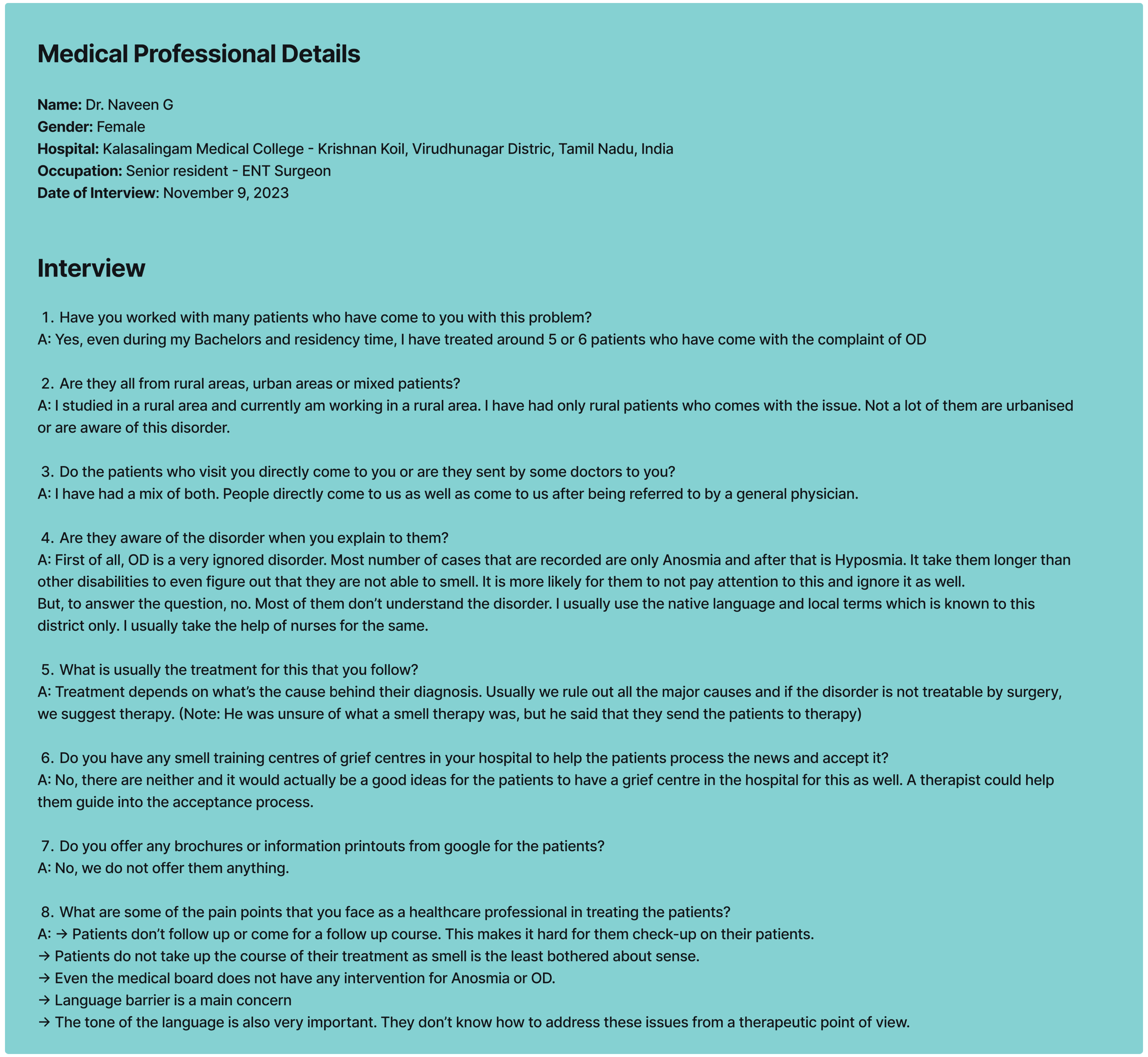
A: Really a brochure would be the most useful thing. We can hand it over to the patients so that they could take it home and read it and understand at leisure. This could also be in a video format so that we can circulate it using Social Media and other channels. We can also create a support groups in India that people can attend physically.

10. As a designer, can I just create a brochure and hand it over to you guys or is there a system in place that I will have to use?

A: These brochures obviously will have to be approved by the Indian Medical Board (National Medical Commission). After the medical board approves these pamphlets, they will provide it to all the hospitals in the country to circulate it

Image 24: Interview Transcript of Dr Kavya Murali

(4.4) Interview with Dr Naveen G



Medical Professional Details

Name: Dr. Naveen G
Gender: Female
Hospital: Kalasalingam Medical College - Krishnan Koil, Virudhunagar Distric, Tamil Nadu, India
Occupation: Senior resident - ENT Surgeon
Date of Interview: November 9, 2023

Interview

1. Have you worked with many patients who have come to you with this problem?

A: Yes, even during my Bachelors and residency time, I have treated around 5 or 6 patients who have come with the complaint of OD

2. Are they all from rural areas, urban areas or mixed patients?

A: I studied in a rural area and currently am working in a rural area. I have had only rural patients who comes with the issue. Not a lot of them are urbanised or are aware of this disorder.

3. Do the patients who visit you directly come to you or are they sent by some doctors to you?

A: I have had a mix of both. People directly come to us as well as come to us after being referred to by a general physician.

4. Are they aware of the disorder when you explain to them?

A: First of all, OD is a very ignored disorder. Most number of cases that are recorded are only Anosmia and after that is Hyposmia. It take them longer than other disabilities to even figure out that they are not able to smell. It is more likely for them to not pay attention to this and ignore it as well.
But, to answer the question, no. Most of them don't understand the disorder. I usually use the native language and local terms which is known to this district only. I usually take the help of nurses for the same.

5. What is usually the treatment for this that you follow?

A: Treatment depends on what's the cause behind their diagnosis. Usually we rule out all the major causes and if the disorder is not treatable by surgery, we suggest therapy. (Note: He was unsure of what a smell therapy was, but he said that they send the patients to therapy)

6. Do you have any smell training centres of grief centres in your hospital to help the patients process the news and accept it?

A: No, there are neither and it would actually be a good ideas for the patients to have a grief centre in the hospital for this as well. A therapist could help them guide into the acceptance process.

7. Do you offer any brochures or information printouts from google for the patients?

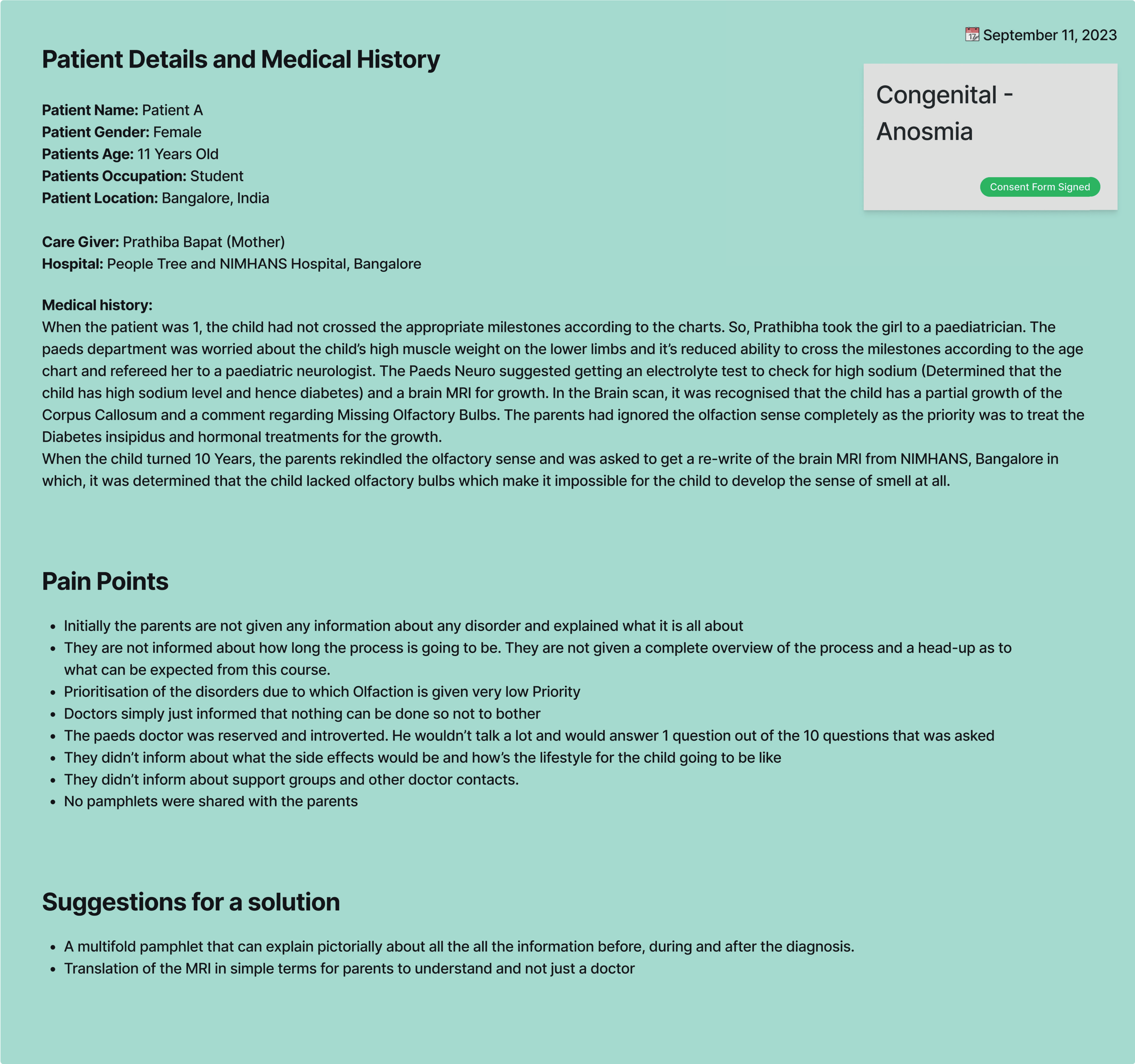
A: No, we do not offer them anything.

8. What are some of the pain points that you face as a healthcare professional in treating the patients?

A: → Patients don't follow up or come for a follow up course. This makes it hard for them check-up on their patients.
→ Patients do not take up the course of their treatment as smell is the least bothered about sense.
→ Even the medical board does not have any intervention for Anosmia or OD.
→ Language barrier is a main concern
→ The tone of the language is also very important. They don't know how to address these issues from a therapeutic point of view.

Image 25: Interview Transcript of Dr Naveen

(4.5) Interview with Prathiba



📆 September 11, 2023

Congenital - Anosmia

Consent Form Signed

Patient Details and Medical History

Patient Name: Patient A
Patient Gender: Female
Patients Age: 11 Years Old
Patients Occupation: Student
Patient Location: Bangalore, India

Care Giver: Prathiba Bapat (Mother)
Hospital: People Tree and NIMHANS Hospital, Bangalore

Medical history:
When the patient was 1, the child had not crossed the appropriate milestones according to the charts. So, Prathibha took the girl to a paediatrician. The paeds department was worried about the child's high muscle weight on the lower limbs and it's reduced ability to cross the milestones according to the age chart and refereed her to a paediatric neurologist. The Paeds Neuro suggested getting an electrolyte test to check for high sodium (Determined that the child has high sodium level and hence diabetes) and a brain MRI for growth. In the Brain scan, it was recognised that the child has a partial growth of the Corpus Callosum and a comment regarding Missing Olfactory Bulbs. The parents had ignored the olfaction sense completely as the priority was to treat the Diabetes insipidus and hormonal treatments for the growth.
When the child turned 10 Years, the parents rekindled the olfactory sense and was asked to get a re-write of the brain MRI from NIMHANS, Bangalore in which, it was determined that the child lacked olfactory bulbs which make it impossible for the child to develop the sense of smell at all.

