Research and Strategy Report

Developing a Popular Mobilisation Campaign around Digital Health & Health Data Governance amongst Youth in India

Table of contents

Part I

What's the Vibe?

Understanding Norms and Perceptions around Digital Health & Health Data Governance amongst Youth in India

Setting the Scene

The Sustainable Development Goals (SDGs), adopted by the United Nations in 2015, represent a global commitment to fostering sustainable development across various dimensions. Among these goals, SDG-3 outlines the fundamental health goal, aiming to "ensure healthy lives and promote well-being for all at all ages," reflecting the aspiration for comprehensive health and well-being for everyone. This notion of Universal Health Coverage (UHC) is set out in the International Convention on Economic, Social, and Cultural Rights and India ascended to the covenant in 1976.

Primary Health Care (PHC) serves as the essential "programmatic engine", vital for the implementation of Universal Health Coverage (UHC). Primary health care plays a pivotal role in supporting the health needs of individuals by addressing a broad spectrum of health services, ranging from health promotion and disease prevention to treatment, rehabilitation, and palliative care. One of the central tenets of Primary Health Care is its commitment to ensuring access to high-quality health services for all individuals, their families, and communities. The ultimate goal is to remove any financial barriers that may hinder people from obtaining essential medical assistance.

In a post-COVID world, there has been an acknowledgment of the immense value that digital technologies, particularly digital health interventions, can bring to the advancement of UHC. Here, digital health is seen to enable the public health infrastructure and institutional architecture to increase the scale of UHC.

Digital health encompasses various digital technologies used to support health and related fields. It includes mobile health (using wireless technology for health), electronic health records, tele-health, tele-medicine, wearable devices, robotics, and artificial intelligence (WHO, 2019)[1]. In 2020, India initiated the National Digital Health Mission (NDHM) to establish a national digital health ecosystem facilitating seamless health information exchange among various stakeholders in the healthcare system. The potential of digital health in India is substantial, especially given a robust IT sector, a thriving start-up ecosystem, as well as increasing mobile and broadband penetration. This has led to the development of the National Health Stack for data sharing and a dedicated teleconsultation platform.

Achieving universal health coverage in India, through "Digital Health for All" (National Digital Health Mission) is a multifaceted endeavour requiring a human-centred approach to ensure that digital health policies and interventions

---

[1] World Health Organization. (2019, June). Recommendations on digital interventions for health system strengthening. Retrieved from https://www.who.int/publications/i/item/9789241550505

effectively address real-world challenges. In view of UHC - Ayushman Bharat, India's flagship insurance scheme, also leverages digital health technologies under the National Digital Health Mission to enhance healthcare access and delivery to over 500 million people, offering subsidised and accessible healthcare to low-income households. [(ABDM Website)](#)[2]

Source: https://nha.gov.in/NDHM[3]

Digital Health in India

The ubiquitous digital technologies and innovations inform the healthcare landscape in India. These technologies include the use of digital tools, platforms, and data in healthcare delivery, management, and patient engagement. Along with this the experiences, challenges, and opportunities from use of technology shape the digital health landscape. Further, the digital health narrative

---

[2] Government of India. (n.d.). Ayushman Bharat National Health Protection Mission. Retrieved from https://www.india.gov.in/spotlight/ayushman-bharat-national-health-protection-mission
[3] National Health Authority. (n.d.). Ayushman Bharat Digital Mission. Retrieved from https://nha.gov.in/NDHM

encompasses discussions about the impact of technologies on healthcare systems, providers, patients, and society as a whole. It evolves as technological advancements, policy changes, and societal shifts shape the way one perceives and interacts with digital health solutions.

While internet penetration has shown consistent growth, the National Family Health Survey (NFHS, 2019–21) , however, shows a significantly larger gender gap in internet usage[4]. According to the NFHS 57.1% of the male population and only 33.3% of the female population have ever used the internet. Further, rural areas often experience lower digital literacy levels. This lack of digital health literacy also extends to healthcare providers, creating a critical gap in managing health information, privacy, and security. Challenges in rural-urban development, coupled with restrictive socio-cultural and gender norms, contribute to the limited access to digital infrastructure, hindering the potential to realise digital health benefits for all segments of society.

In the [Lancet, 2021 global survey][56], completed with over 23,000 young people, 88% were found to have used some form of digital technology for health-related purposes. The report also found that young people are apprehensive about online risks like cyberbullying, question the reliability of health information online, and are worried about their data privacy. Despite recognising the benefits of digital transformation such as improved accessibility, choice of digital health channels and new tools, their priority also remains in ensuring safety, trustworthy information, and data protection. In this context, it becomes important to assess how these global findings resonate with the current digital health context, and in particular, the understandings and perceptions of young people in India.

The current population of India is estimated to be more than 1,407 million (World Population Prospects, 2022). Fifty percent of the population is under the age of 25 and 65% below the age of 35 ([UN Department of Economic and Social Affairs)[7]. In this context where young people correspond to a significant proportion of the population, it becomes pivotal to understand how young people view digital health and data governance in their everyday lives.

The research conducted for this report aims to understand the broader context of digital health in relation to young people, with an emphasis on women and other marginalised groups. It also aims to understand young people's perception and

---

[4]National Family Health Survey (NFHS-5), India, 2019-21. International Institute for Population Sciences (IIPS) and ICF. 2021. Mumbai: IIPS. Retrieved from https://rchiips.org/nfhs/

[5] Tracking digital behaviours for young people globally.

[6] Governing Health Futures 2030 Commission. (2021). Governing health futures 2030: Growing up in a digital world. Youth Edition. Geneva. Retrieved from https://www.governinghealthfutures2030.org/

[7] United Nations Department of Economic and Social Affairs, Population Division. (2022). World Population Prospects 2022: Demographic indicators by region, subregion and country. Retrieved from https://population.un.org/wpp/

practices of digital health and data governance. These are aimed to generate key insights to support in the development of a communication campaign centred around young people.

About the Research

Kaboom is a social impact agency that responds to on-ground social and development challenges by designing powerful narratives, campaigns, and movements to enable social change. Kaboom Social Impact as a member of the Transform Health India Coalition, will actively work towards promoting digital health and increasing awareness of data governance in India, with a special focus on women, young people, and vulnerable groups.

Kaboom has undertaken this research to understand prevalent norms and perceptions around digital health and data governance. It also seeks to assess the existing knowledge, attitudes, as well as practices of women and youth in India, including those from the marginalised communities. The research will support the creation of a campaign strategy to inform the larger public narrative that will directly speak to audiences about their digital health.

As part of the research, a secondary literature review along with primary data collection was conducted. An understanding of the existing perception on digital health and digital health governance nationally was gained with Key Informant Interviews (KIIs). Kaboom analysed the existing narrative on digital health prevalent amongst the target audience (young people 18-35 years) with reference to dedicated FGDs conducted in Rajasthan. For the purpose of this study young people are defined as people between the ages of 18 and 35. This cohort was selected because of their extensive digital presence on social media and prevalent use and adoption of digital technologies, including healthcare. A Knowledge, Attitude and Practice (KAP) survey - rolled out nationally to understand knowledge, attitudes, and experiences of digital health and health data. The research was supported by a desk review of existing literature, media reports, etc.

Research Questions

- What is the prevalent community perception surrounding digital health, health data protection and privacy in India among young people?

- How do young people view and prioritise the importance of digital health and corresponding issues such as health data privacy and protection?

- What insights can be identified regarding the health and safety concerns of young people online that could contribute to the development of a communication campaign?

Methodology

The research utilised a **mix-method participatory approach** to collect qualitative and quantitative data, primarily to understand young people's perception and practices around digital health and digital security with a focus on women, and marginalised groups. The research utilised **purposive sampling** to gain specific insight with respect to various sub-cohorts as detailed in the sections below. The use of purposive sampling techniques was done based on the mandate for youth and gender-focus, while attempting to place emphasis on subjective experiences. The research did not attempt to generalise the findings for a broader population but **identified actionable steps/ insights for an iterative communication campaign development.**

As part of the study, due to time constraints, it was essential to prioritise selected health issues in order to gain deeper insights. The study is anchored around SRHR, as this is a priority health issue for young people, women, and other marginalised identities. SRHR is also a complex issue that raises key concerns about digital health, data privacy, and governance.

The research utilised three distinct methods as part of the primary data collection detailed below:

- **Key Informant Interviews (KII)** included domain experts who provided key information on digital health through their experience of either working on some aspect of digital health or their engagement on youth issues.

- **Knowledge, Attitudes, Practice (KAP) Survey** targeted young people across India (18-35 yrs) to gather insights that can be used to develop a digital campaign that will be rolled out online.

- **Focus Group Discussions (FGD)** were conducted with young people in Rajasthan (18-35 yrs) to support and align efforts of Transform Health Coalition's dedicated policy interventions in Rajasthan.

In the data analysis phase, the information acquired from **secondary research** as well as the **key informant interviews** was utilised to understand the **big picture** - the overview of the larger digital health context corresponding to government policies and program; influence of market and community on young people's digital health behaviour. The qualitative data from key informant interviews and

focus group discussions was analysed thematically, using a systematic coding process to identify **common themes** and understand **people's lived experiences, knowledge, understandings and perception of digital health**. The quantitative data from KAP surveys was analysed using **descriptive statistics**. The findings from both qualitative and quantitative data, using secondary and primary research, were **triangulated** to provide a comprehensive understanding of the research outcomes.

KII Overview

Fourteen key informant interviews (KIIs) were conducted to understand the context and perception surrounding digital health, health data protection, and privacy in India for young people. The 'informants' in this context were **experts** and **community leaders** working on digital health themes. These included - service providers (public and private); digital health technology and design specialists; policy and legal specialists; civil societies and implementing agencies; youth and gender specialists,, digital rights advocates and journalists.

The KIIs were conducted both online using Zoom and also in-person, with a dedicated interview schedule. The research team provided informed consent and choice to remain anonymous for participants. Each KII lasted for 50-90 minutes, depending on the direction of the interviews. The detailed list of the key informants and their expertise can be found below in **Table 1**.

#	Name of Key Informant	Affiliation/Organization	Type of Respondent
1	Sanjay Purohit	Societal Thinking	Technology Specialist.
2	Radharani Mitra	BBC Media Action	Communication & Campaign Expert
3	Kavita Ayyagari	Howard Delafield International	Youth Consumer Game Lead, Marketing Expert
4	Anonymous	Digital Health Social Business	Technology & Partnership Specialist

#	Name of Key Informant	Affiliation/Organization	Type of Respondent
5	Franklin Paul	Restless Development	Youth Organization Representative
6	Sameer Kanwar	PATH	Government Technology Advisory Expert
7	Alok Vajpeyi, Tejwinder Singh Anand	Population Foundation of India	Girl Centric SRHR & Online Safety Digital Platform
8	Ayesha Bashir	Independent	SRHR Activist & Communication Expert
9	Siddharth Shetty	Sahmati (Government Advisory & Advocacy)	Techno-legal & Data Architecture Expert
10	Dr Subhash Chandra Ghosh	YRG Care	Implementing Organization (Key Population)
11	Dr Jalpa Thakkar	John Hopkins University (Multilateral funded)	Public Health Specialist
12	Dr Pallavi Vinarkar	Family Planning Association of India	Health Service Provider
13	Anjali Kashyap	Durga Vahini	Youth Political Representative
14	Faye D'Souza	Beatroot News (Secondary Review)	Journalist

Table 1: List of Informants for KIIs

The KIIs provided an understanding of the **digital health context in India through lived experiences of the interviewees**. It also provided vital information on a range

of interventions, campaigns and various initiatives on digital health. It provided key information on implementation of digital transformation projects ranging from digital banking, digital health, to youth centric digital health projects and interventions. These interviews provided prevailing societal perceptions with direct and in-direct impact of digital health on young people, women and marginalised groups. Also, these KIIs provided critical information and viewpoints on how data governance is viewed by various stakeholders with respect to digital health data. Through these KIIs key stakeholders and relevant partners for the upcoming communication campaign were also identified.

FGD Overview

In understanding the young people's use of digital health platforms - **four FGDs were conducted with young people (18-35 yrs)**. The focus group discussions (FGDs) were conducted in Jaipur, the capital of Rajasthan. The participants included college students and working professionals living in Jaipur. The minimum education level for participants was completion of schooling. Basic digital literacy was a general recruitment criterion for participant selection, so they could engage and share their digital experiences in the FGDs. The FGDs aimed to understand **how they use digital platforms** to access health information and services along with their experiences and **challenges** in accessing digital platforms for health or related fields. The FGDs, involved sensitive topics such as **sexual and reproductive health and rights (SRHR)**. Ensuring participant privacy, confidentiality, and informed consent became crucial to protect the rights and well-being of the participants and were ensured through seeking informed consent.

Employing participatory tools, the FGDs fostered participant interactions and facilitated valuable insights in a targeted manner within four distinct groups to accurately capture key information rapidly .

In order to gain access to the focus groups, Kaboom collaborated with partner organisations in Jaipur. As part of this collaboration, the partner organisations also nominated session facilitators to ease communication with the beneficiary groups. Prior to the FGDs, facilitators received comprehensive orientation, ensuring their alignment with the research objectives.

Within the focus groups, four digital health scenarios were delineated, providing a framework for participants to share their personal digital health experiences. The design tool underwent iterative refinement based on internal testing, feedback from community partners and facilitators, who possessed extensive experience in addressing a variety of health issues among young individuals.

FOCUS GROUP DISCUSSION
CONDUCTED IN JAIPUR, ORGANISED INTO 4 DEDICATED GROUPS

Notably, participants provided informed consent before engaging in the research process. The FGDs were exclusively conducted in Jaipur, Rajasthan, organised into four dedicated groups with 24 participants as outlined in Table 2. Each FGD was conducted over a two-hour duration, incorporating breaks as per the participants' requirements.

Group Number	FGD Group	Age	Number of Participants
1.	Young Women	18-24 Yrs	6
2.	Women	25-35 Yrs	10
3.	Young Men	18-24 Yrs	5
4.	Young LGBTQ+	18-35 Yrs	3

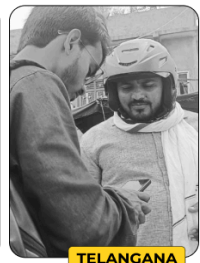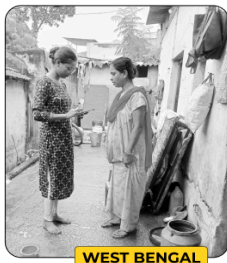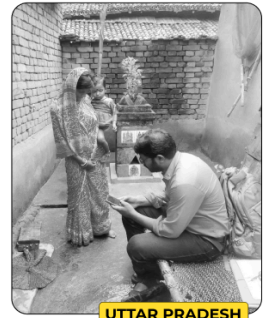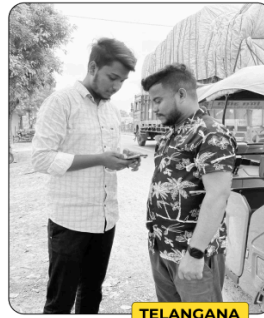**Table 2: FGD Participant Groups**

KAP Overview

A survey aimed at assessing the **knowledge, attitudes, and practices (KAP)** of young individuals, with a specific emphasis on their behaviour related to digital health, was undertaken. This survey sought to uncover prevalent experiences among young people, particularly focusing on their digital interactions with a focus on understanding their knowledge levels, concerns, feelings and digital safety behaviours. An **online survey tool** was meticulously developed, including user-testing and translation, prior to its distribution online. The reliance on self-reported data through surveys and interviews could have been subject to bias. Participants may have provided socially desirable responses or may not have accurately recalled or reported their experiences, attitudes, and practices related to digital health. In order to circumvent this, Kaboom engaged a combination of **self-reporting** (via digital dissemination) and a **field data collection team**, collaborating with partner organisations to execute this KAP survey.

As part of the survey dissemination process, Kaboom partnered with digital and on-ground implementation partners. The digital partners disseminated the survey within their professional and beneficiaries networks. Whereas, the on-ground partners conducted the surveys amid respondents from their local neighbourhoods. Through this approach, the Kaboom team could ensure that the survey was nationally distributed and representative of young people, with an emphasis on women and socio-economically marginalised populations. The partner organisations have been provided in the Annexure.

KAP SURVEY
CONDUCTED ACROSS DIFFERENT STATES IN INDIA

UTTAR PRADESH | WEST BENGAL | TELANGANA | UTTAR PRADESH

WEST BENGAL | WEST BENGAL | TELANGANA | TELANGANA

The KAP survey encompassed a diverse participant pool, of which **548 responses** were utilised, representing a wide spectrum of youth, nation-wide aged 18 to 35. A breakdown of the respondents is depicted below. To elaborate, this inclusivity extended to encompass women, individuals from sexual and gender diverse backgrounds, geographical regions, and marginalised communities such as urban poor, caste minorities and tribal populations, characterised by limited access to digital resources.