Pain Points

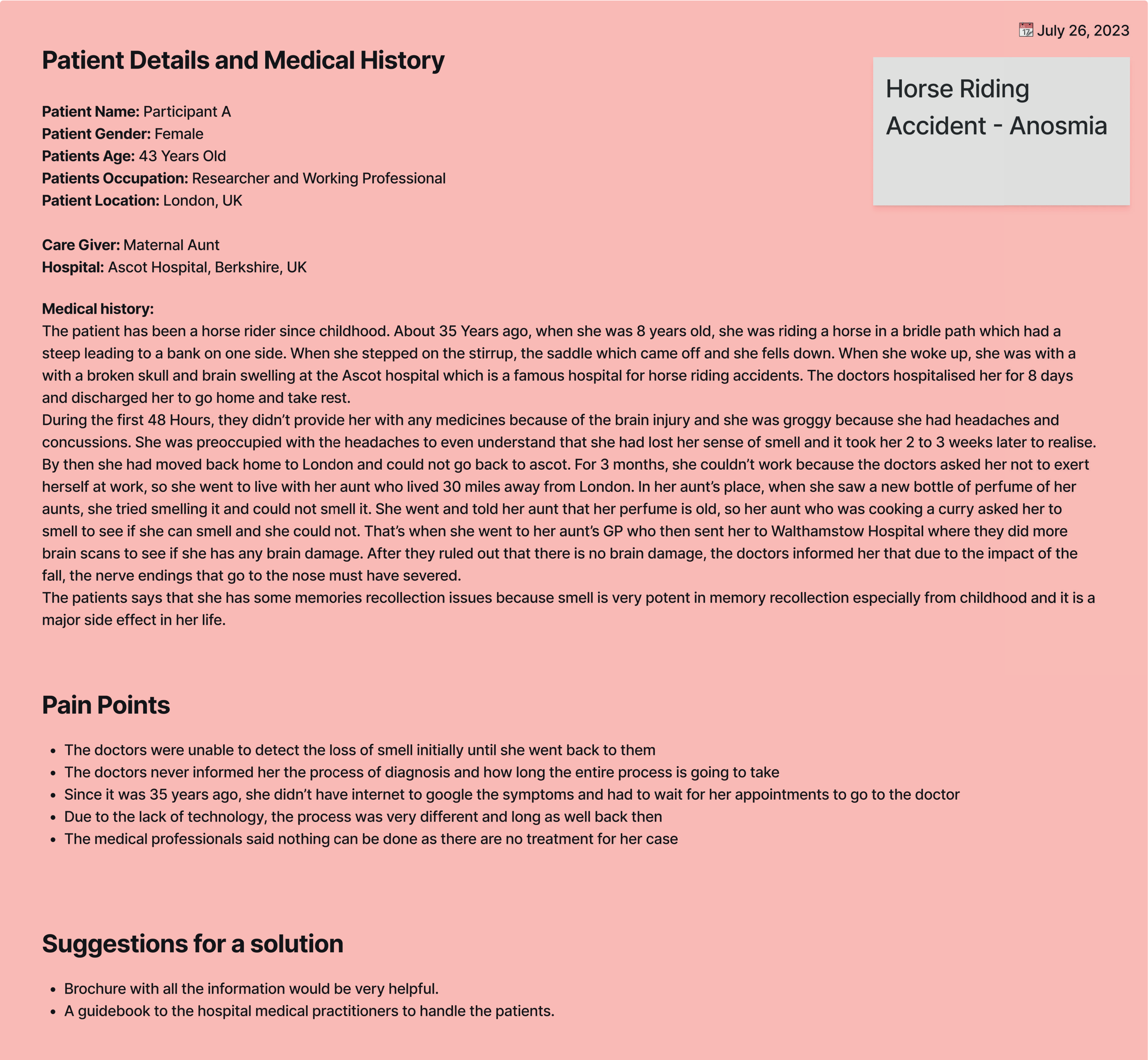
- Initially the parents are not given any information about any disorder and explained what it is all about
- They are not informed about how long the process is going to be. They are not given a complete overview of the process and a head-up as to what can be expected from this course.
- Prioritisation of the disorders due to which Olfaction is given very low Priority
- Doctors simply just informed that nothing can be done so not to bother
- The paeds doctor was reserved and introverted. He wouldn't talk a lot and would answer 1 question out of the 10 questions that was asked
- They didn't inform about what the side effects would be and how's the lifestyle for the child going to be like
- They didn't inform about support groups and other doctor contacts.
- No pamphlets were shared with the parents

Suggestions for a solution

- A multifold pamphlet that can explain pictorially about all the all the information before, during and after the diagnosis.
- Translation of the MRI in simple terms for parents to understand and not just a doctor

Image 26: Interview Transcript of Prathiba

(4.6) Interview with Patient A



📆 July 26, 2023

Patient Details and Medical History

Horse Riding Accident - Anosmia

Patient Name: Participant A
Patient Gender: Female
Patients Age: 43 Years Old
Patients Occupation: Researcher and Working Professional
Patient Location: London, UK

Care Giver: Maternal Aunt
Hospital: Ascot Hospital, Berkshire, UK

Medical history:
The patient has been a horse rider since childhood. About 35 Years ago, when she was 8 years old, she was riding a horse in a bridle path which had a steep leading to a bank on one side. When she stepped on the stirrup, the saddle which came off and she fells down. When she woke up, she was with a with a broken skull and brain swelling at the Ascot hospital which is a famous hospital for horse riding accidents. The doctors hospitalised her for 8 days and discharged her to go home and take rest.
During the first 48 Hours, they didn't provide her with any medicines because of the brain injury and she was groggy because she had headaches and concussions. She was preoccupied with the headaches to even understand that she had lost her sense of smell and it took her 2 to 3 weeks later to realise. By then she had moved back home to London and could not go back to ascot. For 3 months, she couldn't work because the doctors asked her not to exert herself at work, so she went to live with her aunt who lived 30 miles away from London. In her aunt's place, when she saw a new bottle of perfume of her aunts, she tried smelling it and could not smell it. She went and told her aunt that her perfume is old, so her aunt who was cooking a curry asked her to smell to see if she can smell and she could not. That's when she went to her aunt's GP who then sent her to Walthamstow Hospital where they did more brain scans to see if she has any brain damage. After they ruled out that there is no brain damage, the doctors informed her that due to the impact of the fall, the nerve endings that go to the nose must have severed.
The patients says that she has some memories recollection issues because smell is very potent in memory recollection especially from childhood and it is a major side effect in her life.

Pain Points

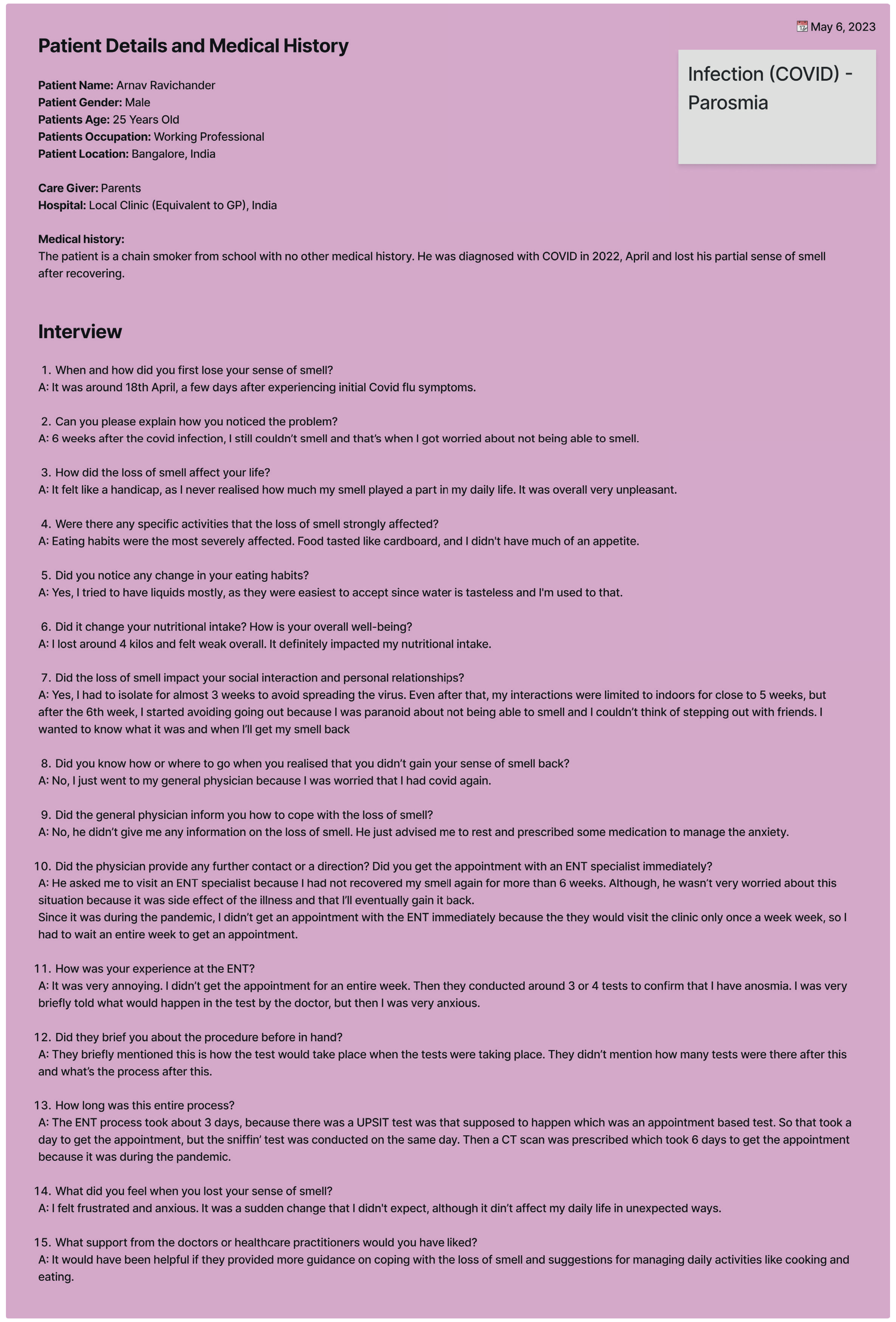
- The doctors were unable to detect the loss of smell initially until she went back to them
- The doctors never informed her the process of diagnosis and how long the entire process is going to take
- Since it was 35 years ago, she didn't have internet to google the symptoms and had to wait for her appointments to go to the doctor
- Due to the lack of technology, the process was very different and long as well back then
- The medical professionals said nothing can be done as there are no treatment for her case

Suggestions for a solution

- Brochure with all the information would be very helpful.
- A guidebook to the hospital medical practitioners to handle the patients.

Image 27: Interview Transcript with Patient A

(4.7) Interview with Arnav Ravichander



📆 May 6, 2023

Patient Details and Medical History

Infection (COVID) - Parosmia

Patient Name: Arnav Ravichander
Patient Gender: Male
Patients Age: 25 Years Old
Patients Occupation: Working Professional
Patient Location: Bangalore, India

Care Giver: Parents
Hospital: Local Clinic (Equivalent to GP), India

Medical history:
The patient is a chain smoker from school with no other medical history. He was diagnosed with COVID in 2022, April and lost his partial sense of smell after recovering.

Interview

1. When and how did you first lose your sense of smell?
A: It was around 18th April, a few days after experiencing initial Covid flu symptoms.

2. Can you please explain how you noticed the problem?
A: 6 weeks after the covid infection, I still couldn't smell and that's when I got worried about not being able to smell.

3. How did the loss of smell affect your life?
A: It felt like a handicap, as I never realised how much my smell played a part in my daily life. It was overall very unpleasant.

4. Were there any specific activities that the loss of smell strongly affected?
A: Eating habits were the most severely affected. Food tasted like cardboard, and I didn't have much of an appetite.

5. Did you notice any change in your eating habits?
A: Yes, I tried to have liquids mostly, as they were easiest to accept since water is tasteless and I'm used to that.

6. Did it change your nutritional intake? How is your overall well-being?
A: I lost around 4 kilos and felt weak overall. It definitely impacted my nutritional intake.

7. Did the loss of smell impact your social interaction and personal relationships?
A: Yes, I had to isolate for almost 3 weeks to avoid spreading the virus. Even after that, my interactions were limited to indoors for close to 5 weeks, but after the 6th week, I started avoiding going out because I was paranoid about not being able to smell and I couldn't think of stepping out with friends. I wanted to know what it was and when I'll get my smell back

8. Did you know how or where to go when you realised that you didn't gain your sense of smell back?
A: No, I just went to my general physician because I was worried that I had covid again.

9. Did the general physician inform you how to cope with the loss of smell?
A: No, he didn't give me any information on the loss of smell. He just advised me to rest and prescribed some medication to manage the anxiety.

10. Did the physician provide any further contact or a direction? Did you get the appointment with an ENT specialist immediately?
A: He asked me to visit an ENT specialist because I had not recovered my smell again for more than 6 weeks. Although, he wasn't very worried about this situation because it was side effect of the illness and that I'll eventually gain it back.
Since it was during the pandemic, I didn't get an appointment with the ENT immediately because the they would visit the clinic only once a week week, so I had to wait an entire week to get an appointment.

11. How was your experience at the ENT?
A: It was very annoying. I didn't get the appointment for an entire week. Then they conducted around 3 or 4 tests to confirm that I have anosmia. I was very briefly told what would happen in the test by the doctor, but then I was very anxious.

12. Did they brief you about the procedure before in hand?
A: They briefly mentioned this is how the test would take place when the tests were taking place. They didn't mention how many tests were there after this and what's the process after this.

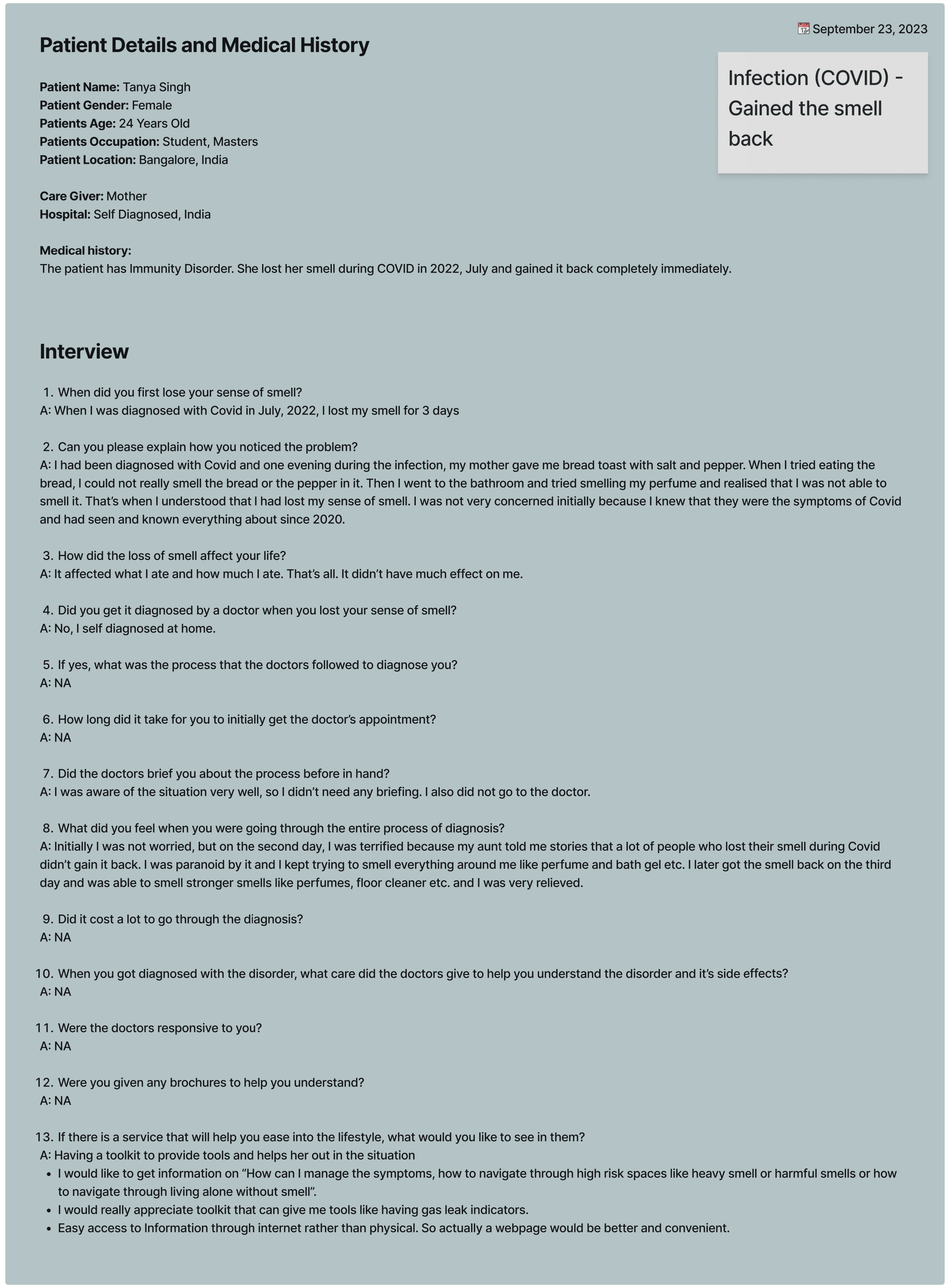
13. How long was this entire process?
A: The ENT process took about 3 days, because there was a UPSIT test was that supposed to happen which was an appointment based test. So that took a day to get the appointment, but the sniffin' test was conducted on the same day. Then a CT scan was prescribed which took 6 days to get the appointment because it was during the pandemic.

14. What did you feel when you lost your sense of smell?
A: I felt frustrated and anxious. It was a sudden change that I didn't expect, although it din't affect my daily life in unexpected ways.

15. What support from the doctors or healthcare practitioners would you have liked?
A: It would have been helpful if they provided more guidance on coping with the loss of smell and suggestions for managing daily activities like cooking and eating.

Image 28: Interview Transcript of Arnav

(4.8) Interview with Tanya



September 23, 2023

Patient Details and Medical History

Infection (COVID) - Gained the smell back

Patient Name: Tanya Singh
Patient Gender: Female
Patients Age: 24 Years Old
Patients Occupation: Student, Masters
Patient Location: Bangalore, India

Care Giver: Mother
Hospital: Self Diagnosed, India

Medical history:
The patient has Immunity Disorder. She lost her smell during COVID in 2022, July and gained it back completely immediately.

Interview

1. When did you first lose your sense of smell?

A: When I was diagnosed with Covid in July, 2022, I lost my smell for 3 days

2. Can you please explain how you noticed the problem?

A: I had been diagnosed with Covid and one evening during the infection, my mother gave me bread toast with salt and pepper. When I tried eating the bread, I could not really smell the bread or the pepper in it. Then I went to the bathroom and tried smelling my perfume and realised that I was not able to smell it. That's when I understood that I had lost my sense of smell. I was not very concerned initially because I knew that they were the symptoms of Covid and had seen and known everything about since 2020.

3. How did the loss of smell affect your life?

A: It affected what I ate and how much I ate. That's all. It didn't have much effect on me.

4. Did you get it diagnosed by a doctor when you lost your sense of smell?

A: No, I self diagnosed at home.

5. If yes, what was the process that the doctors followed to diagnose you?

A: NA

6. How long did it take for you to initially get the doctor's appointment?

A: NA

7. Did the doctors brief you about the process before in hand?

A: I was aware of the situation very well, so I didn't need any briefing. I also did not go to the doctor.

8. What did you feel when you were going through the entire process of diagnosis?

A: Initially I was not worried, but on the second day, I was terrified because my aunt told me stories that a lot of people who lost their smell during Covid didn't gain it back. I was paranoid by it and I kept trying to smell everything around me like perfume and bath gel etc. I later got the smell back on the third day and was able to smell stronger smells like perfumes, floor cleaner etc. and I was very relieved.

9. Did it cost a lot to go through the diagnosis?

A: NA

10. When you got diagnosed with the disorder, what care did the doctors give to help you understand the disorder and it's side effects?

A: NA

11. Were the doctors responsive to you?

A: NA

12. Were you given any brochures to help you understand?

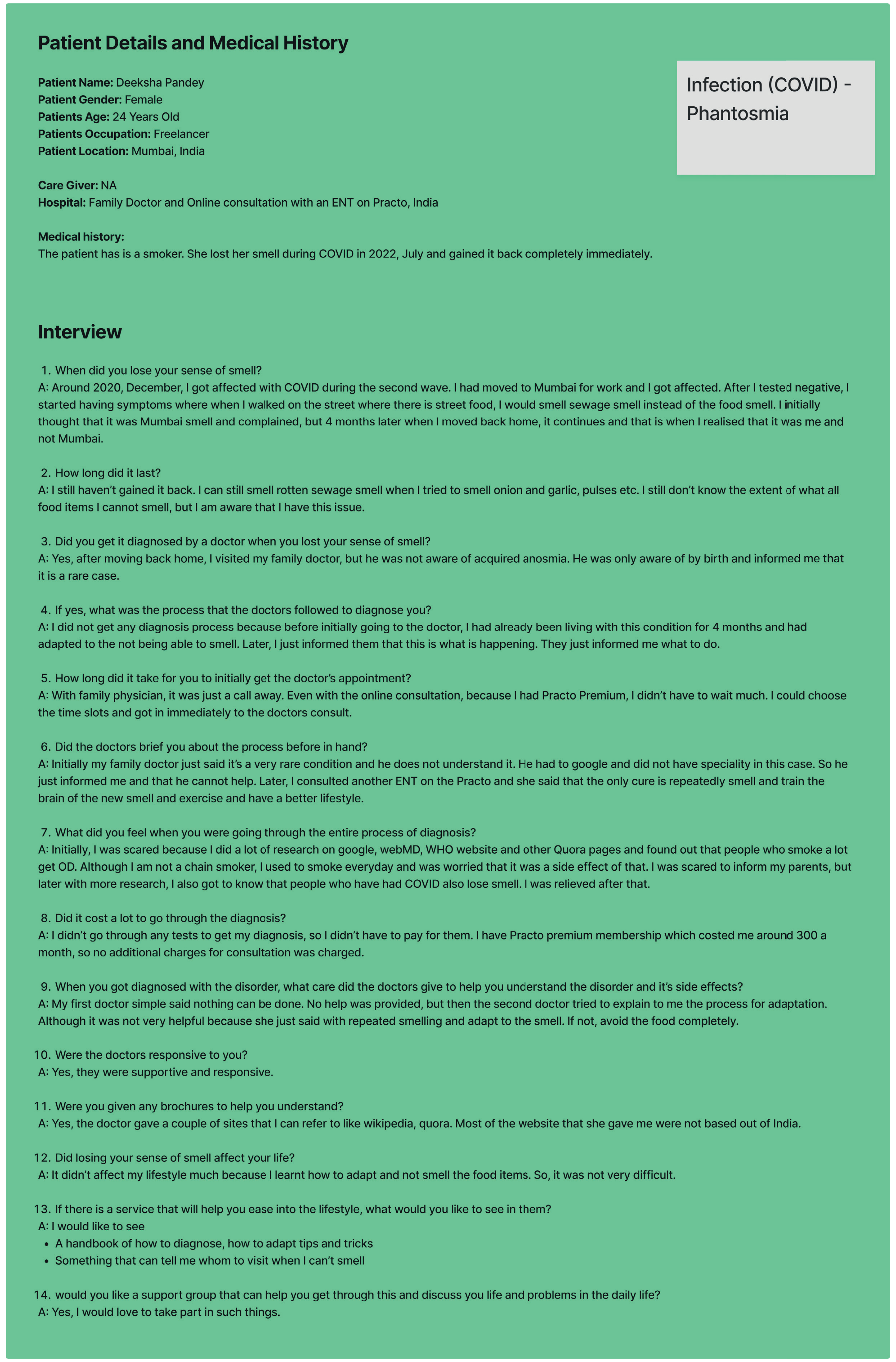
A: NA

13. If there is a service that will help you ease into the lifestyle, what would you like to see in them?

A: Having a toolkit to provide tools and helps her out in the situation
- I would like to get information on "How can I manage the symptoms, how to navigate through high risk spaces like heavy smell or harmful smells or how to navigate through living alone without smell".
- I would really appreciate toolkit that can give me tools like having gas leak indicators.
- Easy access to Information through internet rather than physical. So actually a webpage would be better and convenient.

Image 29: Interview Transcript of Tanya

(4.9) Interview with Deeksha



Patient Details and Medical History

Infection (COVID) - Phantosmia

Patient Name: Deeksha Pandey
Patient Gender: Female
Patients Age: 24 Years Old
Patients Occupation: Freelancer
Patient Location: Mumbai, India

Care Giver: NA
Hospital: Family Doctor and Online consultation with an ENT on Practo, India

Medical history:
The patient has is a smoker. She lost her smell during COVID in 2022, July and gained it back completely immediately.