18%
31-35 Years

47%
18-24 Years

35%
25-30 Years

AGE
DISTRIBUTION

1%
Others*

40%
Males

58%
Females

GENDER
DISTRIBUTION
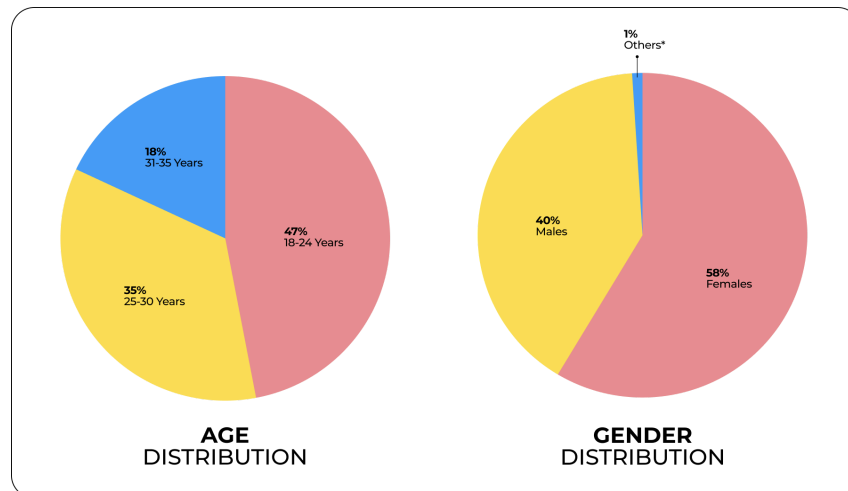
Source: KAP Survey (n=548)

STATE-WISE DISTRIBUTION

Bar chart — NUMBER OF RESPONDENTS by STATES:

- Uttar Pradesh: 159
- West Bengal: 108
- Delhi: 64
- Telangana: 42
- Bihar: 38
- Rajasthan: 22
- Jharkhand: 18
- Karnataka: 17
- Maharashtra: 12
- Assam: 11
- Tamil Nadu: 8
- Uttarakhand: 7
- Kerala: 7
- Gujarat: 7
- Haryana: 6
- Andhra Pradesh: 5
- Madhya Pradesh: 4
- Goa: 4
- Nagaland: 2
- Puducherry: 1
- Odisha: 1
- Manipur: 1
- Ladakh: 1
- Himachal Pradesh: 1
- Chandigarh: 1
- Arunachal Pradesh: 1
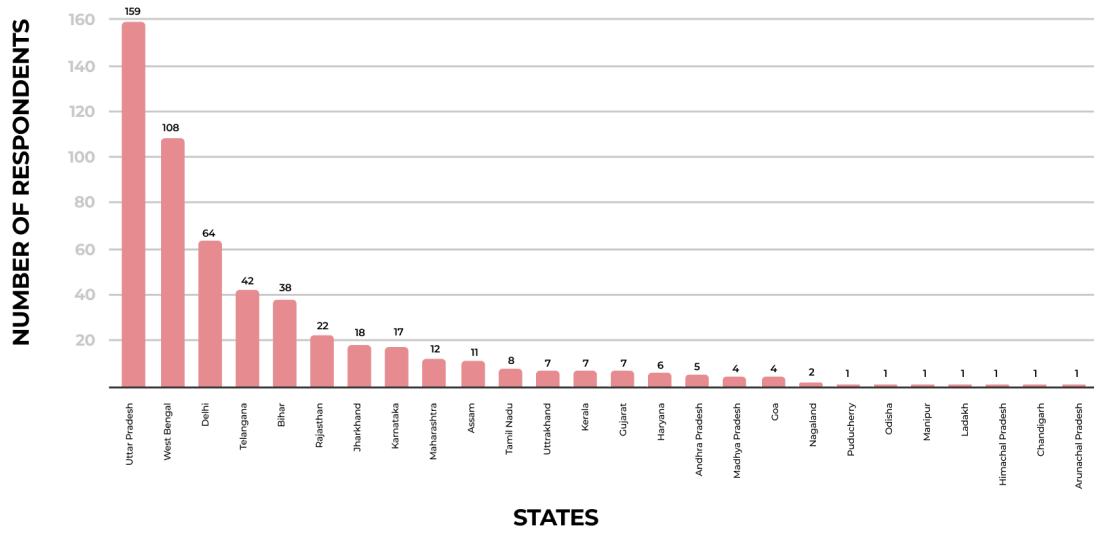
Source: KAP Survey (n=548)

TYPE OF SMARTPHONE USED

- FEMALES: 13.8% (Shared), 86.2% (Personal)
- MALES: 7.7% (Shared), 92.3% Personal
- OTHERS: 100% Personal
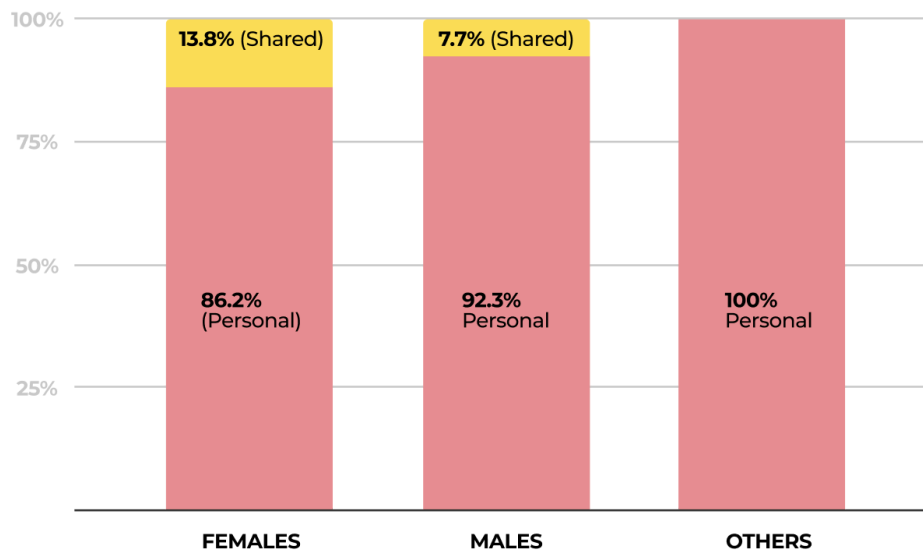
Source: KAP Survey (n=548)

Challenges

The Kaboom team encountered the following challenges in undertaking this research:

- **Connecting with partners remotely and convincing them to join this research with no partnership budget or remuneration to surveyors.** In order to convince partners to join the research, the potential benefits of the research, identifying common strategic objectives and the need to gather evidence to further advocate was shared to bring partners on board based on former relationships and sharing possibilities of this research for future scope of work and partnership.

- **Identifying key points of intersection in the work undertaken by Kaboom and the partner, to form a mutually beneficial collaboration.** It was observed that every organisation and initiative has been contributing to something meaningful to digital health and how Kaboom intends to support in bringing various interests in a meaningful manner.

- **Gaining access to organisation reports, knowledge material, etc.** that verify lived experiences has been difficult. Given the novel nature of digital health and data governance work- many organisations wanted to publish their work- before sharing it in public. This limitation was recognised, and the resources available online and media reports were utilised for knowledge generation.

- **Translating the KAP survey from English to Hindi** was challenging due to the different linguistic nuances and the need to contextualise key digital and health terms for self-reporting purposes. Three rounds of testing the data tool and translation with an expert translator was conducted to ensure that the translation was easily understood by young people for self-reporting.

- **Gaining access to certain key sets of groups such as LGBTQ participants** was difficult due to the lack of monetary incentives. The group was most challenging to gain access due to strong community norms and ethical limitations set by participants there and information without an incentive exchange. This was addressed by using established community networks and through establishing one-on-one relationships with LGBTQ individuals.

Research Limitations

It was important to acknowledge and address the potential limitations to ensure that the research was ethically conducted, as well as to appropriately interpret and apply the findings to inform communication campaigns and mobilisation efforts centred around digital health and data governance.

- **Purposive Sampling:** The use of purposive sampling techniques was done based on the mandate for youth and gender-focus while attempting to place emphasis on subjective experiences. The research did not attempt to generalise the findings for a broader population but identified actionable steps/insights for an iterative communication campaign development.

- **Limited Representation:** While efforts were made to include diverse perspectives and marginalised groups, the selection of participants may still not have captured the full range of experiences and perspectives within these groups. These results lend a limited understanding of the digital health rights concerns and gendered nuances, which were attempted to be captured here.

- **Subjectivity in Data Analysis:** The thematic analysis of qualitative data and the coding process may have involved subjective interpretation by the research team. The subjectivity introduced the possibility of bias or misinterpretation, which could have impacted the validity and reliability of the findings. These were, however, tested for developing action points.

- **Self-Reporting Bias:** The reliance on self-reported data through surveys and interviews may have been subject to bias. Participants may have provided socially desirable responses or may not have accurately recalled or reported their experiences, attitudes, and practices related to digital health.

- **Ethical Considerations:** The research, especially FGDs, involved sensitive topics such as sexual & reproductive health and rights (SRHR). Ensuring participant privacy, confidentiality, and informed consent became crucial to protect the rights and well-being of the participants and were ensured through seeking informed consent.

- **Anchor in health issue:** As part of the study, it was essential to prioritise selected health issues in order to gain deeper insights. The study is anchored around SRHR, as this is a priority health issue for young people, women, and other marginalised identities. SRHR is also a complex issue that raises key concerns about digital health data, privacy, and governance.

The Big Picture

The narrative on digital health is rapidly evolving and is shaped by various stakeholders. Specifically, understanding the perspectives of the government, market, and the community can help us understand how these forces shape the future of digital health for young people.

Government

The government plays a major role in developing the techno-legal and policy framework, where digital health operates through regulations and funding. It essentially provides the operational framework for policy design, implementation, and monitoring.

Market
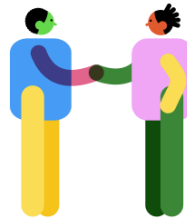
The market is a major driver of digital health innovation including larger and small businesses. There is a growing emergence and stake of technology and pharmaceutical companies to develop system and consumer-facing digital health solutions.

Community

The community, consisting of general citizen groups remains the prime stakeholder in digital health is impacted by the state and market. These groups play a role in shaping the demand, development and adoption of digital health.

Government Perspective

The **Ayushman Bharat Digital Mission (ABDM)** is an initiative to revolutionise India's healthcare system through digital transformation, similar to the success of the Jan Dhan-Aadhaar-Mobile (JAM) trinity in banking. ABDM aims to create a unified digital health infrastructure, leveraging unique IDs, registry systems, and data analytics. The approach enhances accessibility, efficiency, and affordability in healthcare.

Ayushman Bharat: Building Blocks

ABDM has three main building blocks:
Health Facility Registry (HFR): A comprehensive repository of all health facilities in India, both public and private. **Health Professional Registry (HPR):** A registry of all health professionals in India, including doctors, nurses, and other healthcare providers. **Ayushman Bharat Health Account (ABHA):** A unique health ID for every Indian citizen.
ABDM has two system-level building blocks:
Universal Health Interface (UHI): A standard API that allows different health systems to communicate with each other. **Health Claim Exchange (HCE):** A platform that allows patients to file health claims seamlessly across different insurance providers.

---

[8] Agarwal, A. (2023, March 21). India has taken 'quantum leap' in digital health: Mandaviya at WHO-led conference in Delhi. Times CNBC TV18. Retrieved from https://www.cnbctv18.com/healthcare/mansukh-mandaviya-digital-health-india-data-artificial-intelligence-delhi-who-global-conference-marshall-islands-16219891.htm

Fin-tech Success Paving the Way for Digital Health Transformation

The Ayushman Bharat Digital Mission (ABDM) is attempting to adapt the success of the Jan Dhan-Aadhaar-Mobile (JAM) trinity - which has been used as the building blocks, to revolutionise the banking sector in India. The implementation of Aadhaar significantly improved gender and youth disparities in bank ownership.

The JAM trinity refers to three government initiatives:

- **Jan Dhan Yojana (financial inclusion program)**
  It supported opening bank accounts for millions of Indians, previously unbanked.

- **Aadhaar (unique identification program)**
  This program provides a unique digital identification number to over 1.3 billion Indians linking them to various services.

- **Mobile Number Portability (MNP) system**
  This system allows people to switch mobile phone operators without losing their phone number.

The JAM trinity has made it possible for people to access financial services more easily and securely. ABDM aims to do the same for healthcare services by allowing and integrating public and private providers to create software and applications that can be used to access healthcare and health records.

"Aadhaar: Your Digital Identity, Your Future" Impact of Aadhaar on Bank Account Ownership in India - Addressing Gender and Youth Gaps

As per a report by World Bank (2017[9]) till 2008, 2% of men and 65% of people over the age of 35 years had bank accounts in India. On the contrary, only 24% of women and 35% of people under the age of 35 had bank accounts in India due to various structural barriers.

In 2010, the implementation of Aadhaar, a unique biometric identification system in India, brought about a transformative impact on the country's financial landscape. It simplified the opening of bank accounts. It contributes to reducing

---

9 Banerjee, A. V., Duflo., Glennerster, R., & Khemani's. (2017). Aadhaar: Digital Inclusion and Public Services in India. Washington, DC: World Bank.Retrieved from https://thedocs.worldbank.org/en/doc/655801461250682317-0050022016/original/WDR16BPAadhaarPaperBanerjee.pdf

gender and youth disparities in bank account ownership, fostering greater financial inclusion. Aadhaar's introduction led to a 58% increase in the number of bank accounts held by women and a remarkable 71% increase in accounts held by individuals under 35 between 2014 and 2017.

"Dil ke Account se: PayTM Karo" Empowering Small Businesses Through Digital Payments - Redistributing Financial Authority

Small businesses in India, crucial contributors to the economy, have historically faced challenges in accepting digital payments due to costs and infrastructure requirements. The emergence of UPI (Unified Payments Interface) has brought transformative changes to this landscape.

UPI's influence has expanded the reach of digital payments, with the number of POS machines growing from 5-6 million in 2016 to over 120 million in 2023, and QR code acceptance points increasing from 50,000 to 12 million. (Source: Key Informant)

The growth has not only facilitated small businesses but has also heightened customer awareness of digital payment options. UPI's continued growth has enhanced digital payment adoption, benefiting both small businesses and consumers.

Data sovereignty and **open-source technologies** are central to ABDM's approach, allowing individuals to link data sources and initiate consent requests. However, the journey to widespread adoption is in its nascent stages, requiring efforts to establish trust and proficiency in interacting with these systems.

In the healthcare context, digital health is evolving similarly to the progress of digital banking.

"We are extremely comfortable today with using UPI for rickshaws, taxis, or even a chaiwala (tea-vendor). In a couple of years, we have become very comfortable with it. It's only now a mental hurdle that we can't do a similar thing with health. That's exactly how healthcare is going to operate."
- Sameer Kumawat, PATH

The **implementation of innovative systems,** like Digilockers, and the application of lessons from digital banking will shape the trajectory of digital health, driving advancements in data management and customisation.

The rollout of ABDM is anticipated to drive further **data management advancements**, influencing the trajectory of digital health's maturity. The understanding of consent in emergency situations and its evolving nature for health data is a key consideration in this journey.

Overall, the adaptation of successful digital transformation strategies from banking to healthcare is expected to shape the trajectory of digital health, refining policies, and addressing evolving consent challenges.

Health System Strengthening: Telemedicine

A study examined telemedicine's influence on primary healthcare in Jharkhand, India by Agarwal et. al. (2023)[10] using a before-and-after approach. The study compared data from 401 patients utilising telemedicine with data from 200 patients without such services. **The study found that telemedicine improved care accessibility, enhanced quality, and reduced costs**. It led to higher satisfaction levels among telemedicine users (80%) to non-users (60%) and reduced expenses- ₹1200 (in-person) to ₹900 (telemedicine consultations).

In India e-Sanjeevani, the telemedicine platform that was launched by the Government of India in 2019 supports remote consultation between patients and doctors. Since COVID-19, the telemedicine interventions have also gained substantial traction in how they have enabled access, reduced health expenses, and ensured quality service in rural areas.

Fragmented Consent Management

Fragmented Architecture: The federated architecture of consent management is a design pattern in enterprise architecture that enables interoperability and information sharing between semi-autonomous, decentralised entities, information technology (IT) systems, and applications as described in the following diagram.