Interview

1. When did you lose your sense of smell?

A: Around 2020, December, I got affected with COVID during the second wave. I had moved to Mumbai for work and I got affected. After I tested negative, I started having symptoms where when I walked on the street where there is street food, I would smell sewage smell instead of the food smell. I initially thought that it was Mumbai smell and complained, but 4 months later when I moved back home, it continues and that is when I realised that it was me and not Mumbai.

2. How long did it last?

A: I still haven't gained it back. I can still smell rotten sewage smell when I tried to smell onion and garlic, pulses etc. I still don't know the extent of what all food items I cannot smell, but I am aware that I have this issue.

3. Did you get it diagnosed by a doctor when you lost your sense of smell?

A: Yes, after moving back home, I visited my family doctor, but he was not aware of acquired anosmia. He was only aware of by birth and informed me that it is a rare case.

4. If yes, what was the process that the doctors followed to diagnose you?

A: I did not get any diagnosis process because before initially going to the doctor, I had already been living with this condition for 4 months and had adapted to the not being able to smell. Later, I just informed them that this is what is happening. They just informed me what to do.

5. How long did it take for you to initially get the doctor's appointment?

A: With family physician, it was just a call away. Even with the online consultation, because I had Practo Premium, I didn't have to wait much. I could choose the time slots and got in immediately to the doctors consult.

6. Did the doctors brief you about the process before in hand?

A: Initially my family doctor just said it's a very rare condition and he does not understand it. He had to google and did not have speciality in this case. So he just informed me and that he cannot help. Later, I consulted another ENT on the Practo and she said that the only cure is repeatedly smell and train the brain of the new smell and exercise and have a better lifestyle.

7. What did you feel when you were going through the entire process of diagnosis?

A: Initially, I was scared because I did a lot of research on google, webMD, WHO website and other Quora pages and found out that people who smoke a lot get OD. Although I am not a chain smoker, I used to smoke everyday and was worried that it was a side effect of that. I was scared to inform my parents, but later with more research, I also got to know that people who have had COVID also lose smell. I was relieved after that.

8. Did it cost a lot to go through the diagnosis?

A: I didn't go through any tests to get my diagnosis, so I didn't have to pay for them. I have Practo premium membership which costed me around 300 a month, so no additional charges for consultation was charged.

9. When you got diagnosed with the disorder, what care did the doctors give to help you understand the disorder and it's side effects?

A: My first doctor simple said nothing can be done. No help was provided, but then the second doctor tried to explain to me the process for adaptation. Although it was not very helpful because she just said with repeated smelling and adapt to the smell. If not, avoid the food completely.

10. Were the doctors responsive to you?

A: Yes, they were supportive and responsive.

11. Were you given any brochures to help you understand?

A: Yes, the doctor gave a couple of sites that I can refer to like wikipedia, quora. Most of the website that she gave me were not based out of India.

12. Did losing your sense of smell affect your life?

A: It didn't affect my lifestyle much because I learnt how to adapt and not smell the food items. So, it was not very difficult.

13. If there is a service that will help you ease into the lifestyle, what would you like to see in them?

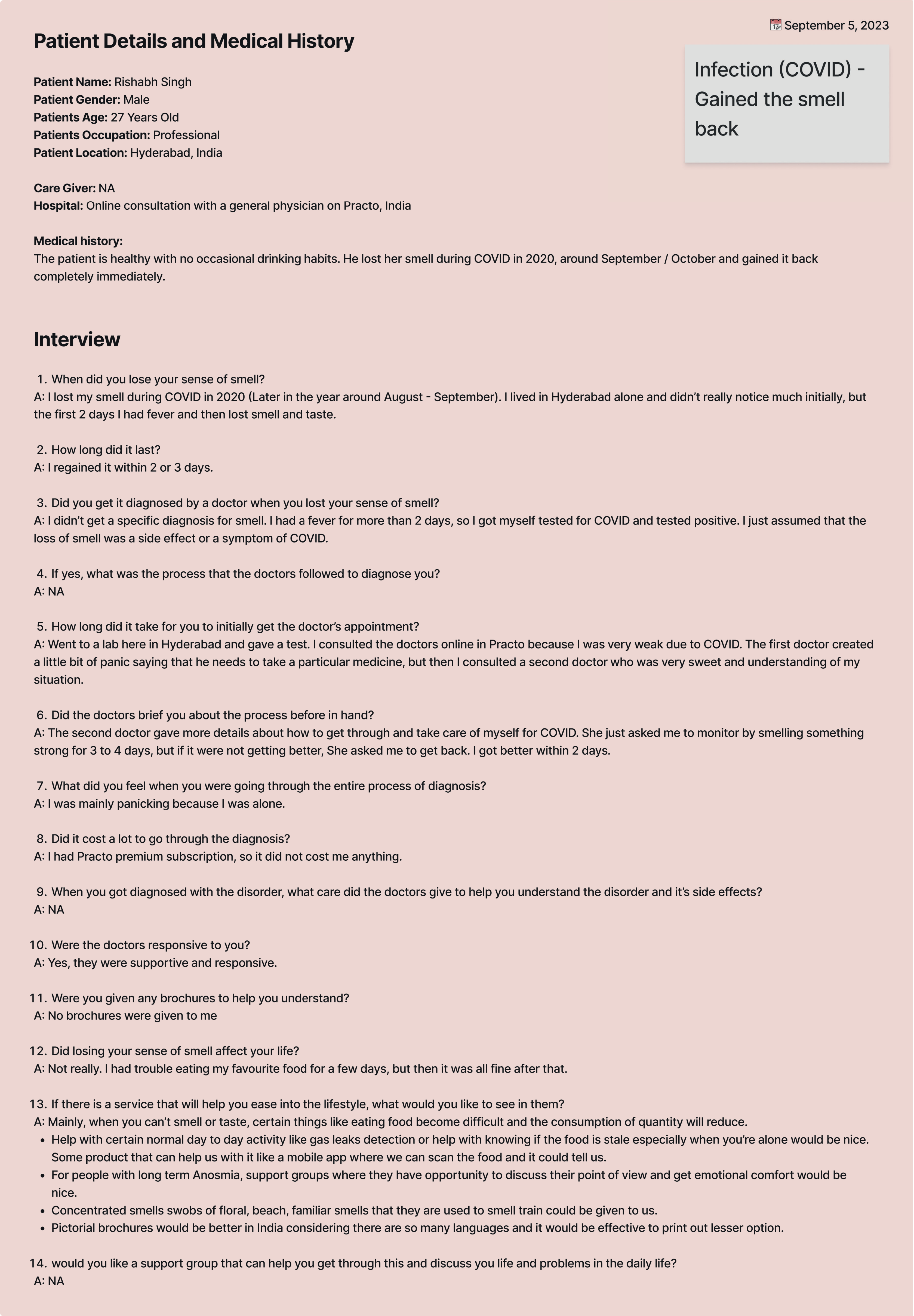
A: I would like to see
- A handbook of how to diagnose, how to adapt tips and tricks
- Something that can tell me whom to visit when I can't smell

14. would you like a support group that can help you get through this and discuss you life and problems in the daily life?

A: Yes, I would love to take part in such things.

Image 30: Interview Transcript of Deeksha

(4.10) Interview with Rishabh Singh



September 5, 2023

Patient Details and Medical History

Infection (COVID) - Gained the smell back

Patient Name: Rishabh Singh
Patient Gender: Male
Patients Age: 27 Years Old
Patients Occupation: Professional
Patient Location: Hyderabad, India

Care Giver: NA
Hospital: Online consultation with a general physician on Practo, India

Medical history:
The patient is healthy with no occasional drinking habits. He lost her smell during COVID in 2020, around September / October and gained it back completely immediately.

Interview

1. When did you lose your sense of smell?
A: I lost my smell during COVID in 2020 (Later in the year around August - September). I lived in Hyderabad alone and didn't really notice much initially, but the first 2 days I had fever and then lost smell and taste.

2. How long did it last?
A: I regained it within 2 or 3 days.

3. Did you get it diagnosed by a doctor when you lost your sense of smell?
A: I didn't get a specific diagnosis for smell. I had a fever for more than 2 days, so I got myself tested for COVID and tested positive. I just assumed that the loss of smell was a side effect or a symptom of COVID.

4. If yes, what was the process that the doctors followed to diagnose you?
A: NA

5. How long did it take for you to initially get the doctor's appointment?
A: Went to a lab here in Hyderabad and gave a test. I consulted the doctors online in Practo because I was very weak due to COVID. The first doctor created a little bit of panic saying that he needs to take a particular medicine, but then I consulted a second doctor who was very sweet and understanding of my situation.

6. Did the doctors brief you about the process before in hand?
A: The second doctor gave more details about how to get through and take care of myself for COVID. She just asked me to monitor by smelling something strong for 3 to 4 days, but if it were not getting better, She asked me to get back. I got better within 2 days.

7. What did you feel when you were going through the entire process of diagnosis?
A: I was mainly panicking because I was alone.

8. Did it cost a lot to go through the diagnosis?
A: I had Practo premium subscription, so it did not cost me anything.

9. When you got diagnosed with the disorder, what care did the doctors give to help you understand the disorder and it's side effects?
A: NA

10. Were the doctors responsive to you?
A: Yes, they were supportive and responsive.

11. Were you given any brochures to help you understand?
A: No brochures were given to me

12. Did losing your sense of smell affect your life?
A: Not really. I had trouble eating my favourite food for a few days, but then it was all fine after that.

13. If there is a service that will help you ease into the lifestyle, what would you like to see in them?
A: Mainly, when you can't smell or taste, certain things like eating food become difficult and the consumption of quantity will reduce.
- Help with certain normal day to day activity like gas leaks detection or help with knowing if the food is stale especially when you're alone would be nice. Some product that can help us with it like a mobile app where we can scan the food and it could tell us.
- For people with long term Anosmia, support groups where they have opportunity to discuss their point of view and get emotional comfort would be nice.
- Concentrated smells swobs of floral, beach, familiar smells that they are used to smell train could be given to us.
- Pictorial brochures would be better in India considering there are so many languages and it would be effective to print out lesser option.

14. would you like a support group that can help you get through this and discuss you life and problems in the daily life?
A: NA

Image 31: Interview Transcript with Rishabh

(4.11) Observations from the Hospital

Lack of way finding system at Victoria Hospital. The arrow mark seen here does not direct directly into the ENT departments, but towards a main road

Victoria Hospital, Bangalore, India

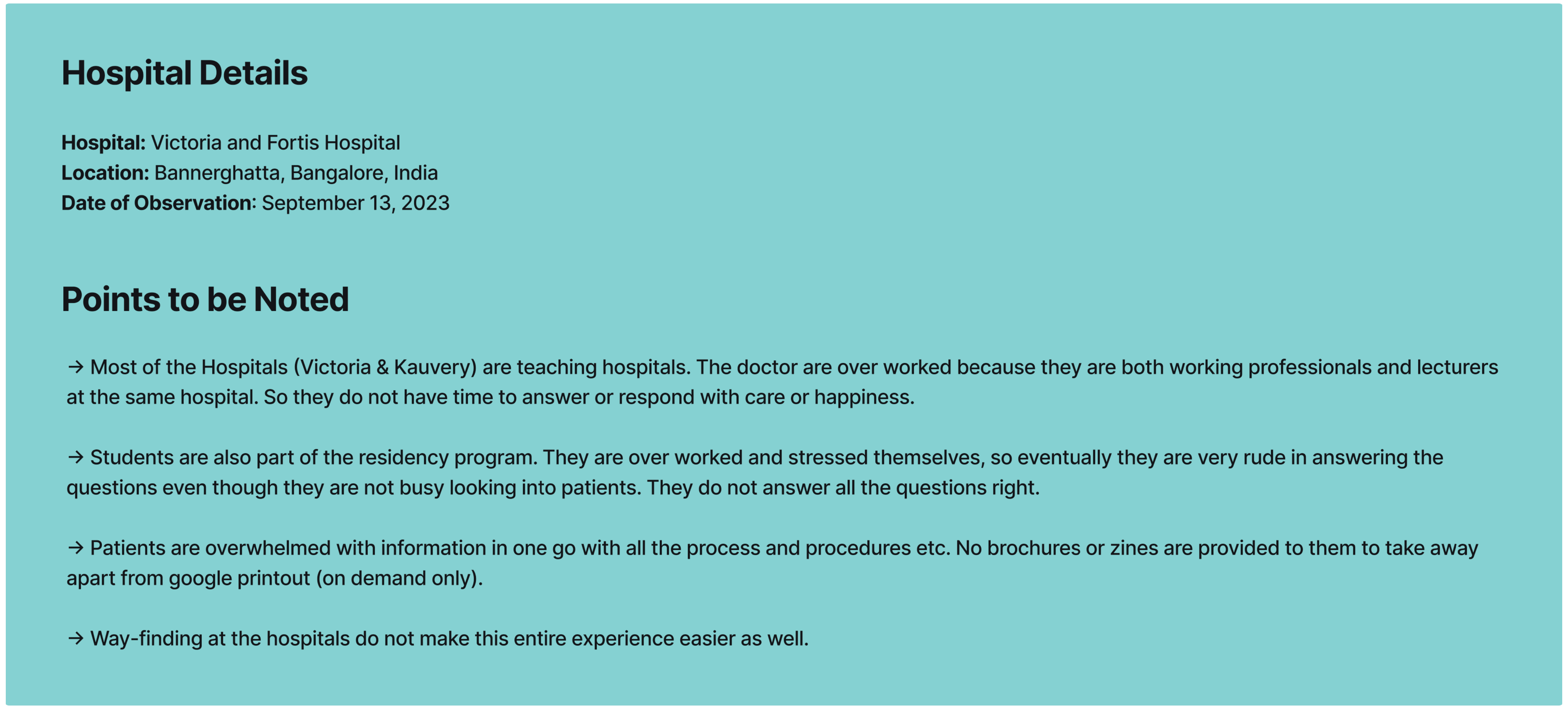
Lack of patient management system, especially in Victoria Hospital. There were no receptionist to manage the crowd.

Victoria Hospital, Bangalore, India

No information brochures regarding olfactory disorders were present on the bulletin board for public view.

Victoria Hospital, Bangalore, India

Image 32: Images clicked during the observation visit to Victoria Hospital in Bangalore (A Tier 1 Cosmopolitan City)



Hospital Details

Hospital: Victoria and Fortis Hospital
Location: Bannerghatta, Bangalore, India
Date of Observation: September 13, 2023

Points to be Noted

→ Most of the Hospitals (Victoria & Kauvery) are teaching hospitals. The doctor are over worked because they are both working professionals and lecturers at the same hospital. So they do not have time to answer or respond with care or happiness.

→ Students are also part of the residency program. They are over worked and stressed themselves, so eventually they are very rude in answering the questions even though they are not busy looking into patients. They do not answer all the questions right.

→ Patients are overwhelmed with information in one go with all the process and procedures etc. No brochures or zines are provided to them to take away apart from google printout (on demand only).

→ Way-finding at the hospitals do not make this entire experience easier as well.

Image 33: Observations from the hospitals

(4.12) Analysis of the Primary Research

During the interviews with doctors and patients, it was observed that the diagnostic process is tedious. However, Dr. Aravind, as observed from Appendix 7.2, explains the diagnosis process to patients in simple terms. Additionally, Dr. Naveen takes the extra step of explaining the information to patients in their native language with the help of local nurses to achieve the nuances in the language of the local area. Dr Arvind explains that caring for patients after their diagnosis involves doctors and mental healthcare professionals, as it involves dealing with patients emotionally and handling their moods, which is not the expertise of an ENT specialist. However, hospitals need grief centres or interventions from mental healthcare professionals to achieve this process and ease patients into the newly received news, making the process tedious for ENT specialists as well. As a result, patients often complain about the lack of information and response.

Dr Naveen also highlighted that most of his patients do not return for follow-up sessions, making it hard for doctors to keep track of their health records. He even highlights the need for a centralised database in hospitals nationwide due to the hardship of being unable to follow up with patients. The reason, as highlighted by the PESTLE analysis, could be social stigma, economic constraints, lack of amenities in hospitals, and the fact that most patients have this disorder along with another disorder. Hence, the main focus goes away from OD as the other disorder overshadows it. Therefore, working towards an intervention that addresses this issue is essential. Three out of six participants highlighted that they attended appointments online and preferred it to be online because it cut down wait time. Mobile health technologies like Practo, Tata OneMG, and other companies have been developing innovations such as online consultation with doctors, especially during the pandemic, due to the lack of PHC and shortage of medical staff. This opens up an opportunity for the intervention space.

During the interviews, it was observed that there is a lack of support groups for the Indian crowd. This was highlighted by Prateeksha, Prathiba, and Arnav, as well as Dr Naveen and Aravind in their interviews. This is due to the lack of focus on OD as a disorder and again goes back to the fact that the country has not focused much on hidden disabilities.

Appendix 5

(5.1) Screengrabs of the sentiment analysis of the interviews

Sentiment Analysis of Arnav Ravichander's Interview Transcript

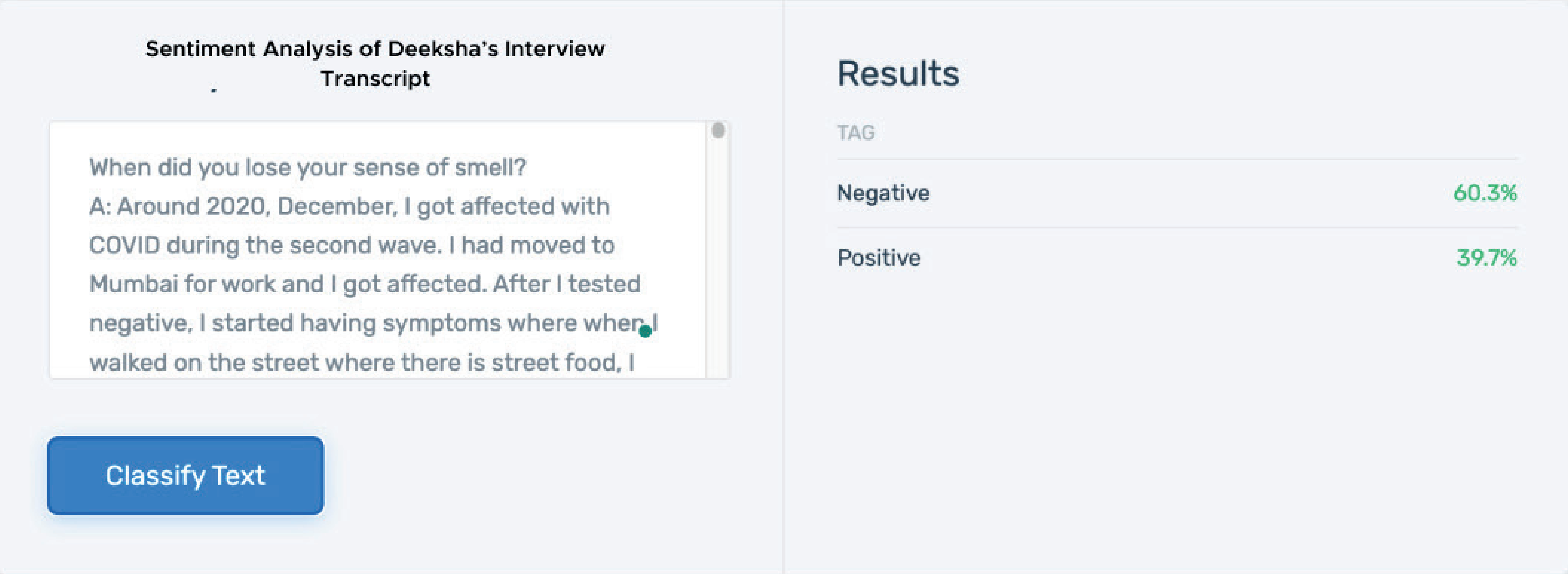
When and how did you first lose your sense of smell?
A: It was around 18th April, a few days after experiencing initial Covid flu symptoms.

Can you please explain how you noticed the

Classify Text

Results

TAG	
Negative	89.2%
Positive	10.8%



Sentiment Analysis of Deeksha's Interview Transcript

When did you lose your sense of smell?
A: Around 2020, December, I got affected with COVID during the second wave. I had moved to Mumbai for work and I got affected. After I tested negative, I started having symptoms where when I walked on the street where there is street food, I

Classify Text

Results

TAG	
Negative	60.3%
Positive	39.7%

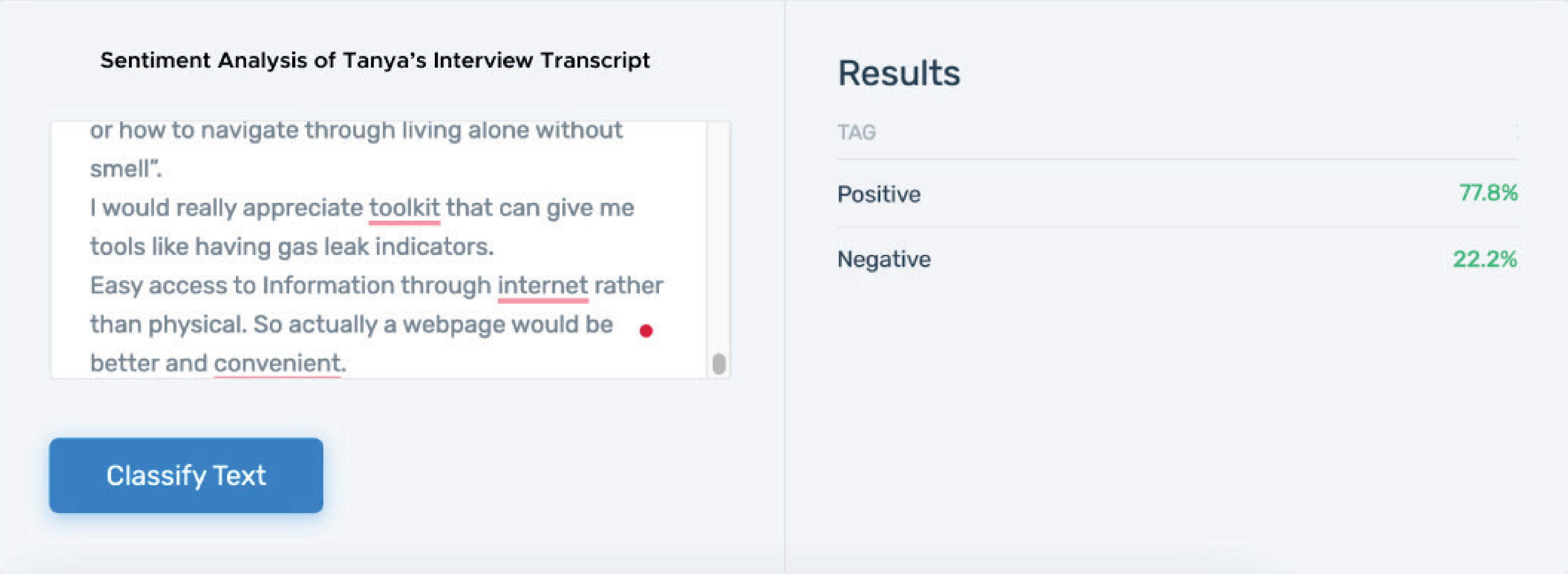
Sentiment Analysis of Patient A's Interview Transcript

Since it was 35 years ago, she didn't have internet to google the symptoms and had to wait for her appointments to go to the doctor
Due to the lack of technology, the process was very different and long as well back then
The medical professionals said nothing can be done as there are no treatment for her case