---

[10] Agarwal, A., Tiwary, A., Kumar, S., & Singh, V. (2023). Impact of telemedicine services on primary health care: Before and after analysis–Jharkhand digital dispensary model. International Journal of Community Medicine and Public Health. Retrieved from
https://www.ijcmph.com/index.php/ijcmph/article/view/10898#:~:text=Conclusions%3A%20Telemedicine%20is%20strong%20enabler,system%20by%20reaching%20the%20unreached
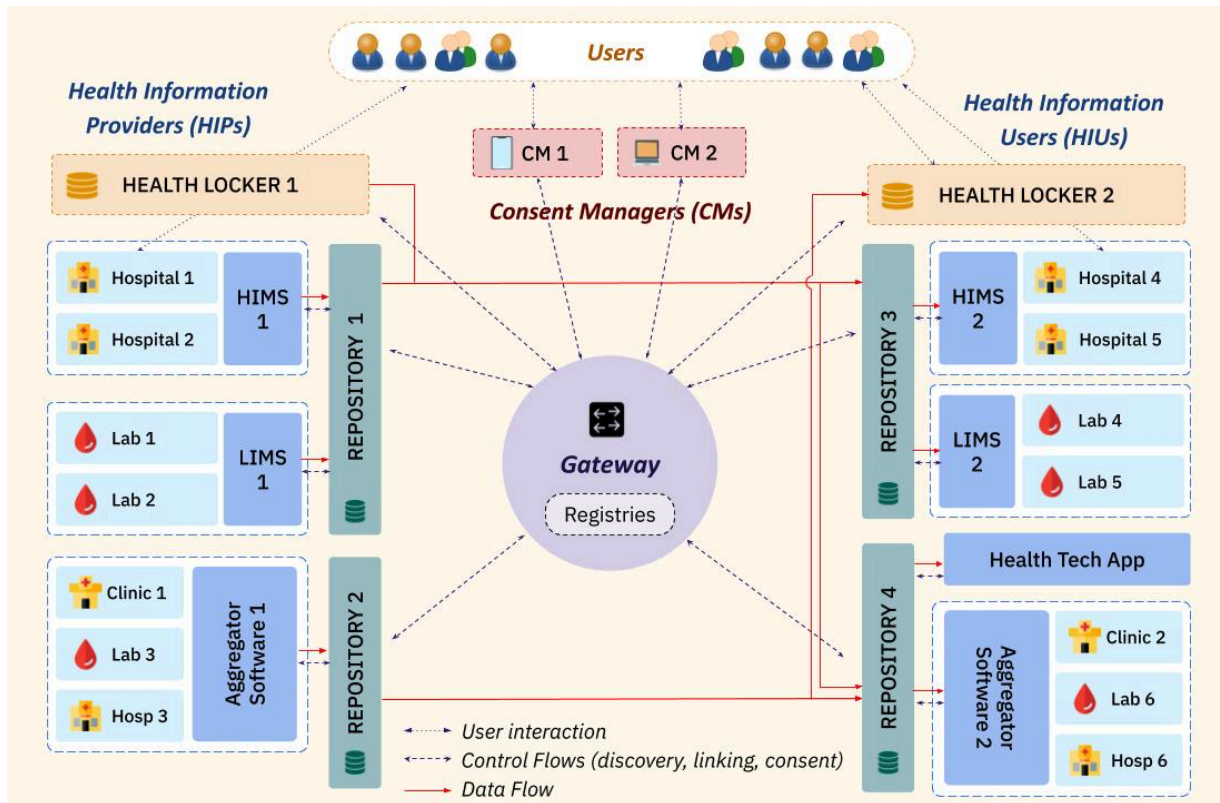
Data Sovereignty and Open-Source Technologies: A Paradigm Shift

In this evolving landscape of data management, a notable shift is observed towards preserving data at its source while harnessing the capabilities of open-source technologies. This progressive approach involves individuals linking their data sources to third-party platforms like UPI (Unified Payments Interface). These platforms then initiate consent requests that delineate the specific timeframes and purposes for which data can be utilised. Through the implementation of encryption, data extraction, and transmission mechanisms, the transformation from physical to digital collateral is facilitated.

Early Stages: Navigating Consent and Trust

As this novel approach gains traction, it is crucial to recognize that the journey is still in its nascent stages. To fully embrace this paradigm, individuals must grow accustomed to the act of granting consent and interacting with these emerging systems. Establishing trust in interoperable systems emerges as a paramount challenge that requires meticulous attention. The path to widespread adoption involves not only technical proficiency but also the creation of a conducive environment where individuals feel secure in utilising these innovative platforms.

Parallel Realities: Personal Data Management and Health Ecosystem

Drawing parallels, similar systems have been devised for personal data management, albeit catering to distinct use cases. Notably, the healthcare ecosystem in India operates within a relatively less regulated framework compared to the intricacies of the financial sector. In a relatable context, the concept of Digilockers mirrors certain attributes, functioning as a repository for diverse data forms, including the emergent sources like e-commerce transactions. While digital banking has made substantial strides in operational efficiency, the domain of digital health is still in its formative stages.

Future Outlook: Catalyst for Refinement

As these innovative systems are poised for rollout, they are anticipated to catalyse further advancements in the landscape of data management. These implementations will offer invaluable insights that shape the customization and enhancement of their application within the broader healthcare sector. The trajectory of digital health will be significantly influenced by these early developments, as lessons learned and refinements made will play a pivotal role in shaping its trajectory towards maturity.

The Digital Personal Protection Act

In August 2023, the Digital Personal Data Protection Act, 2023 was enacted to safeguard personal data processing. The interpretation, implementation, citizen empowerment, and impact on equitable competition remain subjects of scrutiny (Bar and Bench, 2023)[11]

The Act aims to protect the privacy of individuals in relation to the processing of their personal data. It also defines processing of personal data as any operation or set of operations that is performed on personal data, such as collecting, storing, using, disclosing, or transferring it.

The Digital Personal Data Protection Act, 2023 (the Act) is a new law that has been passed by the Indian Parliament. The Act aims to protect the privacy of individuals by regulating the processing of their personal data.

The Act defines personal data as any information that can be used to identify an individual. This includes information such as name, address, phone number, email address, and biometric data.

The Act applies to the processing of personal data in India, including both online and offline data. The Act also applies to the processing of personal data outside

---

[11] Ahuja, I., & Kapadia, S. (2023, August 22). Digital Personal Data Protection Act, 2023 – A Brief Analysis. Bar & Bench. Retrieved from https://www.barandbench.com/law-firms/view-point/digital-personal-data-protection-act-2023-a-brief-analysis

India if the data is related to the offering of goods or services to individuals in India. The Act sets out a number of principles that must be followed when processing personal data. These principles include:

Consent: Personal data can only be processed with the consent of the individual.

Purpose limitation: Personal data can only be processed for the purposes for which it was collected.

Data minimization: Only the necessary personal data should be collected and processed.

Storage limitation: Personal data should only be stored for as long as necessary.

Accuracy: Personal data should be accurate and up-to-date.

Security: Personal data should be protected against unauthorised access, use, disclosure, or destruction.

Individual rights: Individuals have a number of rights with respect to their personal data, such as the right to access, correct, and delete their data.

Institution Formed: The Act also establishes a Data Protection Board (DPB) to oversee the implementation of the Act. The DPB will have a number of powers, including the power to investigate complaints, impose penalties, and issue directions.

Rights & Accountability: The Act is a significant piece of legislation that will help to protect the privacy of individuals in India. It is important for businesses and organisations to be aware of the Act and to comply with its requirements.

Source: Bar and Bench (2023)[12]

The digital protection and regulations leave a big room open for interpretation and how regulation actually operates - when a law has been just passed. When we think of regulation, the question arises - are these regulations for private entities or it also becomes a legitimate means to surveillance and control. Also, how does it empower citizens? How the new regulation creates a level playing field.

Digital Personal Protection

raises The following quote exemplifies the existing situation related to digital health and health data governance in India

---

[12] Ahuja, I., & Kapadia, S. (2023, August 22). Digital Personal Data Protection Act, 2023 – A Brief Analysis. Bar & Bench. Retrieved from
https://www.barandbench.com/law-firms/view-point/digital-personal-data-protection-act-2023-a-brief-analysis

A lot of people don't know that many of us have Ayushman Bharat Health Account IDs - as these were created from the CoWIN platform. In many cases, these IDs were automatically generated, without any information or consent from the user, when we booked our vaccination slots.

- Anonymous, Digital Health Social Business Technology Specialist

This raises important questions around how health IDs are designed and how consent becomes pivotal. Along with this, large medical institutions witnessing cyber attacks raises key questions on the importance of robust cybersecurity measures in protecting sensitive healthcare data. It raises the need for having strong cybersecurity systems in place to protect their data from attack.

Vaccination Data Breach

The CoWIN portal is a centralised digital platform that was developed by the Government of India to manage the COVID-19 vaccination program. The portal allows citizens to register for vaccination, book vaccination slots, and track their vaccination status.

- On June 12, 2023, reports emerged that a data breach had occurred on the CoWIN portal. The data that was leaked included names, Aadhaar numbers, and phone numbers of people who had been vaccinated.
- A Telegram bot has been able to access the CoWIN data from a third-party database. The government proceeded with investigating the matter and steps to strengthen the security of the CoWIN portal.

Source: Hindu, (2023)[13]

Cyber Attack in one of India's Biggest Government Hospital

- On June 6, 2023, All India Institute of Medical Sciences (AIIMS) in New Delhi faced a renewed cyber threat as it thwarted a malware attack on its systems. Swift action by AIIMS' cybersecurity systems prevented any data breach or disruption in patient services.
- A similar attack in November 2022, the hospital's servers were compromised, causing service disruptions and necessitating the implementation of Standard Operating Procedures (SoP) as an alternative to manual processes.

---

[13] Perappadan, B. S. (2023, June 12). CoWIN vaccination data out, Centre denies breach. The Hindu. https://www.thehindu.com/news/national/health-ministry-responds-to-massive-cowin-data-breach/article66960250.ece.

- The collaborative investigation involving multiple agencies including Delhi Police, CERT-In, NIC, and NIA further highlighted the seriousness of the situation.
- The incident underscored the essential role of robust cybersecurity measures in safeguarding critical infrastructure and protecting sensitive healthcare data from evolving cyber risks.

Source: ABP News (2023)[14]

Market Perspective

"India today is one of the largest and most exciting markets for technology companies to build and if you look at the potential for cloud, all the cloud penetration in India is still in single digits. The role of healthcare and health tech organisations is pivotal,"

- Puneet Chandok, President, AWS India and South Asia.

Source: Business Today, 2023[15]

The success of the National Digital Health Mission (NDHM) is dependent on its wide adoption by both the Centre and State governments, as well as public and private entities. Its adoption rests heavily upon the clear definition of the role and responsibilities of NDHM (NDHM, Blueprint, 2020)[16]. Big tech and the private sector are significantly contributing to healthcare transformation. These initiatives have greatly impacted India's digital health landscape. Few large initiatives have been listed here -

WhatsApp Incubation Program for Health Interventions: It provided start-ups with incubation support to leverage WhatsApp Business Platform to facilitate health interventions at scale, enabling organisations to provide impactful health

---

[14] Another Cyber Attack At Delhi AIIMS, No Data Breach Says Hospital. (2023, June). ABP News.https://news.abplive.com/news/india/aiims-new-delhi-reports-malware-attack-services-functional-no-breach-detected-1607339

[15] Sharma, N. C. (2023, June 05). Amazon Web Services wants to invest more in health and pharma market; here's why. Business Today. Retrieved from https://www.businesstoday.in/latest/corporate/story/amazon-web-services-wants-to-invest-more-in-health-and-pharma-market-heres-why-377290-2023-04-13

[16] Ministry of Health & Family Welfare, Government of India. (2020). National Digital Health Blueprint (NDHB). Retrieved from https://main.mohfw.gov.in/sites/default/files/Final%20NDHB%20report_0.pdf

services and information to a broader audience. (Source: Economic Times, 2021)[17]

Microsoft & AIIMS Jodhpur's Mixed Reality Initiative: The partnership aims to digitally innovate medical education, healthcare services, and research for improved patient care and medical knowledge dissemination. (Source: Times of India, 2022)[18]

Google & Apollo Health Collaboration for Medical Insights: The collaboration aims to develop AI-powered tools, enhancing medical diagnosis and interpretation, notably for medical prescriptions and identification of conditions such as tuberculosis in X-ray results.

(Source: Analytica Magazine, 2021[19])

As big tech's role expands, the impact on small businesses in healthcare remains an area of exploration on health data.

Within the **SRHR** space, the integration of chatbots and virtual platforms with social media and dating platforms in youth-centric digital health initiatives has been a creative way to enhance engagement. However it poses privacy and security challenges. Redirecting users to third-party platforms as part of service linkage compromised data protection, posing risks to users' personal information. Other potential risks related to data collection, sharing, misuse, security vulnerabilities, and lack of transparency remain. A list of popular platforms have been provided below:

#	Chatbots/ Virtual Platforms	Outreach Channels	States
1	Just Ask!	UNFPA India Website, WhatsApp messaging platform	Madhya Pradesh and Pan-India
2	Disha Didi	Ipas Development Foundation website, WhatsApp messaging	Jharkhand, Madhya Pradesh

[17] Chaturvedi, A. (2021). WhatsApp launches incubator programme to help organisations build digital solutions for healthcare issues. The Economic Times. Retrieved from https://economictimes.indiatimes.com/tech/technology/whatsapp-launches-incubator-programme-to-help-organisations-build-digital-solutions-for-healthcare-issues/articleshow/88121441.cms?from=mdr

[18] AIIMS Jodhpur collaborates with Microsoft India to set up Mixed Reality (2022) The Times of India http://timesofindia.indiatimes.com/articleshow/91545058.cms?utm_source=contentofinterest&utm_medium=text&utm_campaign=cppst

[19] Google Uses Apollo Hospitals' X-Ray Data To Identify Chest Abnormalities. (2021, September 6). Analytics India Magazine. Retrieved from https://analyticsindiamag.com/google-uses-apollo-hospitals-x-ray-data-to-identify-chest-abnormalities/

#	Chatbots/ Virtual Platforms	Outreach Channels	States
		platform	
3	SnehAI	Population Foundation of India website, WhatsApp & Facebook Messenger	Pan-India
4	Bol Behen	WhatsApp messaging platform	North India (BolBehen)
5	MiMo	Mysuru Mithra website, WhatsApp messaging platform	Bihar, Rajasthan, Uttar Pradesh, Assam, Maharashtra, North India, Pan-India
7	AskNIVI	Ask Nivi website, WhatsApp messaging platform	Bihar, Rajasthan, UP, Assam, Jharkhand, Pan-India
8	Use a Pill	WomenFirst Digital Website chatbot	Pan-India
9	AskParo	Go Nisha Go Website and Game	Rajasthan, Bihar & Delhi
10	Safe Zindagi	Safe Zindagi Website, Grindr, Blued, etc. Dating Apps	Pan-India

Table 3: Youth Centric Digital Health Platforms in India

Examining Youth Centric Digital Health Platforms

In the segment of digital health engagement for young individuals, the integration of chatbots and virtual platforms with Social Media Platforms and Dating Platforms presents a unique landscape. This convergence is primarily driven by the aim to maximise outreach and engagement among the target demographic. However, several nuances and associated concerns may not be immediately evident to young people seeking health information online. There are several associated risks ranging from:

● **Data Collection and Storage:** The personal data acquired during user interactions - encompassing sensitive details such as name, age, location, and

sexual orientation - might not be safeguarded adequately. This exposes users to potential breaches of their personal information, compromising their privacy.

- **Data Sharing:** User data, harvested during health-related engagements, can be shared with third parties for targeted advertisements. This exchange of information could infringe upon user privacy and make them susceptible to manipulative marketing practices.

- **Data Misuse:** The proliferation of data can give rise to unscrupulous activities, including the creation of fake profiles, scams, and the dissemination of misinformation. Young individuals seeking genuine health information could inadvertently become targets of such deceptive practices.

- **Security Vulnerabilities:** Resource limitations in platform development might render them vulnerable to security breaches. It could result in unauthorised access to user data, potentially endangering the privacy of the very individuals they intend to support.

- **Lack of Transparency:** Clear and comprehensive communication regarding data practices may be absent, leaving users uncertain about how their information is handled. The lack of transparency could foster mistrust and undermine the credibility of these digital health platforms.

Market Regulation for Technology Platforms

The market regulations for the private sector in the NDHM are designed to create a level playing field and to ensure that the private sector plays a responsible role in the development and delivery of digital health solutions. These regulations become essential to protect the privacy and security of health data and to ensure that patients have access to high-quality digital health solutions.

Key market regulations for the private sector in the NDHM include:

Interoperability: The NDHM requires that digital health solutions be interoperable, meaning that they can be used to exchange data with other systems. This will make it easier for patients to access their health records and for healthcare providers to collaborate.

Security: The NDHM requires that digital health solutions be secure, meaning that they protect the privacy and security of health data. This is essential to ensure that patients' data is safe and that it is not misused.

Transparency: The NDHM requires that digital health solutions be transparent, meaning that patients and healthcare providers should be aware of how their data is being used. This will help to build trust and confidence in digital health solutions.

Standards: The NDHM requires that digital health solutions meet certain standards, such as those for health data governance and privacy. This will help to ensure that the quality of digital health solutions is high.

Source: NDHM, Blueprint, 2020[20]

The NDHM requires that digital health solutions comply with all applicable laws and regulations. This will help to ensure that the private sector plays a responsible role in the development and delivery of digital health solutions. **This, however, is not clearly answered -** the overall understanding remains fragmented - how do these regulations operate, especially when the health regulations remain compromised to begin with. When we talk about a fair playing field, are we actually helping small businesses succeed, especially with big tech companies dominating digital health?

---

[20] **Ministry of Health & Family Welfare, Government of India. (2021). National Digital Health Blueprint (NDHB). Retrieved from https://main.mohfw.gov.in/sites/default/files/Final%20NDHB%20report_0.pdf**

Community Perspective - Youth Narrative

Considering Transform Health's focus on young people, this section describes community perspective through an emphasis of the youth narrative in India. The youth narrative around digital health is shaped by adoption of digital technologies, key health concerns along with socio-economic factors, including family and cultural dynamics, access to health services. Based on the primary data, a framework was developed to represent the findings in a meaningful manner to understand the youth narrative. The thematic analysis of qualitative data and the coding process may have involved subjective interpretation by the research team. The subjectivity introduced the possibility of bias or misinterpretation, which could have impacted the validity and reliability of the findings. These were, however, tested for developing action points. **The data analysis framework for understanding the youth narrative encompasses two key components: youth digital behaviours and digital health behaviours.**

Digital Behaviour of Young People

This component captures the different ways that young people use digital technologies, including their phone usage, content consumption, and online interactions.

By understanding these behaviours, we can get a better understanding of how young people are using digital technologies in their everyday lives.

This information will help to understand digital consumption patterns and inform the campaign on digital health and data governance to the immediate digital realities of young people.

Digital Health Behaviour of Young People

This component captures what dictates young peoples digital health behaviour, the specific ways that young people use digital technologies for health-related purposes. This includes things like seeking health information online, managing chronic conditions, and connecting with healthcare providers.

By understanding these behaviours, we can get a better understanding of how young people are using digital technologies to improve their health.

This information can support in identifying the end-user, their motivations, fears, and concerns supporting campaign strategy ideation.

By capturing phone use, and content consumption, a comprehensive understanding of youth digital behaviour can be achieved, providing valuable insights into their online habits, preferences, and interactions. The FGD and KAP data supported in identifying key themes on digital health behaviour. **The following four important questions aims to capture behavioural trends of young people:**

1. **What are the socio-economic factors (external) that dictate young people's digital health behaviour?**

2. **What are the motivational factors (internal) leading young people to go online for healthcare?**

3. **How does seeking health information online influence the everyday digital behaviour of young people?**

4. **How do young individuals address a new set of challenges while seeking health information online?**

   Through the research Kaboom found that young people often struggle to understand and differentiate between the broader concept of "digital" and "digital health," and what it truly encompasses. For some, it refers to the use of technology to improve health outcomes. This could include things like using wearable devices to track fitness, using telemedicine to consult with a doctor, or using mobile apps to manage chronic conditions. For others, digital health refers to the use of technology to gather and share health information. For many young people it also could include things like using social media to connect with other young people seeking health information on social media, accessing online health communities to learn about health conditions, or using health data to track trends in public health.

   So, what does digital health mean to young people?

   An understanding of digital health is still evolving, but it is clear that it is more than just searching for health information online. **It is open, not completely understood, unless oriented differently.** Beyond this, young people also have trust issues on social media platforms and severe concerns to use it for intimate health purposes because social media is often linked to misinformation. **They use digital health tools all the time, but don't often think about it as "digital health". It shows that the everyday digital health is not very conscious for most[21].**

---

[21] Understanding developed from primary data.

Digital Behaviour of Young People

A clock mapping activity was conducted to map out a typical day in a young person's life to assess their digital behaviours and gain insights to their phone usage habits and digital lives. It involved a participatory activity with 24 participants as detailed in Table 2 , where participants were asked to map the digital platforms they use throughout the day. In this activity, participants were provided with a clock image, where they wrote down the digital activities, number of hours, and the most frequently used apps throughout the day. The activity initiated a dialogue about the concept of the **"digital everyday"** and facilitated discussions about the role of smartphones in our daily lives.

Clock Activity to map out a typical day in young person's life to assess their **digital behaviour**

The following findings were drawn from the participatory clock activity -

Actual time spent over the phone is much higher than perceived:
People are spending more time on their phones than they realise. While the hours spent varies amongst people, there is a vast difference between the amount of time they think they are on the phone and what they are actually spending online.

Phone usage is disrupting sleep patterns:
High phone use interferes with sleep patterns often leaving young people sleep deprived. Many young people stay up late and start their day very late.

Phones are the first point of contact in a day:
People check their phones as soon as they wake up, it is the first thing each and every young person goes to. Everything from time, to news to music - everything is on the phone.

Consistent doom scrolling:
Once people start checking their phones, they often get sucked into a cycle of doom scrolling, mindlessly scrolling through social media and news feeds. And when they stop, they need to get back to it as soon as possible, commonly understood by young people as FOMO- the fear of missing out.

Instagram as a news platform:
Instagram has become the go-to app for everything and its convenience allows them to stay up-to-date on current events. It has become the online platform for major sources of news for young people beating X (twitter) hands down.

Online payments:
Young people are increasingly using digital payment platforms like PhonePay and Paytm for convenience and time efficiency. The use of financial transaction apps changes when the youth are financially independent.

Social interaction:
Young people use social media platforms like WhatsApp, Instagram, and Snapchat to stay connected with friends and family. They also use these platforms to seek and share news and information.

Preferred content:
Young people enjoy a diverse range of digital content, including Korean dramas, K-pop music, Punjabi songs, as well as watching interviews, videos related to physical activities, cooking, arts & crafts, dance, and sports. Spirituality too seems high on the minds of young people.

Influencers:
Youth follow influencers on social media to learn about new products and services, get fashion and beauty tips, and stay up-to-date on current trends. However, the youth have understood the influencer marketing model, which has reduced overall credibility of influencers. Therefore, the need to follow micro-influencers has reduced.

Leisure entertainment:
Youth use streaming platforms like YouTube, Netflix, and Disney Hotstar to watch movies, TV shows, and videos for entertainment.

The most frequently mentioned apps below have been collated from the KAP survey.

DIGITAL BEHAVIOUR OF YOUNG PEOPLE

Bar chart showing:
- SOCIAL MEDIA: 71%
- GOOGLE SEARCH: 64%
- STREAMING: 52%
- SHOPPING: 46%
- ONLINE BANKING: 37.5%
- DATING APPS: 12%
- GAMING: 14%
- NONE: 2.5%
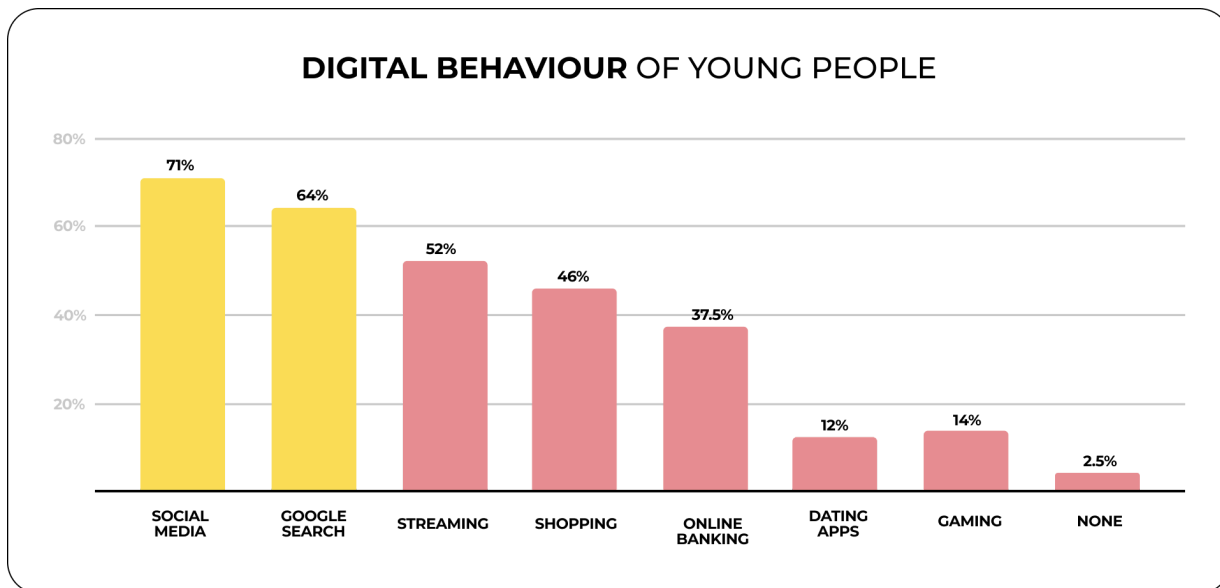
Source: KAP Survey (n=548)

Digital Health Behaviours of Young People

This section captures the specific ways that young people use digital technologies for health-related purposes. It includes things like seeking health information online, managing chronic conditions, and connecting with healthcare providers. By understanding these behaviours, we can get a better understanding of how young people are using digital technologies to improve their health. This information can help in identifying the end-user, their motivations, fears, and concerns.

What are the socio-economic factors (external) that dictate young people's digital health behaviour?

Community or society perspectives shape how technologies are adopted by the larger public and ordinary citizens. These perspectives include how different interest groups, civil societies and individuals shape the larger discourse.

I vs. We

In thinking about the perspectives regarding digital health and data-governance - there is an important need to understand how we view **privacy**. Celebrated, Indian

sociologist, Yogendre Singh's analysis (2007)[22] provides a seminal understanding of the concept of privacy in India, where he argues **privacy is not limited to individuals but extends to families and communities**. Indian society is collectivist, and people place a high value on group identity and relationships. As a result, individuals may feel pressure to conform to the expectations of their family and community, even if this means sacrificing their own privacy.

In Indian Society, we are bound by support systems, which often are our families. When we get old, our family members care about us, about our health. The entire family knows about our health concerns and supports us. In my work with people living with HIV in India, now we are experiencing older PLHIV- who do not have family support. For these people the community is the support system. Digital Health is very individualised, and health data and its governance is also very individualised. How do we bring community and support systems in place......how to rethink consent from an individualised view to a support system view?

- Dr Subhash Gosh, Project Lead, YRG Care

It becomes important to understand the cultural context of privacy in India - as privacy is not individualised - and extends to families and communities. The question here remains **how to balance the individual's right to privacy with the need to share health information within health care when there is no one-size-fits-all solution.**

Gender Differences

There are significant gender differences in the way young people use mobile phones to access health information. Socio-cultural norms in India define the access as well as use of digital devices amongst girls and women in India. There are lower numbers with access to mobile phones and internet and have varying restrictions around the usage even when digitally active. For girls, there is a strong expectation that they seek permission from their families for using mobile phones and the internet to access health information online. These restrictions stem from patriarchal beliefs, cultural norms and religious beliefs.[23]

"If a woman is working, is educated, and also married then having her mobile phone is seen as 'okay'. However, when it comes to her phone for health issues - she is looked down upon as she must have done something wrong that's why she is seeking health information online - be it a Hindu or Muslim girl. "
- Anjali Kashyap, Youth Political Representative

---

[22] Singh, Y. (2007). Privacy in India: A Sociological Exploration. New Delhi: Sage Publications India.
[23] Understanding developed from primary data.

For some girls their mothers, sisters, and friends become their only source of health information. If their mothers and sisters are not well educated or informed - girls are left with limited options. Often educated families see lesser restrictions on women using phones.

Boys are often seen as being more independent and more likely to have access to mobile phones and the internet. The internet can prove to be the medium to ask questions on health for boys, since there is less of an expectation to seek permission from their families before accessing health information online [24].

Digital Surveillance

"For women their healthcare is hinged on privacy. Women across India are dependent on the government healthcare system for birth control pills and other contraceptives. We do not know who is handling this data. We don't have laws right now about our privacy."
- Faye D'Souza, Journalist[25]

Issues related to abortion, contraception, and sexual health are often stigmatised and taboo. This can make it difficult for people to seek help and information online, as they may be afraid of being judged or discriminated against.[26]

Gender-diverse people also face unique challenges when it comes to digital privacy. They may be concerned about their identity being revealed, which could make them vulnerable to discrimination or violence.[27]

"As a Muslim woman, who posts a lot on the internet, on issues of identity, gender, and health, I'm worried about my privacy and how I might be tracked. I have developed my own digital safeguarding and cyber-security means. In the beginning, switching off data access and opening a new browser, and going through so many security checks was difficult, but now I have made it a habit - so it comes naturally to me."
- Ayesha Bashir, SRHR Activist

Marginalised groups in India, such as Dalits, Muslims, and other minorities are also more likely to be affected by digital surveillance. They experience gaps in access to resources to protect their privacy, and they may be more likely to be targeted by discrimination or violence[28]. With sensitive health conditions, these people become further marginalised. Digital surveillance and limiting freedom of expression have

---

[24] Understanding developed from primary data.
[25] Digital Health ID: Is Data Safety A Challenge? | Faye D'Souza (2021) Retrieved from
https://www.youtube.com/watch?v=mZGcjxQfLuM
[26] Understanding developed from primary data.
[27] Understanding developed from primary data.
[28] Understanding developed from primary data.

forced individuals to switch to hyper-vigilant behaviours for digital safeguarding or self-censorship.

Insensitive Health Care System

"Agar mere periods time par nahi hote, aur mein doctor ke pass jaati hoon..doctor mujhse bohot se sawal puchte..aur soch lete kahi mene kuch galat toh nahi kdiya..mein yahi baat online ja kar bhi pata kar sakti hoon"

"If my periods are not on time, and I go to the doctor, the doctor asks me a lot of questions. He presumes/thinks that maybe I have done something wrong (hinting towards her having unprotected sex). I can find out the same thing by going online."
- Anjali Kashyap, Youth Political Representative

For girls, who manage to visit a doctor to ask basic questions about their health, especially on issues such as periods, can be a daunting experience. They are often subjected to a long list of questions that are not asked in a sensitive or comfortable manner. This leads to girls feeling stigmatised and/or embarrassment, and it can discourage them from seeking medical care in the future.

In the past, there were few alternatives to going to the doctor. **As social norms are changing and internet penetration is increasing for girls who are online. However, with the advent of the internet, some girls now have access to online health information.** With the internet, they can possibly find accurate and up-to-date information on topics such as menstruation, contraception, and sexually transmitted infections. It can also connect with other girls and women who are going through the same experiences.

"Sensitive doctors and sensitive providers play a huge role. Big medicine is like patriarchy in the health sector. The kind of judgement that, gynaecologists - female gynaecologists themselves have like with regards to pleasure or sexual health or the kind of stigma that they perpetuate is again forcing people to kind of go-to online mediums - because in our families also - the doctor is a 'family doctor' mostly."
- Ayesha Bashir, SRHR Activist

The following barriers affect the Indian healthcare system -

● **Women may feel judged or ashamed** if they ask questions about their sexual health or pleasure. This can make them reluctant to seek care from a doctor, and those who have internet access may lead them to look for information online instead.

- **Doctors may hold personal beliefs and make moral judgements** that conflict with women's sexual health needs. It can lead them to refuse to provide care or to make judgmental comments, which can discourage women from seeking care.

- In most cases - **the family doctor is often the first point of contact for people seeking health care, often seen as a moral authority figure.** Lack of privacy and comfort have led women to seek information online with anonymity[29].

The internet has made it possible for girls with internet access to get the information they need about their health without feeling judged or uncomfortable. It led to a drastic change in the way girls interact with the healthcare system - giving them options, asking questions, and managing their own health.

Digital is Beyond My Control

Despite being aware of the risks, taking steps to limit the amount of data we share, and using privacy - protective tools and settings, digital essentially becomes beyond the reach of individuals. It also means demanding that businesses and governments be more transparent about how they collect and use our data.

"The more we are getting digitised, the more we are giving out personal data...Are we enabling ourselves or just getting threats in our lives...We are aware of the risks, but rarely concerned about the digital...we all are just pawns in the game."

- Kavita Ayyagari, Country Director and India Team Lead at Howard Delafield International

The digital age has made it easier than ever to collect personal data and use it without one's knowledge or consent. It has also made it complex to take steps to protect oneself - especially protecting privacy and ensuring that data is used in an informed manner.

What are the motivational factors (internal) leading young people to go online for healthcare?

Convenience and comfort

Many young people find **anonymity** and **convenience** in discussing personal health issues online, without fear of judgement. *"Online platform ek easy process hai, jise asaani se dekha ja sakta hai." (Online platforms are an easy process that can be easily accessed.)* These include online searches which include the use of

---

[29] Understanding developed from primary data.

keywords like 'reason for late periods', 'why periods are not happening on time?' and 'what to eat?'

SOCIAL MEDIA APPS
USED TO ACCESS HEALTH INFORMATION

70% Youtube   **48%** Instagram   **43%** WhatsApp   **38%** Facebook

Source: KAP Survey (n=548)

The KAP survey identified "social media platforms" (70%) followed by health-related websites (55%) as the two most preferred digital platforms for accessing health information. Amongst social media platforms, YouTube emerged as the leading platform (70%), followed by Instagram (48%), WhatsApp (43%), and then Facebook (38%) as preferred platforms.

Foster relationships
Online platforms are pivotal for young people to explore their intimate health needs, and other physical desires. Online resources facilitate building relationships with partners or peers, and enabling discussions on sensitive health topics.

"I'll search online, how shall I proceed with my partner in a physical relationship. Mummy khul kar nahi bataegi isliye online jaungi." (I will go online because my mother is not open to talking about this.)

Preserve personal privacy
Online platforms provide a private space to explore personal health issues, addressing concerns about societal judgement and breaches of privacy. *"Online karungi kyunki darr hai parivar ka, lekin baat dhyaan se karna," (I will use online resources because I am worried about my family, but I will be careful about what I say.)*

Also, through the KAP 85.9% of young people felt the control of their health data as very important to them.