Classify Text

Results

TAG	
Negative	54.0%
Positive	46.0%



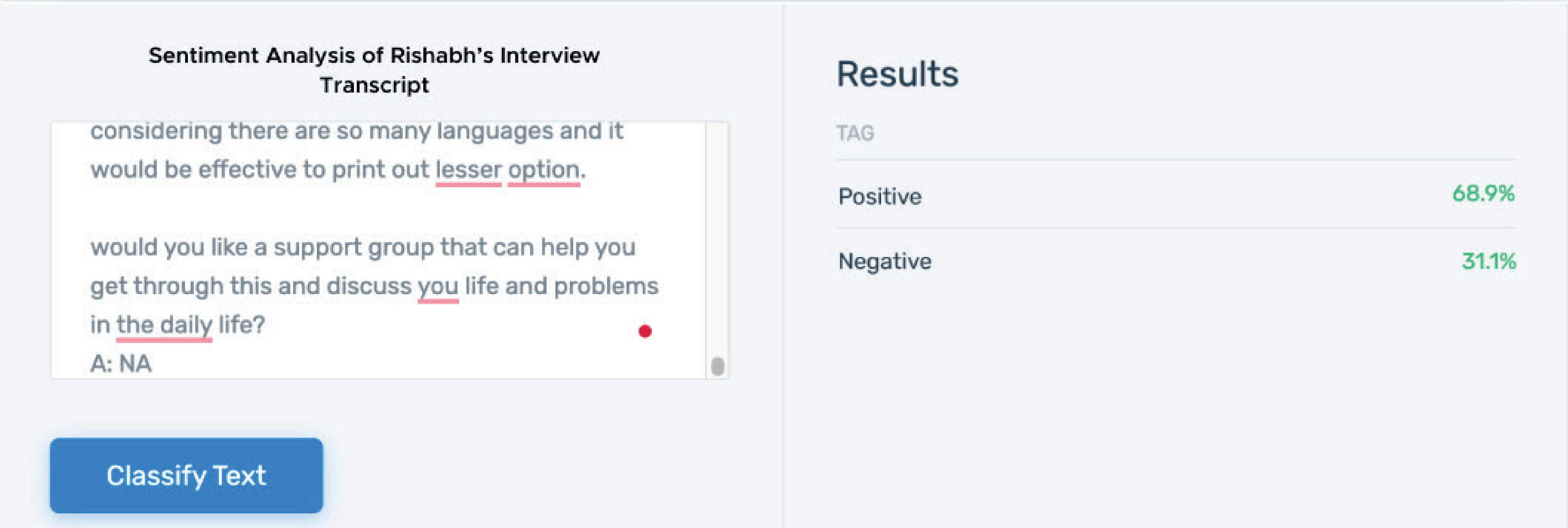
Sentiment Analysis of Tanya's Interview Transcript

or how to navigate through living alone without smell".
I would really appreciate toolkit that can give me tools like having gas leak indicators.
Easy access to Information through internet rather than physical. So actually a webpage would be better and convenient.

Classify Text

Results

TAG	
Positive	77.8%
Negative	22.2%



Sentiment Analysis of Rishabh's Interview Transcript

considering there are so many languages and it would be effective to print out lesser option.

would you like a support group that can help you get through this and discuss you life and problems in the daily life?
A: NA

Classify Text

Results

TAG	
Positive	68.9%
Negative	31.1%

Sentiment Analysis of Prathiba's Interview Transcript

When the patient was 1, the child had not crossed the appropriate milestones according to the charts. So, Prathibha took the girl to a paediatrician. The paeds department was worried about the child's high muscle weight on the lower limbs and it's reduced ability to cross the

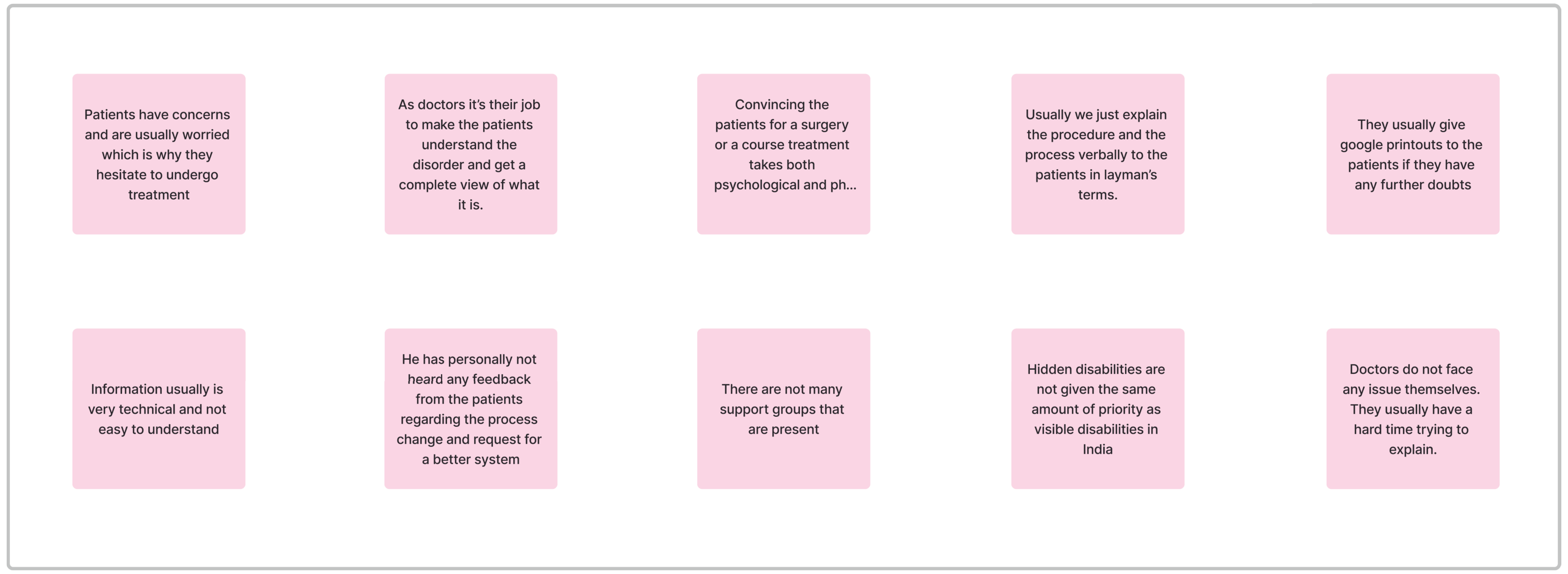
Classify Text

Results

TAG	
Negative	68.4%
Positive	31.6%

Image 34: Sentiment Analysis of all the Interviews with the Patients

(5.2) Analysis of the interviews with the Doctors



Patients have concerns and are usually worried which is why they hesitate to undergo treatment

As doctors it's their job to make the patients understand the disorder and get a complete view of what it is.

Convincing the patients for a surgery or a course treatment takes both psychological and ph...

Usually we just explain the procedure and the process verbally to the patients in layman's terms.

They usually give google printouts to the patients if they have any further doubts

Information usually is very technical and not easy to understand

He has personally not heard any feedback from the patients regarding the process change and request for a better system

There are not many support groups that are present

Hidden disabilities are not given the same amount of priority as visible disabilities in India

Doctors do not face any issue themselves. They usually have a hard time trying to explain.

Image 35: Thematic Analysis of transcript with Dr Arvind

Mixed set of patients from varied background visit the hospital

They usually walk the patients through the process. What, why and how long the process will last for

In untreatable cases of OD, they usually suggest smell therapy which is a part o the hospital in Kauvery

Smell therapy is a small process which is time consuming and takes longer to reflect

The hospital has grief centre but that is usually used in terms of Postpartum and death scenarios. It's usually not for OD

There are not many support groups that cater to the Indian audience physically, but there are many on social media

Hidden disorders don't have the same concession as visible disorders

No brochures or awareness about OD is available in the country. Until Covid, nobody really cared about smell

As doctors, making people from tier 2 or 3 cities understand the disorder is very hard.

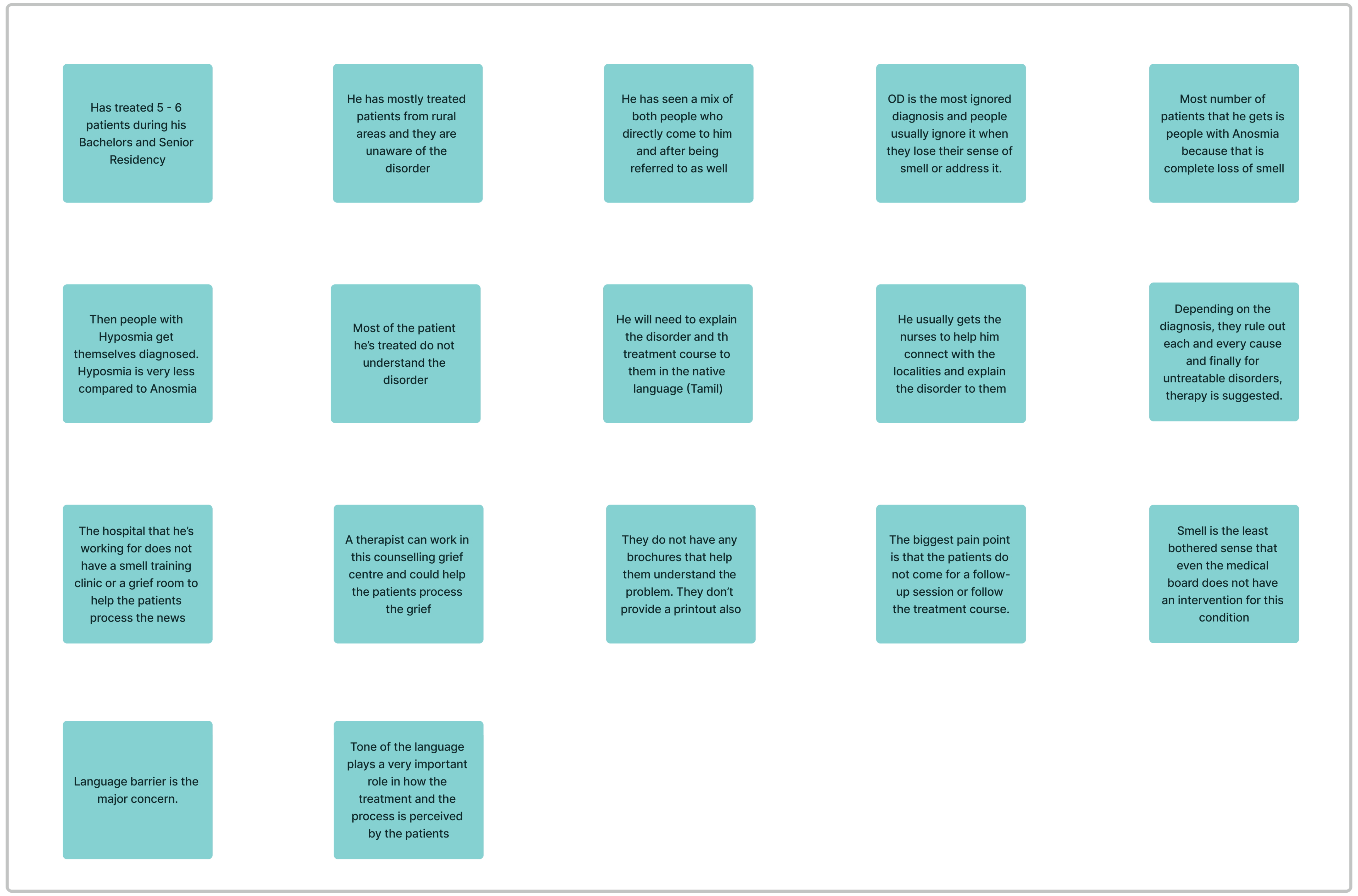
Information pamphlets being understandable by all the audience would make their life easier

A video about the disorder would help in circulating among social media

Support groups physically in India for the people to attend would be helpful

Brochures would have to be approved by Indian Medical board before circulating it among hospitals

Image 36: Thematic Analysis of transcript with Dr Kavya Murali



Has treated 5 - 6 patients during his Bachelors and Senior Residency

He has mostly treated patients from rural areas and they are unaware of the disorder

He has seen a mix of both people who directly come to him and after being referred to as well

OD is the most ignored diagnosis and people usually ignore it when they lose their sense of smell or address it.

Most number of patients that he gets is people with Anosmia because that is complete loss of smell

Then people with Hyposmia get themselves diagnosed. Hyposmia is very less compared to Anosmia

Most of the patient he's treated do not understand the disorder

He will need to explain the disorder and th treatment course to them in the native language (Tamil)

He usually gets the nurses to help him connect with the localities and explain the disorder to them

Depending on the diagnosis, they rule out each and every cause and finally for untreatable disorders, therapy is suggested.

The hospital that he's working for does not have a smell training clinic or a grief room to help the patients process the news

A therapist can work in this counselling grief centre and could help the patients process the grief

They do not have any brochures that help them understand the problem. They don't provide a printout also

The biggest pain point is that the patients do not come for a follow-up session or follow the treatment course.