CONTROL OVER HEALTH DATA

7.1%
Indifferent

7.1%
Not Important

85.9%
Very Important
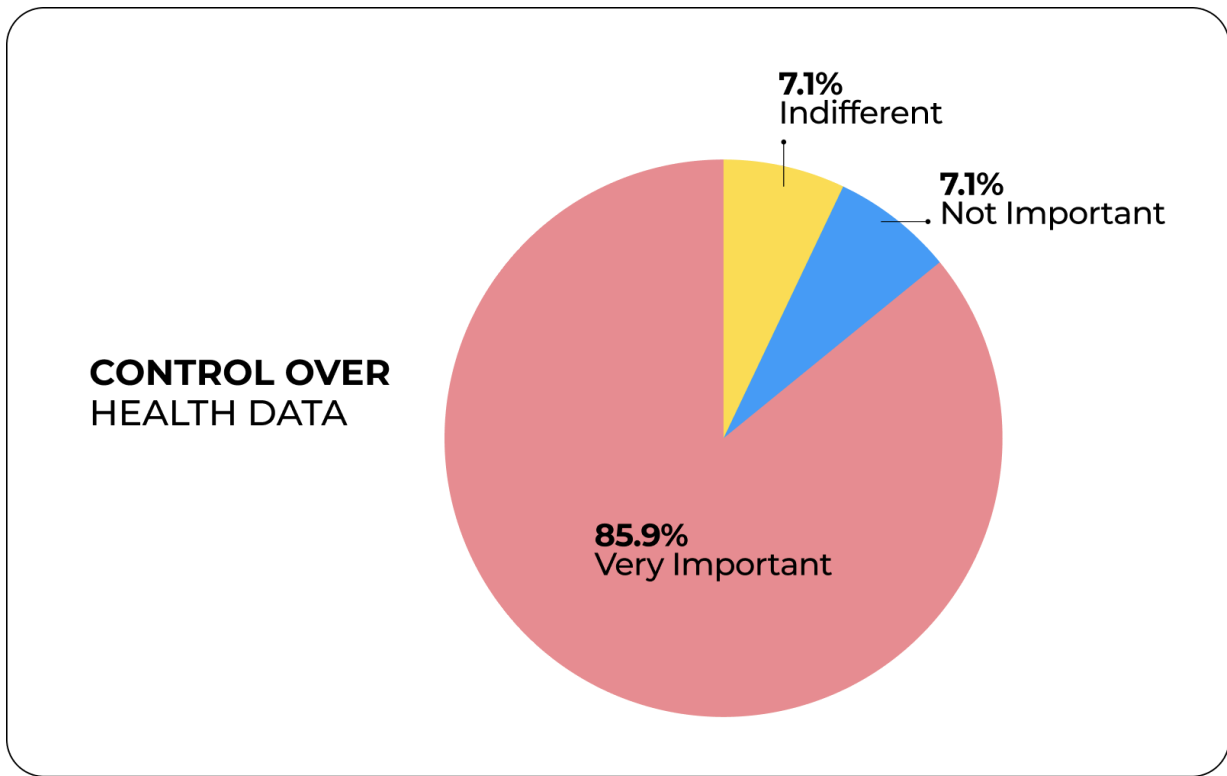
Source: KAP Survey (n=548)

Seeking expert guidance

Seeking advice from online resources becomes crucial for women when discussing health and personal relationships, since these conversations with family or friends may be uncomfortable. The quote from one of our FGD sessions "Discuss with a close friend who has experience. After discussion, if any doubt, I'll google" highlights the role of online platforms in providing additional expert guidance and support. The most searched after health information online includes natural remedies (56%), medication details (49%), and fitness insights (45%).

HEALTH ISSUES SEARCHED

Health Issue	Percentage
HOME REMEDIES	56%
MEDICATION INFO	49%
FITNESS	45%
SKIN	41%
NUTRITION	41%
MENTAL HEALTH	31%
SEX & REPRODUCTION	24%
STRESS	22%
CHRONIC ILLNESS	21%
SLEEP RELATED ISSUES	18%
BODY IMAGE	13%
SUBSTANCE ADDICTION	8%
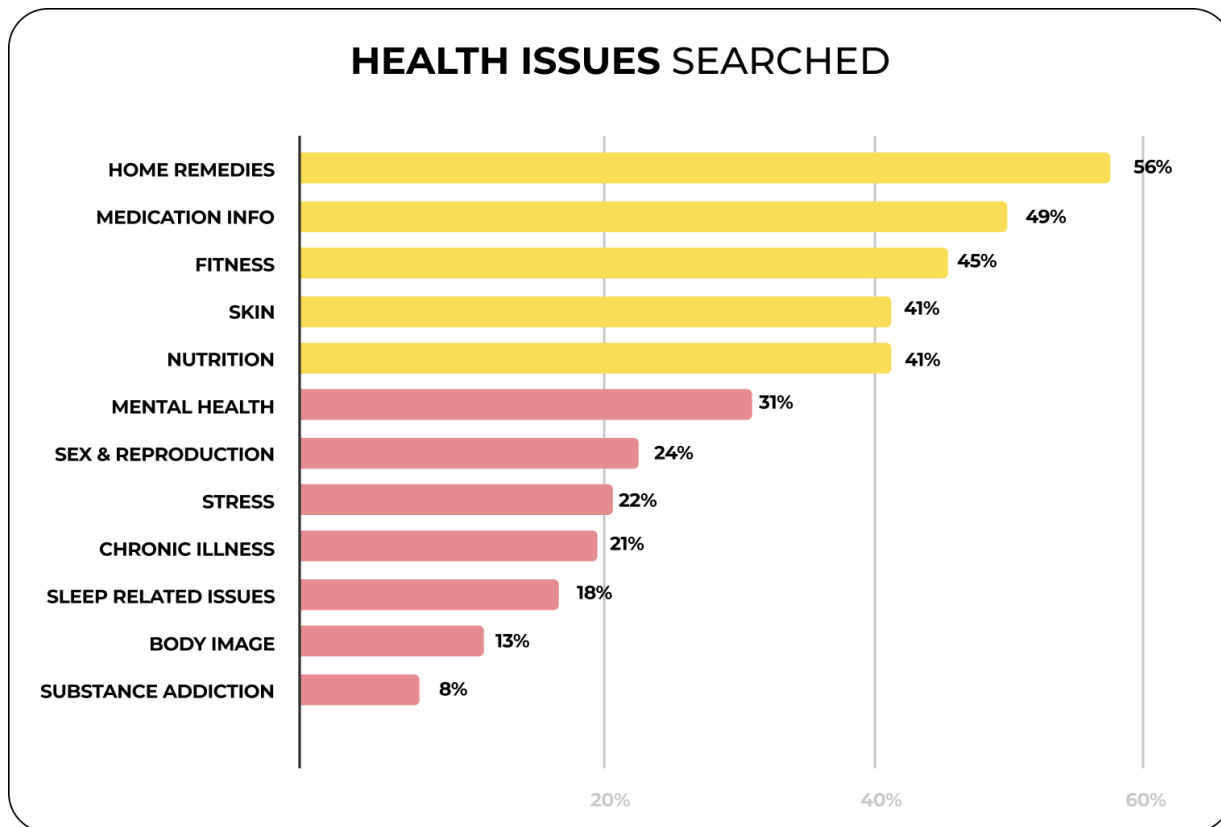
Source: KAP Survey (n=548)

How does seeking health information online influence the everyday digital behaviour of young people?

Privacy and reputation worries

Seeking health information online often comes with concerns about personal health information security and the potential impact on reputation. The KAP data revealed that 8.83% of respondents were indifferent, 6.00% considered it not important, and a substantial 76.17% deemed personal health data control to be very important. In assessing emotions linked to health-data leak: 13% expressed indifference, 31% felt sadness, 32% experienced panic, 51% encountered frustration, and 55% reported feeling angry.

EMOTION WHEN DATA IS LEAKED

😠 55% ANGRY	😖 51% FRUSTATED	😱 32% PANIC	😔 31% SAD	😐 13% INDIFFERENT

Source: KAP Survey (n=548)

The FGDs informed *"Hamara data unke paas rahega jisse voh humein 'blackmail' kar sakte hai." (Our data is with them and therefore they may blackmail us in the future).* This fear of personal information being misused or leaked, leads individuals to adopt privacy-conscious behaviours. The worry around health data leak stems from fear of judgments from family and community.

Social taboos and judgement
The fear of stigmatisation and judgement due to discussing sensitive health-related topics online is another factor reducing health-seeking behaviour online. The quote *"meri pareshani hai ki hamare samaaj ka mahool aesa hai ki inn sabhi baaton ko galat mana jata hai jiske karan mummy hum se khulkar baat nahi karegi" (I am worried that our society is such that all these things are considered wrong, due to which my mother will not talk to me openly)* reflects this apprehension. Some topics remain socially taboo, preventing individuals from seeking information openly online, limiting access to accurate information and informed decisions.
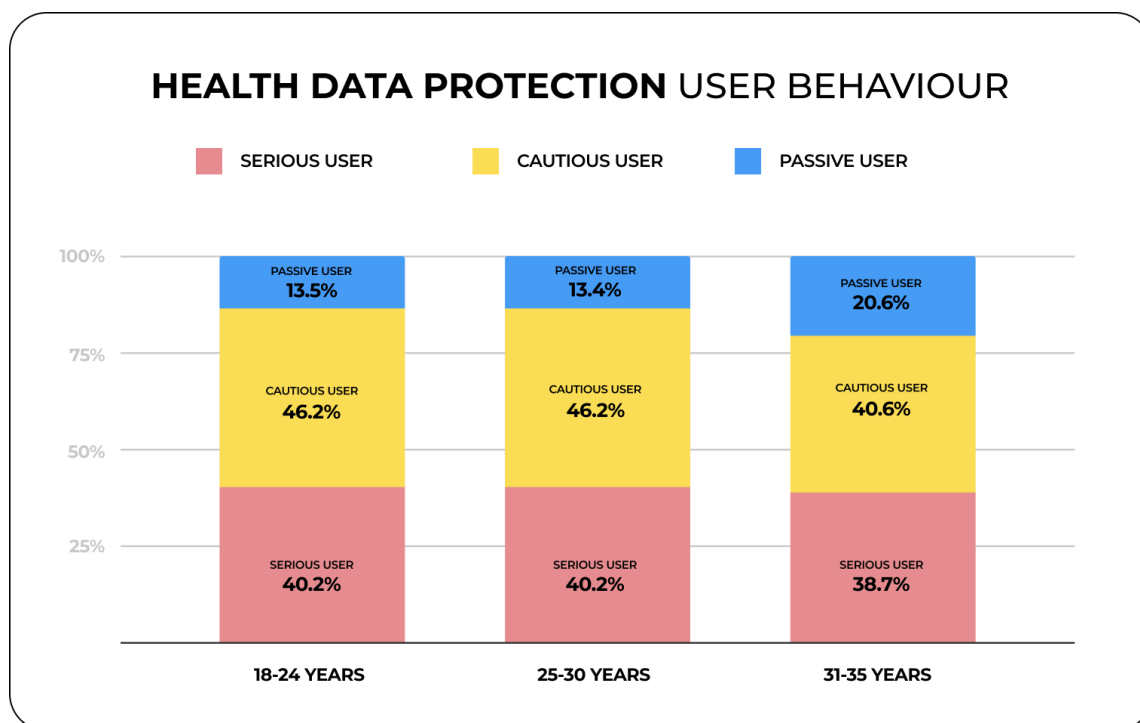
Trust and misinformation fears
56% of the KAP respondents reported that they were very comfortable discussing health concerns with healthcare professionals online but they are wary of the accuracy and reliability of health information found online, which can lead to misinformation. The quote *"Concerned about fake information online"* highlights this concern. The vast amount of available information can be overwhelming, making it challenging to identify trustworthy and relevant sources, and they hide as much as possible: *"kum se kum real information dena."* (Give as little real information as possible).

It suggests that young individuals are selective about the information they trust online. Health professionals online continue to hold high trustworthiness and this is evident in the influence of medical experts like Dr. Cuteres, an Instagram medical influencer, as mentioned by participants in the FGD. We also found young people prefer to passively receive information by consuming content as well as

from the comments section while leaving no visible digital trail, like liking or re-sharing the content publically.

Health Data Security

Young people are deeply concerned about the privacy and potential misuse of their intimate and health information. It is expressed in concerns how Whatsapp chat screenshots can be misused, leaking intimate and health information. When asked about their response to health data leaks, the majority displayed a proactive attitude. Less than 20% indicated passivity, while around 40% would adopt cautious behaviours like changing passwords and attempting to report. Impressively, another 40% would take serious action by reporting the incident to technology service providers and authorities.

HEALTH DATA PROTECTION USER BEHAVIOUR

■ SERIOUS USER   ■ CAUTIOUS USER   ■ PASSIVE USER

	18-24 YEARS	25-30 YEARS	31-35 YEARS
PASSIVE USER	13.5%	13.4%	20.6%
CAUTIOUS USER	46.2%	46.2%	40.6%
SERIOUS USER	40.2%	40.2%	38.7%

Source: KAP Survey (n=548)

How do young individuals address a new set of challenges while seeking health information online?
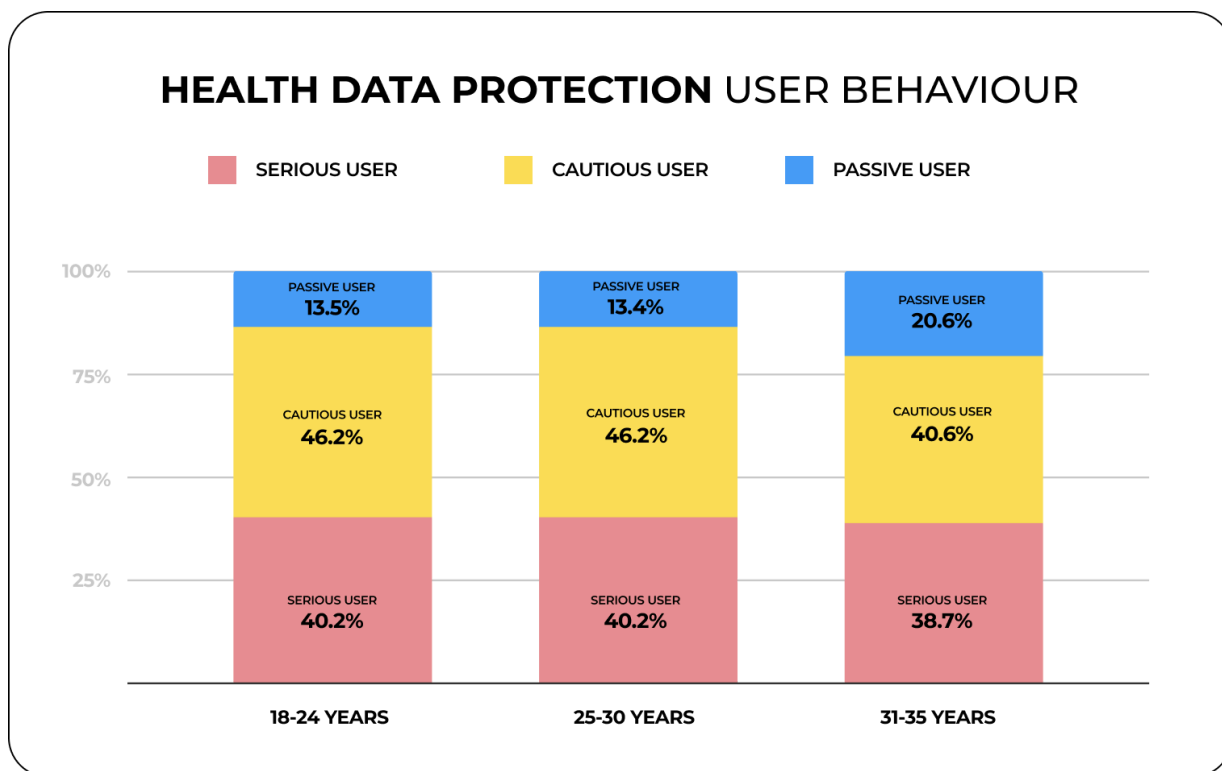
Use of Privacy Features

In terms of digital security knowledge level only 33% could identify the cyber-protection icon correctly indicating low recall and awareness for security icons, whereas for passwords 58% could effectively identify a strong password indicating overall low knowledge and awareness levels. To maintain control over

their personal data, individuals utilise digital privacy tools. The quote *"Use incognito mode so that history will not get recorded"* demonstrates this approach. Strategies like adjusting privacy settings, clearing browser history, creating profiles with fake information, and disguising apps on their phones help them maintain a sense of privacy and control while exploring digital platforms.

It reflects that individuals often possess a limited understanding of technical nuances surrounding privacy and the corresponding terminology. Consequently, they tend to rely on generic privacy practices, which, in turn, lead to heightened concerns about their security.

Selective Information Sharing

Balancing the desire for openness with concerns about privacy, young individuals adopt selective information-sharing strategies. The quote *"unknown person ko personal detail share nahi karungi" (I will not share personal information with an unknown person)* illustrates this approach. They confide personal matters only with those they trust, whether it's close friends or reliable individuals online and offline.