Smell is the least bothered sense that even the medical board does not have an intervention for this condition

Language barrier is the major concern.

Tone of the language plays a very important role in how the treatment and the process is perceived by the patients

Image 37: Thematic Analysis of transcript with Dr Naveen

(5.2) Analysis of the interviews with the Patients

The diagnosis process started with because the child was **not crossing the appropriate milestone**

Parents **visited a paediatrician** to understand why the child is not reaching all the milestones

Paediatrician determined that the child has a **high muscle mass** in the **lower limbs**

Paediatrician referred to a paediatric neurologist. **Parents were not informed what was being detected**

Paediatric neurologist **conducted an electrolyte test for high sodium traces** in the child

Identified that the child had high sodium traces and hence diabetes and wanted to check for a Brain MRI for growth

Brain scan should partially grown of the Corpus Callosum and missing Olfactory Bulbs

At that time the parents didn't focus on the Olfactory issue because there were other priorities to deal with

During this time, the parents focused on getting treatments for the diabetics and brain growth

There was only one comment about missing olfactory bulbs in the scans and nothing further

Ten years later, the parents rekindled this smell issue because the child complained about not being able to smell

They went to the paediatric neurologist who asked them to get a re-write o the brain scan

In the re-write of the scan, it showed that the Olfactory Bulbs were missing in the patient by birth

When they took the scan to the doctor, they said the child will not develop the ability to smell

Doctor informed that since the Olfactory Bulbs are missing, there is no treatment for the same as well

There was no post diagnosis care provided to the patient to adapt to a lifestyle

The doctors did not provide any further information on any of the disorders and how to treat them.

They were not even given any timeline on when and how and how long the diagnosis process is going to take place for.

Since OD comes with other disorder, priority is not given to OD

Sometimes the doctors are very introverted and busy that they do not provide the complete information

Didn't inform about the lifestyle changes and the side effects of the disorder that the patient would face.

They did not provide any support group details or the contact of other doctors who could help them with this process.

No brochures or pamphlets were shared with them which can help them understand the realm of OD

Image 38: Thematic Analysis of transcript with Prathiba

35 Years ago, when she was 8 Yo, she met with a horse riding accident and has a head injury

After the accident, she was rushed to Ascot Hospital where they diagnosed her with a broken skull and a brain injury

She was at the hospital for 8 days where she was given care for the Brain injury and the broken skull for recovery

During the first 48 hours, they did not give her any medication because of the brain injury so she was groggy

She had headaches because of the injury and the doctors were focused on curing that issue

After 8 Days she was discharged and moved into her aunt's house where she tried using her aunt's perfume

While using her aunts perfume is when she realised that she was not able to smell

The doctors conducted a few scans to rule out brain damage and ruled out that there is any further brain damage

She did not have access to the internet as much as today because it was 35 years ago

The doctors determined from the scans that the nerve endings have severed dur to the impact of the fall

She has issues with recollecting memories because she is unable to smell and smell is connected to memories

It was frustrating that doctors paid no attention to this until she went back to them specifically stating the she can't smell

The doctors did not inform her of the process that they were going to follow or even how long it is going to take

After the diagnosis, the doctors informed her nothing can be done and that she would have to adapt to her lifestyle

A brochure and aguidebook would be very helpful

Image 39: Thematic Analysis of transcript with Patient A

The disorder started as a side effect of COVID and never gained his smell back

Waited for 6 weeks to determine that there is some issues with his smell because it was side effect of the illness

Felt helpless in the situation as he was unable to smell any food or fragrances and wanted answers.

It also affected his gustatory system and his food and nutritional intake. It also affected his physical health

He visited a general physicians as he was worried that he might have Covid again

General physician asked him to visit an ENT specialist because he didn't gain his smell even after 6 weeks.

General physician was not very worried about the situation because it was a side effect of Covid and that I'll eventually gain it back.

The wait to receive an ENT appointment was a week because the Specialist would visit the only once a week due to Covid

During the first appointment, he was briefed a little about the procedure of diagnosis

He went through 3 or 4 rounds of tests during the process and it took about 3 to 4 days to get a diagnosis

They conducted a sniff test where they made me sniff a few cotton swobs immediately, but the UPSIT and the CT had appointments

UPSIT test was conducted in 3 days from the initial swob test and then CT took 6 days to get an appointment

Felt frustrated and anxious with the sudden changes in the way of life

It would be helpful if the doctors provide suggestion on how to cope up with life and other daily activities like cooking and eating

Image 40: Thematic Analysis of transcript with Arnav Ravichander

She lost her smell for 3 days when she got affected with Covid in July 2022. She gained it back pretty quickly within 3 days

She identified that she could not smell because she could not smell her food. then eventually no fragrance around her

She was not very concerned because she knew that it was the symptom of Covid and would gain her smell back

Loss of smell affected her consumption o nutrition. It did not have any major effect on her daily life

She was aware of the situation, so self-diagnosed at home and did not go to a doctor

Initially she was not worried about it losing her sense of smell

After hearing stories about people losing their smell permanently after COVID, she was paranoid

She tried using home smells like floor cleaner, perfumes, bath gel etc. to see if she could smell as they have stronger scents

She would prefer if she has a toolkit to provided information that would help her navigate through this situation

She would like a tools that could help her detect gas leaks etc.

Easy access to something on the internet would be better because it's accessible

Image 41: Thematic Analysis of transcript with Tanya Singh

She lost her sense of smell during Covid in 2020, whilst living away from the family at that time. She has not gained her sense back

After she tested negative for Covid, she was walking past a food street and started smelling extremely foul smell

Assumed that it was the smell of the city and complained but then later realised that it was a problem with her

Waited for 4 months to go to a doctor and is still unaware of the extent of what smell has a changed sense of odour

She did not undergo the diagnosis process, but just the consultation process has been completed.

The specialist informed her that nothing can be done and that she has to just adapt to this change. She she undergo tests

Initially she visited her family general practitioner and he was unaware of acquired OD

He classified this as a rare case and nothing could be done about it

She then visited a specialist online via Practo who diagnosed that she has Parosmia

The wait with online visit was not much and got an appointment immediately because she had premium subscription

The family doctor was completely unaware of this case and had to google it himself to understand the extent of side effects

The specialist understood the disorder and informed her that the only cure is to repeatedly smell train her brain

Before going to the doctor, she had googled the symptoms and understood that smokers usually get this disorder

She was a social smoker

She was worried that her family would know that she was a smoker and hence did not inform them or the first few months

With more research on WebMD, Quora, Google search, she understood that this is a side effect of the Covid infection

The diagnosis process did not cost her anything because she did not go through any tests, but paid for the Practo premium

Initially the general physician said nothing can be done, but the specialist informed her about the disorder and how to train herself

Most website that the doctors referred to were not from Indian and the scenarios changed because of the tools available

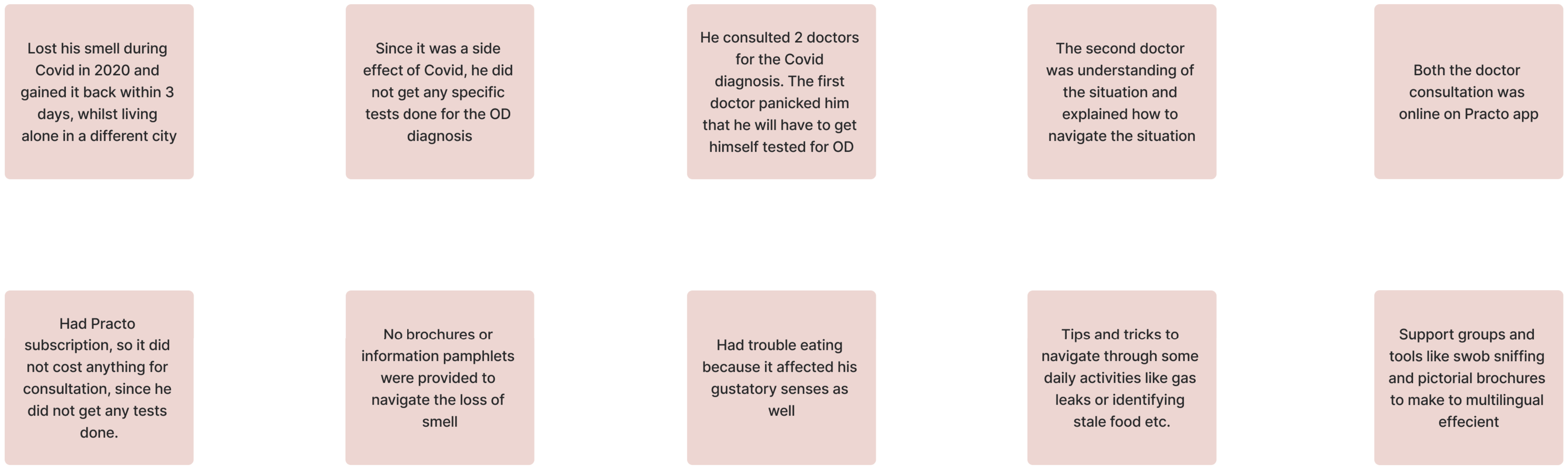
She learnt how to adapt rather than finding a fix for the situation

As a service for this case, a handbook of how to diagnose, how to adapt tips and tricks

A handbook on the process and the right doctors to visit would be nice

Would be interested in participating in Focus Groups and other research process and gain support group help

Image 41: Thematic Analysis of transcript with Deeksha



Lost his smell during Covid in 2020 and gained it back within 3 days, whilst living alone in a different city

Since it was a side effect of Covid, he did not get any specific tests done for the OD diagnosis

He consulted 2 doctors for the Covid diagnosis. The first doctor panicked him that he will have to get himself tested for OD

The second doctor was understanding of the situation and explained how to navigate the situation

Both the doctor consultation was online on Practo app

Had Practo subscription, so it did not cost anything for consultation, since he did not get any tests done.

No brochures or information pamphlets were provided to navigate the loss of smell

Had trouble eating because it affected his gustatory senses as well

Tips and tricks to navigate through some daily activities like gas leaks or identifying stale food etc.

Support groups and tools like swob sniffing and pictorial brochures to make to multilingual effecient

Image 42: Thematic Analysis of transcript with Rishabh Singh

(5.3) Themes of the Problem

Lack of Awareness

- He visited a general physicians as he was worried that he might have Covid again
- Assumed that it was the smell of the city and complained but then later realised that it was a problem with...
- Waited for 4 months to go to a doctor and is still unaware of the extent of what smell has a changed sense of odour
- He visited a general physicians as he was worried that he might have Covid again
- Initially she visited her family general practitioner and he was unaware of acquired OD
- Sometimes the doctors are very introverted and busy that they do not provide the complete information
- It was frustrating that doctors paid no attention to this until she went back to them specifically stating the she can't smell
- General physician was not very worried about the situation because it was a side effect of Covid and that I'll eventually gain it back.
- The specialist informed her that nothing can be done and that she has to just adapt to this change. She she undergo tests
- He classified this as a rare case and nothing could be done about it
- She was a social smoker
- She was worried that her family would know that she was a smoker and hence did not inform them or the first few months
- He has mostly treated patients from rural areas and they are unaware of the disorder
- Most of the patient he's treated do not understand the disorder
- OD is the most ignored diagnosis and people usually ignore it when they lose their sense of smell or address it.
- The biggest pain point is that the patients do not come for a follow-up session or follow the treatment course.
- Smell is the least bothered sense that even the medical board does not have an intervention for this condition

Lack of Information

- There was only one comment about missing olfactory bulbs in the scans and nothing further
- Doctor informed that since the Olfactory Bulbs are missing, there is no treatment for the same as well
- The doctors did not provide any further information on any of the disorders and how to treat them.
- They were not even given any timeline on when and how and how long the diagnosis process is going to take place for.
- Sometimes the doctors are very introverted and busy that they do not provide the complete information
- No brochures or pamphlets were shared with them which can help them understand the realm of OD
- The doctors did not inform her of the process that they were going to follow or even how long it is going to take
- No brochures or information pamphlets were provided to navigate the loss of s...
- Patients have concerns and are usually worried which is why they hesitate to undergo treatment
- Usually we just explain the procedure and the process verbally to the patients in layman's terms.
- Information usually is very technical and not easy to understand
- A video about the disorder would help in circulating among social media
- As doctors, making people from tier 2 or 3 cities understand the disorder is very hard.
- Information pamphlets being understandable by all the audience would make their life easier
- Brochures would have to be approved by Indian Medical board before circulating it among hospitals
- Lack of information on the website or brochures or information Pamphlets in the hospitals
- They do not have any brochures that help them understand the problem. They don't provide a printout also