HEALTH DATA PROTECTION USER BEHAVIOUR

	SERIOUS USER	CAUTIOUS USER	PASSIVE USER

	18-24 YEARS	25-30 YEARS	31-35 YEARS
PASSIVE USER	13.5%	13.4%	20.6%
CAUTIOUS USER	46.2%	46.2%	40.6%
SERIOUS USER	40.2%	40.2%	38.7%

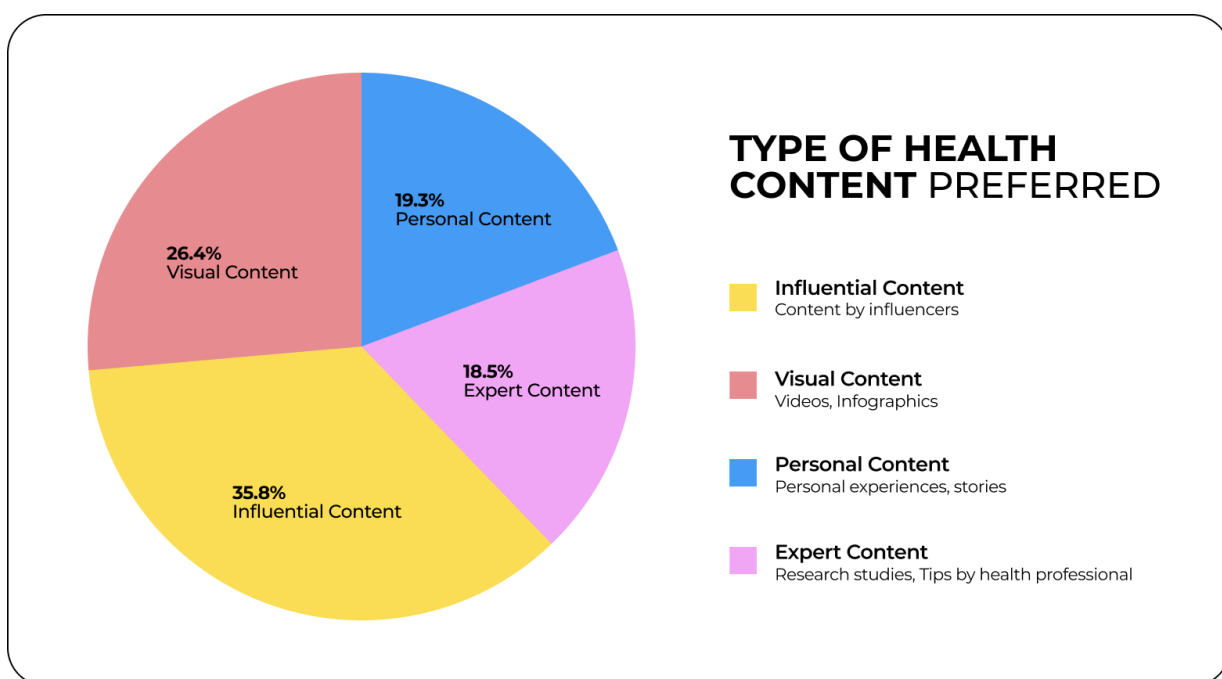Source: KAP Survey (n=548)

Consulting Trusted Sources

To combat misinformation, individuals turn to trusted sources for accurate

information. The quote *"I will prefer a doctor - be honest and share my concerns"* exemplifies this strategy. They seek guidance from credible experts such as doctors, family members, and reputable influencers, ensuring they build their knowledge upon reliable expertise.

Content Preferences to Learn More About Digital Health

As per KAP, only 4% feel they know enough about digital health, while 39% shared that they have some knowledge and would like to learn more. Young individuals favour influential (35.60%) and visual content (26.40%), while also valuing personal (19.60%) and expert content (18.40%). A diverse strategy combining relatable stories, expertise, and engaging visuals is essential for effective engagement.

TYPE OF HEALTH CONTENT PREFERRED

19.3% Personal Content
26.4% Visual Content
18.5% Expert Content
35.8% Influential Content

Influential Content
Content by influencers

Visual Content
Videos, Infographics

Personal Content
Personal experiences, stories

Expert Content
Research studies, Tips by health professional

Source: KAP Survey (n=548)

Key Insights

We contextualise the research findings to develop key user-insights. These insights are fundamental to inform a strong pervasive public narrative that speaks directly with young people. Our key insights from the research include the following -

Digital Citizenship = Global Citizenship - A New Level Playing Field

- The convergence of digital technology and new media has **blurred the lines** separating the digital and physical lives.
- It has **homogenised regional, geographical and linguistic divides,** within India forging digital connections between distant cultures. Young people are connected with one-another from across the country.
- This **global homogeneity** is visible in the **content choices** of young people too. While Punjabi rap is still immensely popular, K-pop is consuming the playlists of Indian youth. Moreover, the captivating charm of K-dramas, intricate storytelling and relatable emotions now resonate deeply with young Indians. The young girls in Jaipur, Rajasthan, have emerged as die-hard fans of a wide array of Korean digital content.
- We observed that digital now provides them a **level playing field** - with a new promise. Digital brings the desire among young people to be global where digital citizenship now equals global citizenship

Language and Understanding

- People don't understand what 'digital health' and 'health data' mean - **the terminology is alien.** For the digitally fluent youth, the terms "data'' and "health" hold meaning independently, intertwined with their digital existence. However, their fusion as "Digital Health Data" introduces a labyrinth of complexity that defies ease of comprehension.
- Data, in most of India, especially outside the top tier, tech savvy population is a term used to describe **mobile internet.** Therefore, people **don't comprehend what health data means.**
- **Hinglish** (an Indian combination of Hindi and English) is the preferred language of communication for a large majority of the country, especially the vulnerable populations. Moreover, many digital terms **do not have direct translations** and cannot be explained in local languages. Therefore, the intricate fusion of digital health data, though part of daily life, often presents itself as an alien idea shrouded by lack of comprehension.

Digital is synonymous with 'Me Time', but has not replaced human connection

- Young people are **spending a substantial amount of time** on their mobile devices, more than they realise. Phones have become the **first point of contact** for most young people, where everything from communication, consuming content, and staying updated is linked with their mobile.
- Therefore, they **suffer from FOMO** and return to their phones constantly even if they don't want to.
- However, the **yearning for care and community persists**. Family and friends remain irreplaceable, indispensable and their significance unaltered. The unwavering essence of human connection and care remains vital as before.

Digital and Social Norms in India

- Digital has come to **mirror** the **social complexities** and **restrictive social norms**, especially for women and marginalised communities.
- Young people often turn to digital platforms as safe havens for complex and stigmatised information they cannot seek from their immediate and loved ones.
- While doing so they **hide their identity** not out of fear of data breach, but the fear of their reputation within family and society.
- Therefore, a lot of what could be considered 'safe digital behaviour' is a result of the fear of society rather than any interest or effort to protect their data online - health or otherwise.

Digital glass ceiling

- While more **women** have access to mobile phones and many more own individual devices, their **devices are open to surveillance** and their **online activity is often monitored.**
- If a **girl** is very active digitally, it is **presumed** she is **indulging in 'something wrong'.**
- There is **re-enactment of restrictive social norms in digital spaces,** especially for women.
- Such restrictive norms have led to manifestations of **gendered digital behaviour** - veiled digital existence, selective information, fake profiles, hypervigilance, etc.
- This is also leading to a **loss of opportunity for young women - 'digital glass ceiling'**
- **Boys,** on the other hand, are **not subject to surveillance**, their privacy is respected and are not expected to share their devices with anyone. Therefore, they are **not vigilant** and are free to live 'open' lives digitally.

Convenience Outplays Safety

- **Convenience takes precedence over safety** when engaging with platforms, including for health purposes.
- The rapid access and immediate outcomes these platforms offer can overshadow concerns about health data governance.
- For young boys it is convenient to be **indifferent** since they remain **unaffected by societal norms**.
- For young girls it is convenient to continue to operate **under the radar**, seemingly free from **surveillance** and **judgement**.

Conclusion

The convergence of digital technology and new media has blurred the lines between digital and physical lives, bringing global cultures closer. Young Indians have embraced new media and diverse platforms for managing their health better without much awareness and thought.

Young people, despite being one of the key stakeholders in the digital health landscape are unaware of their participation in this space. The fusion of digital health data poses complexity, understood in fragments, yet often alien and veiled. Moreover, it is defined by complex lexicon and technical terminology that is not part of everyday vocabulary nor can be translated to make it easily comprehensible for the youth.

Three types of user groups were identified, group one including those people following society's rules. The second group of individuals seek to balance societal norms and personal goals. Lastly, the third group - includes individuals challenging societal norms for better access to digital health, privacy and data governance.

Human connection remains invaluable despite the ubiquity of digital platforms, offering an escape from societal norms. However the complexity of social norms are mirrored by restrictive norms on digital platforms with newer concerns. Digital behaviour of young people is governed by the complex notion of privacy.

As digital health grows rapidly in India, there is a need to increase knowledge and awareness about what it entails. This includes demystifying "digital health","data governance" and "privacy concerns" at an equal speed. For a digitally equal society, the present needs to include the youth's point of view as active informed contributors in shaping the larger digital health narrative.

Part II

That's a Vibe.

Developing a Popular Mobilisation Campaign Strategy around Digital Health & Health Data Governance amongst Youth in India

The Campaign Opportunity

The pace of progress towards achieving **universal health coverage (UHC)** has **decelerated** considerably over the past decade globally. To address this issue in India, the Transform Health India Coalition aims to build a mass movement consisting primarily of **youth, women and marginalised communities** to **advocate and mobilise** for the digital transformation of healthcare systems to achieve UHC.

Kaboom Social Impact joined the Coalition to **influence change** in the **enabling environment** in **Rajasthan**, while simultaneously **propagating the agenda** of digital health for UHC at **both the state and national levels**.

Kaboom is a social impact agency that responds to on-ground social and development challenges by **designing powerful narratives, campaigns, and movements to enable social change**. Kaboom Social Impact, as a member of the Transform Health India Coalition, will design a **public-facing campaign** towards promoting digital health and increasing awareness on data governance in India, with a special focus on women, young people, and vulnerable groups.

In Part I of this Report, Kaboom has elaborated upon the research process as well as the results of the research undertaken to understand the prevalent norms and perceptions around digital health and data governance. The section delineates the findings on the existing knowledge, attitudes, as well as practices of women and youth in India, including those from the marginalised communities.

The research has been undertaken to inform the **creation of a campaign strategy to support the larger public narrative that will directly speak to audiences about their digital health.**

Coalition Objective

Prior to presenting the goals for the popular mobilisation campaign, this section outlines the Transform Health India - Rajasthan Coalition objectives. Once listed, the campaign objectives will be contextualised in line with these larger targets.

The Coalition Partners convened in Jaipur to hold a Strategic Planning Workshop over 12 – 14 April 2023. Through a participatory process, the Coalition delineated the following larger aim - ***Formulation of digital healthcare legislation and policy in Rajasthan by 2030, coherent with national guidelines on digital healthcare.***

In order to achieve this aim, the coalition will work towards the following objectives –

- **Objective I - Draft legislation on digital health tabled in state assembly of Rajasthan, India by 2028**

The Rajasthan State Assembly develops legislation on digital health and data to ensure consistency and coherence with national policies, and other legislation. (Health is a devolved function and state legislation will provide the right legislative and regulatory environment to govern all health providers across the different sectors and will strengthen policy coherence).

- **Objective II - The Government of Rajasthan/India allocates resources for research and technical support for drafting legislation on digital health by 2025.**

  The State government allocates resources to enable Ministry of Health staff to fund the necessary research and technical support to enable them to formulate policies that are coherent, and consistent across departments and with the national level policies and based on evidence and best practices. The State then commissions an assessment of existing policies and legislation and how effectively they are being implemented, how coherent and consistent they are across tiers and across government departments, and how effectively they are understood and implemented. The study should include an assessment of best practices in terms of policy development and implementation across India and beyond to draw out learnings and recommendations that can be applied to the State of Rajasthan.

- **Objective III - Capacity building of different stakeholders in the development of digital health policy by 2025.**

  The State authorities provide training to staff across different government departments on the policies and legislation and compliance rules and regulation relating to digital health and the use of data to ensure consistency and coherence in the understanding and implementation of policies across State structures.

- **Objective IV - Provision of resources (Govt/CSR/others) by 2027 for making policy formulation process more participatory and inclusive of marginalised communities.**

  The State allocates funding for a participatory and inclusive process for policy development and implementation that includes the perspectives of different stakeholders, including marginalised communities.

The Fundamental Campaign Objective

In order to achieve the aforementioned objectives, the Coalition strives to mobilise policymakers and other relevant stakeholders. Parallel to this advocacy component, **Kaboom Social Impact will work to rally popular support from the youth** for

digital health and health data governance. **This support will eventually be channelled to co-create relevant policy asks that have been organically developed by the community.** As part of the Campaign Tactics, Kaboom will plan bottom-up, participatory activities that lead to consolidated policy asks from the various stakeholders that are part of the primary, as well as secondary target audience.

However, Kaboom clarifies that realisation of organic policy asks is a long-term objective. From the research undertaken during Phase I of this engagement, the team observed that the terms 'digital health' and 'data' are conceptually incoherent to the youth. The terminology is alien. Based on this, the team is conscious that mobilising support is a lengthy, and iterative process involving sustained messaging for knowledge increment, awareness generation and gradual shift in attitudes.

Therefore, there exists a long journey to traverse from awareness generation to empathising with the cause, and eventually demanding for inclusive health data governance regulation.

Aligning with the Coalition Objective

The forthcoming Campaign will be consistent with the Coalition Objectives, ensuring the following fundamental components -

- **Popular Mobilisation:** The campaign is primarily aimed at the Indian youth with emphasis on women and members of marginalised communities. Through the Campaign, Kaboom proposes to initiate a **strong, pervasive public narrative** based on the popular norms and perceptions around **digital health** and **health data governance.** Through a process of **awareness generation,** the campaign seeks to **rally popular support** for the cause.
- **Sustainable Partnerships:** This campaign is an opportunity to meaningfully engage with **development sector partners working in the domain of digital health and data governance.** Through such partnerships the Campaign seeks to create a sustainable network and engaged community with both - interest and influence towards digital health. Kaboom will leverage such partnerships, to **scale campaign messages** and ensure continuous engagement of the coalition itself.
- **Advocacy:** The campaign will also consist of strategic tactics that engage partners to develop consolidated **policy asks** that build upon and support the advocacy work undertaken by the Coalition. By using participatory, bottom-up processes, Kaboom will co-create a policy document to **include the voices of end-line beneficiaries within policy demands.**
- **Fundraising and Investment:** As part of our work, Kaboom will undertake coordinated fundraising in collaboration with the Transform Health Team

and WISH Foundation. These funds will specifically be leveraged to scale the campaign to various parts of India.

Campaign Goals

Long-term Approach

At Kaboom, **'DIGITAL'** is viewed as a **participatory** layer of all **communication** that allows for **efficient** and **impactful community engagement. Kaboom leverages the potential of digital platforms** to achieve the following -

- Dissemination of a uniform set of key messages to shift knowledge and change attitudes

- Bridging content, media, actions, iterative messaging as well as acquiring feedback all through a singular medium

- Collect maximum amount of validated learning about users with least spend

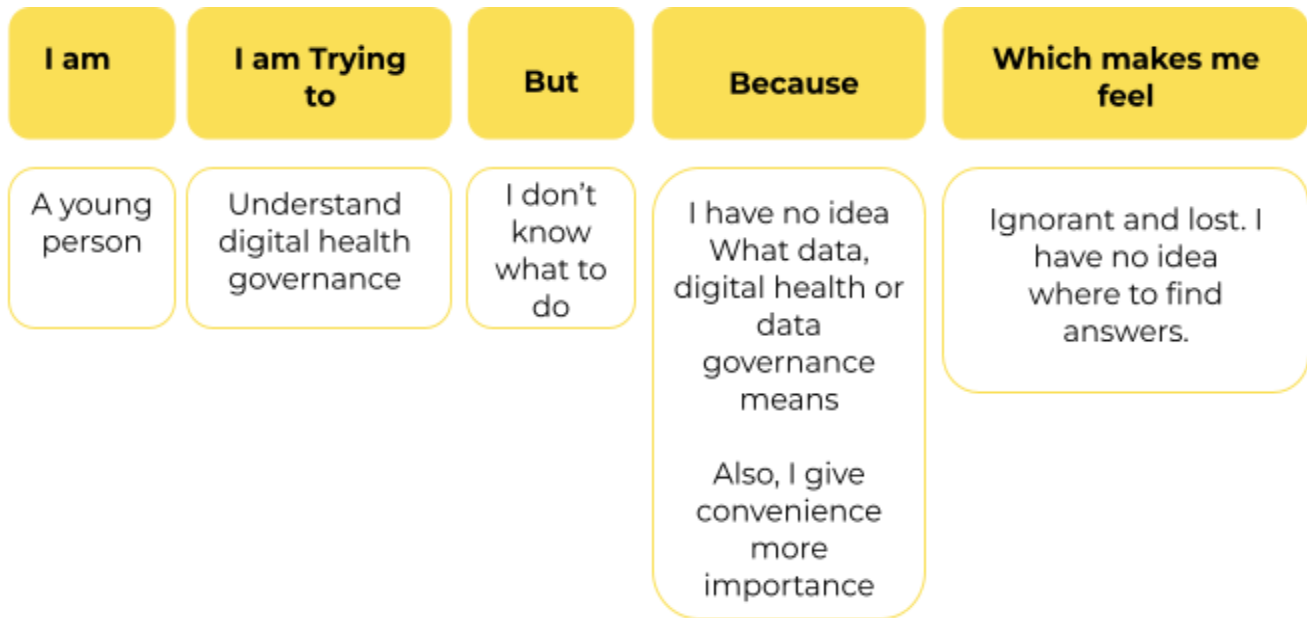- Ultimately, building relationships, networks and communities with optimised reach

Under the current campaign, Kaboom aims to primarily increase awareness-levels of the youth regarding digital health and data governance. Once aware they will be nudged towards positive action. However, over the long-term we aspire to **create a self-sustaining community, activated and engaged towards the cause.**
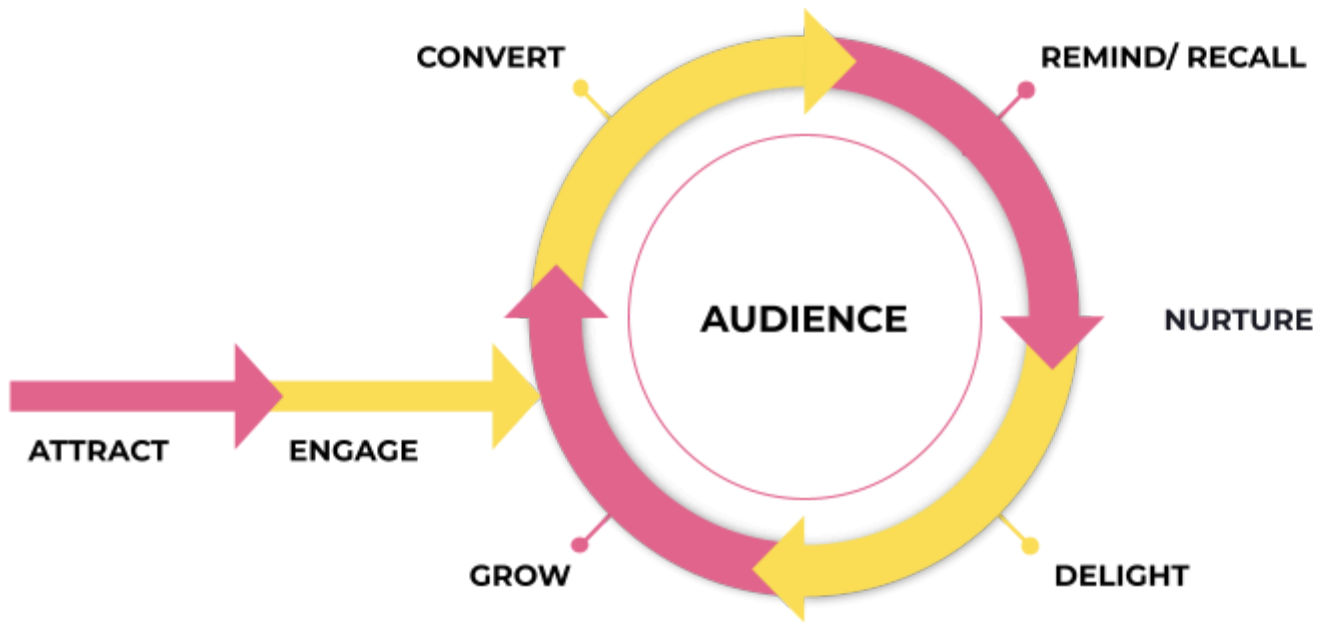
The campaign will engage the **right users,** with the **right messages**, **over and over again** in order to build a **community.** Once engaged, the focus will be to nurture and delight the audience cohort, so it can grow with the increased reach of the campaign. These primary converts then can **champion our initiative**, and be flag bearers of the messages within their individual networks, thus establishing a **self-sustaining cycle**, leading to a growing community.

Short-term Goal

Based upon the findings from the research process, it is concluded that the youth in India are presently operating from a peculiar position of lack of awareness, leading to inaction. This **'starting point'/ baseline** has been illustrated in the diagram below -

I am	I am Trying to	But	Because	Which makes me feel
A young person	Understand digital health governance	I don't know what to do	I have no idea What data, digital health or data governance means Also, I give convenience more importance	Ignorant and lost. I have no idea where to find answers.

In the current scenario, young people are ignorant and lost since they are unaware of the scale of the existing quandary and moreover, have no way forward. Therefore, there exist the following **opportunities** to engage with young people -

- Introduce the concept of digital health data
- Create awareness about digital health and data governance
- What does it mean to own your data and consent to others using data
- Create awareness of the pros and cons of owning one's own data

Given the current scenario, the campaign seeks to achieve the **short-term goal** of **raising awareness and knowledge levels to positively shift attitudes and offering the audiences with real actions that they can take online.** The campaign aims to **positively shift knowledge on digital health and health data governance** through the following attitudinal shifts -
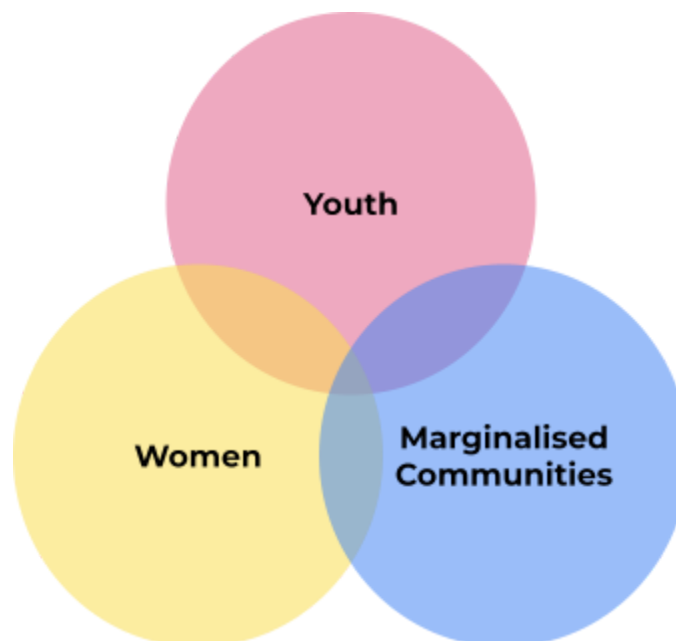
Unaware → Aware
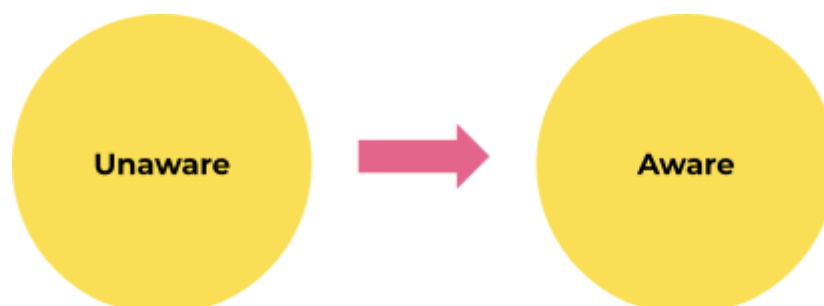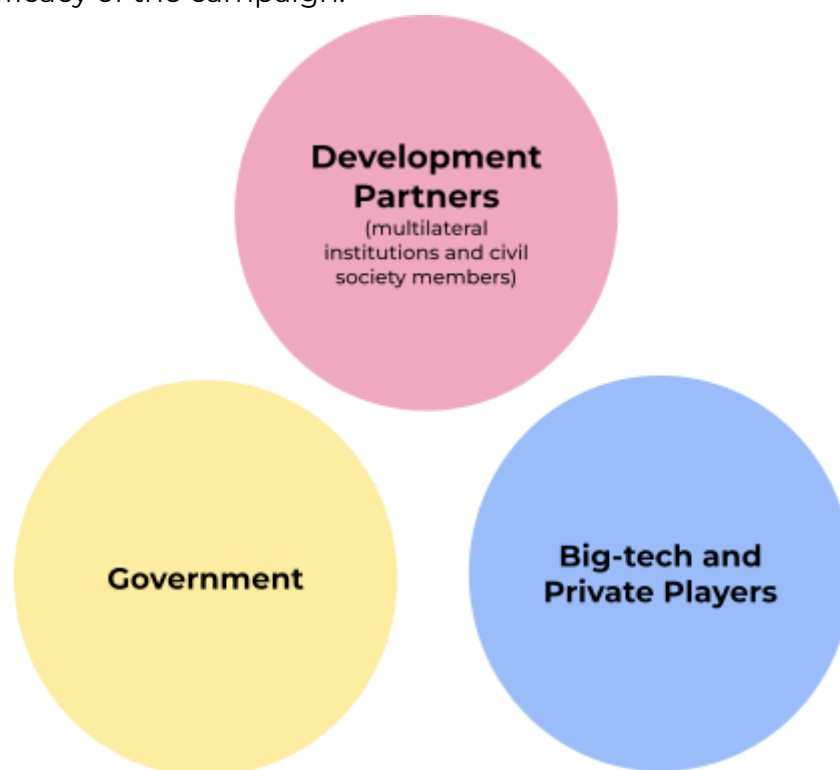
Who is our audience

Primary Stakeholders

As per the mandate provided by Transform Health, the campaign will directly target the following groups of primary stakeholders between ages **18 - 35 years** -

India's growth is currently driven by a dynamic and young population. **65%** of the total population is **under 35** years of age. With an **affinity towards change**, and **increasing digital penetration**, this demographic forms a **key group** for the campaign on digital transformation of the healthcare system. Through the research undertaken, Kaboom found that both the healthcare sector and digital domain **discriminate** against **women** and **members of marginalised communities**. Therefore, the forthcoming campaign lays particular emphasis on these sub-groups within the youth.

Secondary Stakeholders

As mentioned previously, the campaign will also collaborate with the following groups to **scale** the key messages, and **engage them in various ways**, thereby increasing the efficacy of the campaign.

Development Partners
(multilateral institutions and civil society members)

Government

Big-tech and Private Players

The various tactics that will be employed during the campaign period to scale messages, as well as facilitate the advocacy effort have been discussed in the subsequent section of this report.

Potential Reach of the Campaign

Based on the Campaign Channels finalised, the universe of potential reach of the campaign will be the following -

Groups	Age	Facebook		Instagram		SnapChat	
		A City	B City	A City	B City	A City	B City
Male	18-24	13.4M - 15.8M	8M - 9.4M	13.3M - 15.6M	7.9M - 9.2M	19.9M - 26.6M	NA
	25-34	17.3M - 20.4M	8.2M - 9.6M	17.2M - 20.3M	8.1M - 9.5M	10.2M - 13.4M	NA
Female	18-24	8.5M - 10M	3.8M - 4.4M	8M - 9.5M	3M - 4.2M	11.9M - 15.9M	NA
	25-34	8.8M - 10.4M	3.5M - 4.1M	7.8M - 9M	2.5M - 3M	5.3M - 7.7M	NA

These numbers represent the **universe** of people that can be reached through the campaign. Actual reach will be determined by various factors such as media budgets, collaborations, PR activity, etc.

User Personas

User personas are key mutually exclusive groups identified as part of the primary research activity. The following 3 groups have been characterised based on fundamentally distinct personality traits -

1

Resigned
Conformists

Ignorant
Resisting change
Compliant
Imprudent

2

Ambitious
Traditionalists

Balancing tradition
Societal battles
Calculated risks

3

Conscious
Navigators

Risk-aware
Proactive
Vigilant
Action-driven

Considering these traits, specific key messages will be developed to engage members in each of the cohorts. In order to inform the nature of key messages to engage each of these groups, the following table provides a comparative analysis regarding the opportunity areas and challenges for each user persona. The analysis clarifies the groups that form the 'easy to reach' audience and ones that are more hard to reach.

Personas	USER PERSONA 1 - Resigned **Conformists**	USER PERSONA 2 - Ambitious **Traditionalists**	USER PERSONA 3 - Conscious **Navigators**
Character Traits	- Conforming to societal norms - Ignorant to adopt cautious digital behaviors - Lack enthusiasm for change - Disregard privacy and data protection concerns - Reluctant to new - lifestyles and technology	- Often balancing technology with traditions - Fighting societal battles at individual levels - Taking calculated risks - Socio background dictating their everyday life	- Take proactive measures to ensure health data governance and are vigilant - Action oriented - Perceive risks cautiously - Actively navigate and challenge societal norms - Precautionary measure is high
Challenges	- Unable to comprehend the technical terminology - Resistant to change - Neglecting Privacy and Data Protection - Difficult to reach - Time and resource consuming - Operate from a space of convenience rather than data safety	- Unable to comprehend the technical terminology - They form a large cohort of the audience - Traditions can sometimes hold them back - Awareness levels are low in terms of digital health and data privacy - Operate from a space of convenience rather than data safety	- Unable to comprehend the technical terminology - Not a unified cohort and often found operating independently - They have very strong opinions - Can be the 'my way or highway' audience - Operate from a space of convenience rather than data safety

63

Personas	USER PERSONA 1 - Resigned **Conformists**	USER PERSONA 2 - Ambitious **Traditionalists**	USER PERSONA 3 - Conscious **Navigators**
Opportunities	• Consistent and continuous long-term communication • Personalised one-on-one messaging	• Flexibility to adapt to emerging risks and challenges • Open to new ideas • Willing to take action • They form a large cohort of the audience	• Knowledge levels of digital health data and data privacy is high • Champions willing to initiate and lead change • Committed to bring positive change within their communities through idealistic vision

Common Communication Challenges across all Personas with the Youth

Notwithstanding the variations across the user-personas, the following common fundamental challenges were observed across all groups

Language and Terminology

Our target groups are **not necessarily English speaking, tech savvy people.**

They don't:
• Understand what health data means.
• Data has a different connotation.
• There is no unified health data system in India for anyone to understand the concept.

Convenience over safety

For our entire target group, **convenience is more important than safety.**

No one has any semblance of what good owning their health data could bring.

Campaign Approach

In order to circumvent the challenges highlighted above, the campaign needs to **reach the right audience** with the **right message** at the **right time, over and over again**.

Kaboom leverages the insights developed during the research phase to inform both, the Content as well as digital marketing strategy.

Based on this participatory approach, Kaboom will develop a campaign that is **USER-CENTRIC.**

Moreover, **on-ground activities will form a key extension to the digital campaign.** Field-level engagements will be used as an opportunity to differently engage the target audience and develop user-generated/ dynamic content for digital dissemination. Further, the on-ground events will be supported by PR activities to scale the key messages and mobilise larger audience groups.

Campaign Routes

As highlighted previously, the Campaign seeks to engender a shift from a state of **unawareness to a state of motivation for young people to make a change.** In order to spark this change, we propose the following Campaign Routes -

Route I

Setting the scenario -

The 'youth' like to be in control: The target audience **believes they are in control in the digital world.** They have the control of how they portray themselves, who they choose to connect with, how they choose to respond, etc.

They can also choose from an infinite pool of social media channels, content options, digital services and activities. With the world at their fingertips, quite literally, they only fear their reputation within their family, community and society.

However, they do not realise things are beyond their control: The implications of cookies, digital tracking, data trading, targeted ads, etc. are not consciously comprehended by them. Even though **they think they are in control, they are unconscious to the complex, alive, algorithms operating in the background.**

Campaign Route developed from this context -

Given the current scenario that exemplifies the gap between assumed control and actual control, Kaboom has conceived the following route -

'*Control Apne Haath Mein'* (Control in my hands or simply, Take Control)

This route will be supported by the following central hashtag - *#FarakPadtaHai* (It makes a difference)

Campaign Hashtags -

***Kya Farak Padta Hai* (what difference does it make)** is a phrase we hear very often in an Indian context, and heard several times during the FGDs. It encompasses a sense of being in control while not actually in control. The phrase highlights the emotions of giving in, and giving up since the issue at hand does not make much of a difference.

However, through the campaign Kabooms aims to turn that phrase into a positive statement is **"FarakPadtaHai".** It highlights **the need to give a damn, or bother because "it makes a difference".**

Additionally, the campaign will include the following supporting hashtags

#TakeControl

#PrivacyMatters

#MyDataOurHealth - The current campaign route can be viewed as a precursor to the global - **My Data, Our Health Campaign**, where informing the audience about the significance of such data is the primary step. Once this significance has been understood, the audience is motivated to gain ownership of their health data.

Mapping the user-journey

The user journey for this route transitions from a state of ignorance to one of consciousness -

KYA farak padta hai!
(unaware/ignorant)

Kya, farak padta hai?
(concerned/curious)

Haan farak padta hai.
(conscious)

- This campaign is in Hinglish language, targeting a vast population.
- Leverages a highly colloquial and relatable Indian phrase and emotion.
- It is a need-driven campaign targeting the youth.
- It highlights how they can actually be in control if they give a damn.