Need for an alternative care routes with PHCs

- There was no post diagnosis care provided to the patient to adapt to a lifestyle
- Didn't inform about the lifestyle changes and the side effects of the disorder that the patient would face.
- They did not provide any support group details or the contact of other doctors who could help them with this process.
- A brochure and aguidebook would be very helpful
- After the diagnosis, the doctors informed her nothing can be done and that she would have to adapt to her lifestyle
- Felt frustrated and anxious with the sudden changes in the way of life
- It would be helpful if the doctors provide suggestion on how to cope up with life and other daily activities like cooking and eating
- Most website that the doctors referred to were not from Indian and the scenarios changed because of the tools available
- She learnt how to adapt rather than finding a fix for the situation
- Support groups physically in India for the people to attend would be helpful
- Only printout of google searches are provided to the patients who demand more infromation
- Convincing the patients for a surgery or a course treatment takes both psychological and ph...
- They usually give google printouts to the patients if they have any further doubts
- There are not many support groups that are present
- The hospital has grief centre but that is usually used in terms of Postpartum and death scenarios. It's usually not for OD
- There are not many support groups that cater to the Indian audience physically, but there are many on social media
- No brochures or awareness about OD is available in the country. Until Covid, nobody really cared about smell
- A handbook on the process and the right doctors to visit would be nice
- Would be interested in participating in Focus Groups and other research process and gain support group help
- Tips and tricks to navigate through some daily activities like gas leaks or identifying stale food etc.
- Support groups and tools like swob sniffing and pictorial brochures to make to multilingual effecient
- Easy access to something on the internet would be better because it's ac...
- She would like a tools that could help her detect gas leaks etc.

Need for a stronger policy

- Since OD comes with other disorder, priority is not given to OD
- Hidden disabilities are not given the same amount of priority as visible disabilities in India
- Hidden disorders don't have the same concession as visible disorders
- Hospitals are teaching hospitals, so the doctors and the residents are overworked and stressed to answer

Language Barriers

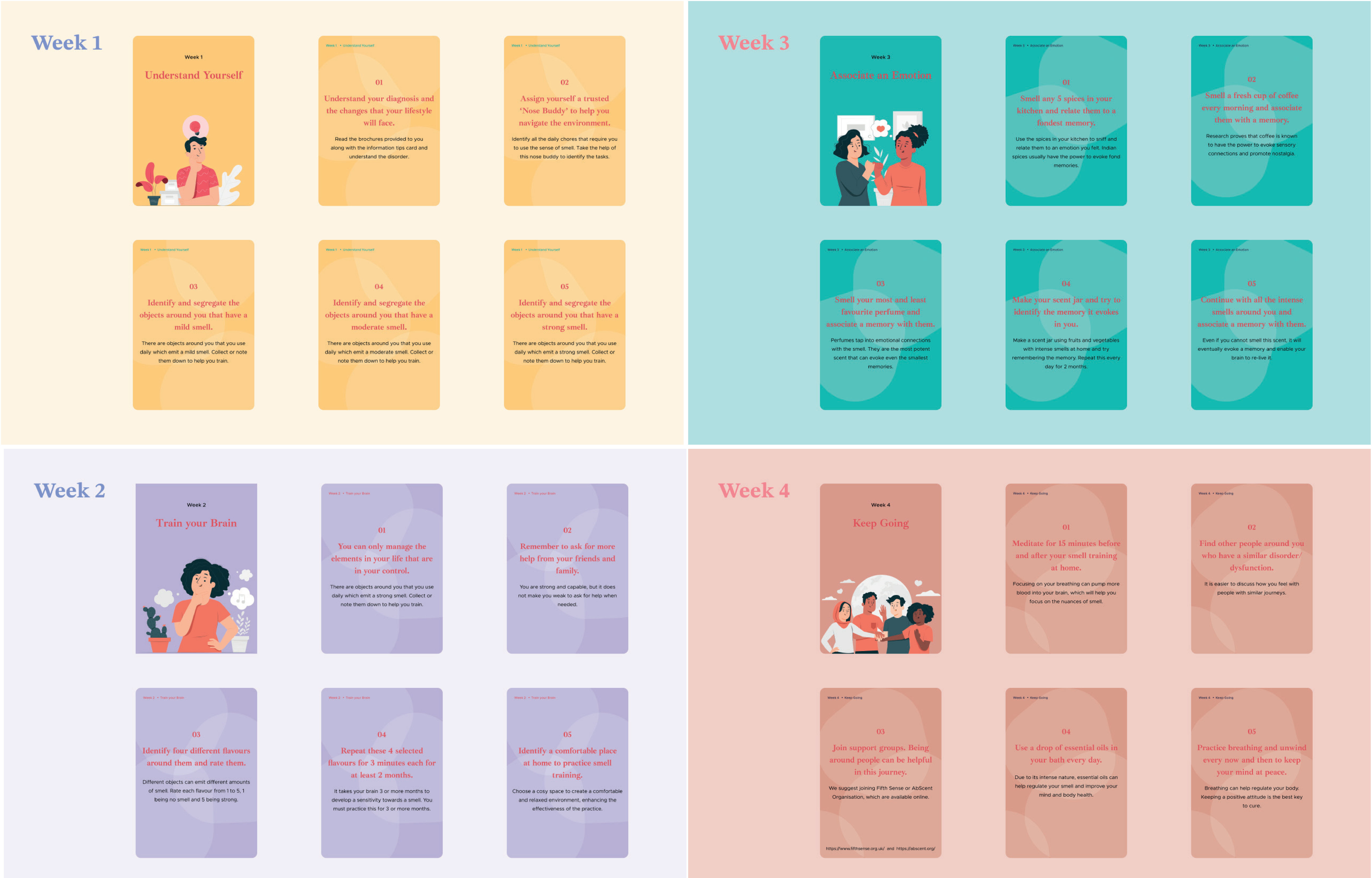
- He has mostly treated patients from rural areas and they are unaware of the disorder
- He will need to explain the disorder and th treatment course to them in the native language (Tamil)
- He usually gets the nurses to help him connect with the localities and explain the disorder to them
- Language barrier is the major concern.
- Tone of the language plays a very important role in how the treatment and the process is perceived by the patients

Image 43: Themes of the Problem Areas

Appendix 6

(6.1) Online Interactive Prototype

Please experience the Online Prototype by clicking on the link https://www.figma.com/proto/Tpk5J4uwljkdTV25ehd6Q9/FMP?page-



Week 1

Week 1

Understand Yourself

Week 1 • Understand Yourself

01

Understand your diagnosis and the changes that your lifestyle will face.

Read the brochures provided to you along with the information tips card and understand the disorder.

Week 1 • Understand Yourself

02

Assign yourself a trusted 'Nose Buddy' to help you navigate the environment.

Identify all the daily chores that require you to use the sense of smell. Take the help of this nose buddy to identify the tasks.

Week 1 • Understand Yourself

03

Identify and segregate the objects around you that have a mild smell.

There are objects around you that you use daily which emit a mild smell. Collect or note them down to help you train.

Week 1 • Understand Yourself

04

Identify and segregate the objects around you that have a moderate smell.

There are objects around you that you use daily which emit a moderate smell. Collect or note them down to help you train.

Week 1 • Understand Yourself

05

Identify and segregate the objects around you that have a strong smell.

There are objects around you that you use daily which emit a strong smell. Collect or note them down to help you train.

Week 2

Week 2

Train your Brain

Week 2 • Train your Brain

01

You can only manage the elements in your life that are in your control.

There are objects around you that you use daily which emit a strong smell. Collect or note them down to help you train.

Week 2 • Train your Brain

02

Remember to ask for more help from your friends and family.

You are strong and capable, but it does not make you weak to ask for help when needed.

Week 2 • Train your Brain

03

Identify four different flavours around them and rate them.

Different objects can emit different amounts of smell. Rate each flavour from 1 to 5, 1 being no smell and 5 being strong.

Week 2 • Train your Brain

04

Repeat these 4 selected flavours for 3 minutes each for at least 2 months.

It takes your brain 3 or more months to develop a sensitivity towards a smell. You must practice this for 3 or more months.

Week 2 • Train your Brain

05

Identify a comfortable place at home to practice smell training.

Choose a cosy space to create a comfortable and relaxed environment, enhancing the effectiveness of the practice.

Week 3

Week 3

Associate an Emotion

Week 3 • Associate an Emotion

01

Smell any 5 spices in your kitchen and relate them to a fondest memory.

Use the spices in your kitchen to sniff and relate them to an emotion you felt. Indian spices usually have the power to evoke fond memories.

Week 3 • Associate an Emotion

02

Smell a fresh cup of coffee every morning and associate them with a memory.

Research proves that coffee is known to have the power to evoke sensory connections and promote nostalgia.

Week 3 • Associate an Emotion

03

Smell your most and least favourite perfume and associate a memory with them.

Perfumes tap into emotional connections with the smell. They are the most potent scent that can evoke even the smallest memories.

Week 3 • Associate an Emotion

04

Make your scent jar and try to identify the memory it evokes in you.

Make a scent jar using fruits and vegetables with intense smells at home and try remembering the memory. Repeat this every day for 2 months.

Week 3 • Associate an Emotion

05

Continue with all the intense smells around you and associate a memory with them.

Even if you cannot smell this scent, it will eventually evoke a memory and enable your brain to re-live it.

Week 4

Week 4

Keep Going

Week 4 • Keep Going

01

Meditate for 15 minutes before and after your smell training at home.

Focusing on your breathing can pump more blood into your brain, which will help you focus on the nuances of smell.

Week 4 • Keep Going

02

Find other people around you who have a similar disorder/dysfunction.

It is easier to discuss how you feel with people with similar journeys.

Week 4 • Keep Going

03

Join support groups. Being around people can be helpful in this journey.

We suggest joining Fifth Sense or AbScent Organisation, which are available online.

https://www.fifthsense.org.uk/ and https://abscent.org/

Week 4 • Keep Going

04

Use a drop of essential oils in your bath every day.

Due to its intense nature, essential oils can help regulate your smell and improve your mind and body health.

Week 4 • Keep Going

05

Practice breathing and unwind every now and then to keep your mind at peace.

Breathing can help regulate your body. Keeping a positive attitude is the best key to cure.

Image 44: Online Prototype of the 4 week Intervention

Appendix 6.2: Online Feedback Workshop Plan

The workshop will be conducted in the LCC building Library in Elephant & Castle. The workshop will take part in 3 parts and will last 2 to 3 hours in duration. All the parts will be conducted on the same day.

Welcome the participants with Refreshments.

* No Arts Supplies need to be brought by the participants. All of them will be provided by the Researcher themselves.

Part 1: Ice Breaker

During this time, all the participants are expected to break the ice by introducing and talking about themselves and their daily routine. What they do for a living. They can discuss how and when they lost their sense of smell. If they have got it diagnosed and one of the quickest life-hack that they have found for this disorder.

Questions to ask the participants during this section:

1. When did they lose their sense of smell?

2. Did they gain it back?

3. Did they get a diagnosis for this or was it a part of COVID?

4. What was their feeling when they lost their sense of smell?

5. How did losing their sense of smell affect their life otherwise?

Part 2: Journey

In this section, the participants will be provided a customer journey mapping image on the laptop and explained how it works. Later, they will be provided with art supplies which can be used to plot the customer journey and all the pain points that they went through during their diagnosis phase. Collect all the pain points and allow the participants to discuss among themselves and provide collective feedback on the system.

Questions to ask the participants during this section:

1. What was their journey into diagnosis like?

2. Whom did they go to first?

3. What happened when they visited their first doctor?

4. How long was the wait time for each visits or tests?

5. What happened after they were diagnosed?

6. Were they given any pamphlets or something after the diagnosis to help them understand?

7. Were they told how to cope up with the loss in smell?

8. How did the nurses or doctors handle?

Part 3: Feedback

In this part, the participants will be provided with the toolkit and explained how and where it will be provided to the patient's post-diagnosis, and they will be asked to experience the output with respect to the user-experience and general experience of the output. They will then be asked to provide their feedback which will be collected using google forms or write-ups.