Route II

Setting the scenario -

The 'youth' are still influenced by their family and community: We would like to contextualise the significance of family and community, especially in healthcare, through the following quote -

"In Indian Society, we are bound by support systems, which often are our families. When we get old, our family members care about us, about our health. The entire family knows about our health concerns and supports us."

As a central tenet, this quote exemplifies the need for protection, as well as the aspirations associated with being the protector. The youth likes being a protector. This is evident from our admiration for the heroes in our stories. It is also evident from the elevated status we accord to our parents as protectors.

Campaign Route developed from this context -

This scenario lends itself to our **next route** where the youth not just protect themselves but also become the protectors, a role they deeply aspire towards -
'I am the change.'
This route will be supported by the following central hashtag -
#ClickRightSahiChuno (Click Right - Choose Right)

Campaign Hashtags -

Additionally, the campaign will include the following supporting hashtags -

#ChooseWisely

#InformedChoice

#MyDataOurHealth - Similar to Route I, this route can be viewed in parallel to the global - My Data, Our Health Campaign, where the audience is motivated to protect their health data, while understanding the importance and need for ownership.

The user journey for this route transitions from a state of unawareness to collective protection against health data breach or misuse-

① **Prepare** (unawareness)   **②** **Prevent** (aware and active)   **③** **Protect** (collective empowerment)

**Merits of "Click Right - Sahi Chuno"**

- This campaign uses catchy phrases like Click Right leveraging youth familiarity in the digital space.
- It uses knowledge as a key driver of choice and agency, leading to collective empowerment.
- The word choice, prevention, protection aligns with larger health specific and digital themes.
- This route uses action-oriented creative sub-routes.
- It introduces technical terminologies while increasing digital awareness and vocabulary.

Campaign Structure

Once a route is selected, the Campaign Structure will be finalised. Kaboom appies a spiral model to ensure messaging and content is delineated to work on multiple levels at the same time. -

Content Strategy

As part of campaigning, we reiterate the key messages through various ways since the audience requires constant awareness building in order to act upon directives in a sustainable

INFORM   **ENGAGE**
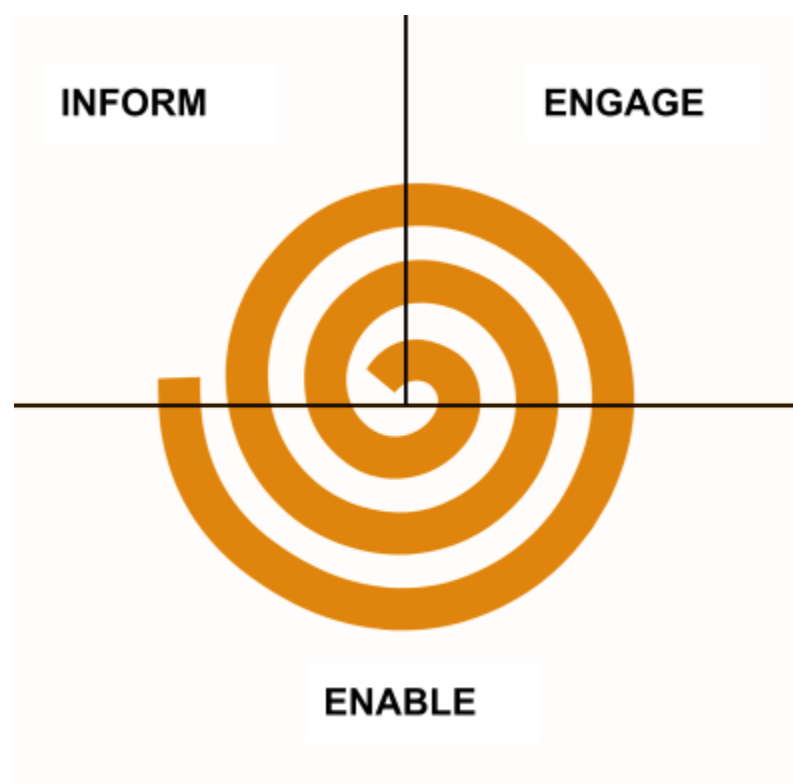
ENABLE

manner. Based on this **cyclical nature** of campaigning, the **Spiral Model** works as a three part process of - **INFORM, ENGAGE, and ENABLE** to maximise the scale and efficacy of the communication material.

The approach combines content creation, audience engagement and digital marketing for the uptake of the key messages to instil a shift in attitudes and norms.

Part I - Inform

The objective of the **INFORM** component is to **increase people's awareness.** This is a continuous and ongoing process that ensures that key messages are clearly communicated to the various audience cohorts through the course of the assignment. This incorporates elements that increase the **stickiness** of the messages, providing a **high recall** factor for the audiences.

Part II - Engage

Once informed, audiences require reiteration of key messages through various modes - discussions, workshops, activities, etc. in order to **ENGAGE** them.

Audience engagement is maximised through interactions that involve conversation. Therefore, as part of this communications effort the campaign will **create networks** and **communities** to **facilitate discussion** and activity for the audiences as well as scale the reach of the key messages .

Part III - Enable

As part of the **ENABLE** component, the campaign will provide the audience with **necessary tools to facilitate action**. This will be provided by a clear **Call To Action (CTA)**.

Campaign Tactics

The following campaign tactics have been determined on the basis of the Spiral Model, and provide a structure of the Campaign for a **24-month period**.

Activity	Timeline	Purpose	Output	Outcome
Announcement of the upcoming campaign on digital health	6-12 November 2023 - Digital	Inform	Announcement Video - delineating the research	**Outcome I:** Stakeholder Mobilisation - Mobilising

Activity	Timeline	Purpose	Output	Outcome
and health data governance	Health Week		findings	relevant partners to support and scale the campaign related to digital health and health data governance
Developing Thought Leadership and Knowledge Products in collaboration with TH Team	December 2023 onwards	Engage	Blogs, articles, working papers, virtual events, webinars, panel discussions, etc.	**Outcome 2:** Thought Leadership - Establishing THIC as a credible leader in the digital health and health data governance domain
Development of THIC Campaign Microsite and timely updation	January 2024 onwards	Engage	Microsite on TH website	**Outcome 2:** Thought Leadership - Establishing THIC as a credible leader in the digital health and health data governance
Contextualising the concept of personal data and personal health data for the youth in India	January 2024 onwards	Inform	10 static posts, 5 reels or videos, 2 GIFs and infographics	**Outcome 1:** Stakeholder Mobilisation - Public-facing campaign to mobilise youths towards digital health and health data governance
Fundraising	January	NA	Funds mobilised	**Outcome 3:**

Activity	Timeline	Purpose	Output	Outcome
with the TH team	2024 onwards		for augmenting campaign efforts	Resource Mobilisation and Fundraising
Transform Thursdays - Creation of a toolkit to build capacity on digital security of target audiences via the Partner Network	February 2024 onwards (one session on the last Thursday every month)	Engage	• Toolkit • Capacity building sessions (vis partner network) • Social Media Content	**Outcome 2:** Thought Leadership - Establishing THIC as a credible leader in the digital health and health data governance
Organise a roundtable discussion for all partners who conducted #TrasformThurs days to together set an agenda for year 2, decide the action points and have a clear point of action that leads to an advocacy point, policy ask or a clear ask from the government.	October/ November 2024	Enable	• Roundtable event • Policy/ Advocacy Asks • Design Collaterals for the event • Social Media Content	**Outcome 4:** Advocacy - Creating policy asks from the public and including it within THIC's ongoing advocacy
Campaign Burst I - Control Apne Haath Mein	April 2024, including World Health Day	Inform	• Mainline Video • Campaign and Digital Media Strategy	**Outcome 1:** Stakeholder Mobilisation - Public-facing campaign to mobilise youths

Activity	Timeline	Purpose	Output	Outcome
			• Social Media Assets • Campaign Execution • Launch Event (World Health Day) - • PR Management (including creation of PR kits)	towards digital health and health data governance
Virtual Ask Me Anything (AMA) Session via Instagram Lives with popular healthcare influencer/s	April 2024 (included as part of the Campaign)	Engage	Live Sessions	**Outcome 1:** Stakeholder Mobilisation - Public-facing campaign to mobilise youths towards digital health and health data governance
Media Sensitisation - Media ko bhi farak padta hain	April 2024 (included as part of the Campaign)	Engage	• Sensitization session • IEC Material • Social Media Collaterals	**Outcome 1:** Stakeholder Mobilisation - Public-facing campaign to mobilise youths towards digital health and health data governance
Public-facing Innovative Digital Newsletter - Farak Padta Hain Series	March 2024 onwards	Inform	Digital Newsletter (once every two months)	**Outcome 1:** Stakeholder Mobilisation - Public-facing campaign to mobilise youths towards digital

Activity	Timeline	Purpose	Output	Outcome
				health and health data governance
Campaign Burst II - Kya, Farak Padta Hai?	6-12 November 2024 - Digital Health Week	Inform	● Mainline Video/ tool ● Campaign and Digital Media Strategy ● Social Media Assets ● Campaign Execution ● Launch Event (World Health Day) - ● PR Management (including creation of PR kits)	**Outcome 1:** Stakeholder Mobilisation - Public-facing campaign to mobilise youths towards digital health and health data governance
Petition by Young People	6-12 November 2024 - Digital Health Week	Enable	● Launch Petition in collaboration with partners ● Event - Interactive Mural ● Social Media Content	**Outcome 4:** Advocacy - Creating policy asks from the public and including it within THIC's ongoing advocacy
Creation of content for all social media channels through the 15 months	December 2023/ January 2024 onwards	Inform	Everyday Social Media Content	**Outcome 1:** Stakeholder Mobilisation - Public-facing campaign to mobilise youths towards digital health and health

Activity	Timeline	Purpose	Output	Outcome
				data governance
Monitoring Campaign Progress	January 2024 onwards	NA	Quarterly Progress Reports	**Outcome 1:** Stakeholder Mobilisation - Public-facing campaign to mobilise youths towards digital health and health data governance

Messaging of the Campaign

The campaign will have the following tone and voice to appeal to the target audience -

- Young - millennial terminology, trends
- Energetic
- Lively
- Entertaining
- Humorous
- Informative
- Action-oriented

This tone will be demonstrated through the following Content Buckets -

- Spoof Videos and Memes
- Musical elements focussed on Punjabi Rap and K-pop
- Human Interest Stories
- Influencer-driven content
- Virtual live sessions
- Webinars and Panel Discussions
- Workshops

Campaign Channels

Kaboom aims to utilise the following digital channels for campaign dissemination

Primary Channels	Secondary Channels
Instagram	Facebook

Youtube	LinkedIn X (Twitter)

Measuring Impact

The following indicators will map the progress and measure impact through the Campaign -

- Total number of boys and men reached as part of the campaign.
- Specially targeting girls and women - an incremental increase in the number of girls and women reached through the campaign.
- Increase in mentions of Digital Health Data and THC in media through media sensitisation and PR activities.
- Increase in uptake of TrasformThursdays
- Number of national youth and women-led organisations, medical professional associations and civil society organisations mobilised.
- Increase in coalition partners representing youth and women.
- 1 petition jointly released by THC and endorsed by youth.
- Atleast 1 donor agency jointly engaged.

Efficacy of Campaign Tactics

This section delineates the efficacy of the campaign tactics utilised in relation to maximising reach, while optimising spend -

- **Uniformly distributing funds:** The funds have been apportioned over multiple tactics across the 15 month period, so no one tactic absorbs the majority of funds. This ensures the campaign will have consistent visibility over the entire campaign duration.
- **Optimising expenditure with impactful tactics:** Tactics have been planned in a way where they do not cost appreciable sums of money, but still manage to create immense impact. The budget mainline videos, user-generated content, Transform Thursdays Platform, petition and interactive mural, etc. are all examples of such optimised spending.
- **Constant content creation:** All activities undertaken are an opportunity for the Creative Team to develop content for dissemination over social media. This allows impactful, organic content generation with least spends.
- **Partnerships**: All collaborations and partnerships have been planned based on a mutually beneficial exchange, rather than remuneration for services. This way we ensure that the partnership is sustainable and long lasting.
- **Media sensitisation:** As part of the tactics, soecial attention has been given

to increase reach via media. A media sensitisation workshop will be conducted to orient the media where best to plug the work being undertaken as part of the campaign. This has been devised as an organic way to increase media visibility.

Aligning with Global Transform Health Outcomes

Through our Campaign, we fundamentally aim to align with the outcomes Transform Health is working to achieve on a global scale. The following outcomes will be achieved through the activities presented in the previous section -

- **Building consensus and driving political will:** Transform Thursdays have been planned as an activity that provides a common set of guidelines and engaging activities for Coalition Partners as well as additional development partners. The platform has been devised as a tactic to keep the Coalition active through the Campaign period. Moreover, the activity concludes with the participating partners co-creating a comprehensive policy ask with respect to scaling capacity building efforts as well as strengthening institutions in the digital healthcare domain.
- **Advocating for a global health data governance framework:** Awareness regarding data health governance is a salient feature presented through both campaign routes. During the concluding phase of the 2-year campaign we have proposed a Petition on health data governance, raised by the engaged youth in partnership with various organisations.
- **Enabling increased & coordinated investment to digital health:** As part of our work, Kaboom will undertake coordinated fundraising in collaboration with the Transform Health Team and WISH Foundation.

References

- Aadhaar: Digital Inclusion and Public Services in India. (2017). By Abhijit Banerjee, Esther Duflo, Rachel Glennerster, and Sunita Khemani. Washington, DC: World Bank. Retrieved from https://thedocs.worldbank.org/en/doc/655801461250682317-0050022016/original/WDR16BPAadhaarPaperBanerjee.pdf
- Agarwal, A. (2023, March 21). India has taken 'quantum leap' in digital health: Mandaviya at WHO-led conference in Delhi. Times CNBC TV18. Retrieved from https://www.cnbctv18.com/healthcare/mansukh-mandaviya-digital-health-india-data-artificial-intelligence-delhi-who-global-conference-marshall-islands-16219891.htm
- Agarwal, A., Tiwary, A., Kumar, S., & Singh, V. (2023). Impact of telemedicine services on primary health care: Before and after analysis–Jharkhand digital dispensary model. International Journal of Community Medicine and Public Health. Retrieved from https://www.ijcmph.com/index.php/ijcmph/article/view/10898#:~:text=Conclusions%3A%20Telemedicine%20is%20strong%20enabler,system%20by%20reaching%20the%20unreached
- AIIMS Jodhpur collaborates with Microsoft India to set up Mixed Reality. (2022, March 8). The Times of India. Retrieved from http://timesofindia.indiatimes.com/articleshow/91545058.cms?utm_source=contentofinterest&utm_medium=text&utm_campaign=cppst
- Analytics India Magazine. (2021, September 6). Google Uses Apollo Hospitals' X-Ray Data To Identify Chest Abnormalities. Retrieved from https://analyticsindiamag.com/google-uses-apollo-hospitals-x-ray-data-to-identify-chest-abnormalities/
- Banerjee, A. V., Duflo., Glennerster, R., & Khemani's. (2017). Aadhaar: Digital Inclusion and Public Services in India. Washington, DC: World Bank. Retrieved from https://thedocs.worldbank.org/en/doc/655801461250682317-0050022016/original/WDR16BPAadhaarPaperBanerjee.pdf
- Chaturvedi, A. (2021). WhatsApp launches incubator programme to help organisations build digital solutions for healthcare issues. The Economic Times. Retrieved from https://economictimes.indiatimes.com/tech/technology/whatsapp-launches-incubator-programme-to-help-organisations-build-digital-solutions-for-healthcare-issues/articleshow/88121441.cms?from=mdr

- Digital Personal Data Protection Act, 2023 – A Brief Analysis. (2023, August 22). By Ishita Ahuja and Siddharth Kapadia. Bar & Bench. Retrieved from https://www.barandbench.com/law-firms/view-point/digital-personal-data-protection-act-2023-a-brief-analysis
- Google Uses Apollo Hospitals' X-Ray Data To Identify Chest Abnormalities. (2021). Analytics India Magazine. Retrieved from https://analyticsindiamag.com/google-uses-apollo-hospitals-x-ray-data-to-identify-chest-abnormalities/
- Government of India. (n.d.). Ayushman Bharat National Health Protection Mission. Retrieved from https://www.india.gov.in/spotlight/ayushman-bharat-national-health-protection-mission
- Ministry of Health & Family Welfare, Government of India. (2020). National Digital Health Blueprint (NDHB). Retrieved from https://main.mohfw.gov.in/sites/default/files/Final%20NDHB%20report_0.pdf
- National Family Health Survey (NFHS-5), India, 2019-20. International Institute for Population Sciences (IIPS). (2021). Mumbai

Annexure

Annexure 1 - KAP Survey Partners

The following survey partner organisations facilitated in collecting responses from the field:

- 90.4 - Agra ki Awaz (via NCC volunteers)
- SKB University
- Media and Communications Department, Maulana Azad National Urdu University

The following survey partner organisations facilitated in digital dissemination of the survey:

- Osmania University
- Childline
- Prayas
- Slum Soccer
- Commutiny
- Ashoka University
- Pravah

Annexure 2 - Data Tools

- KAP Survey
- KII Schedule
- FGD Guide & Tools

Thank you!