Research Report

January 2022

Our Health, Our Voice

Participatory Research with Adolescents Living in Urban Informal Settlements of Gurugram, India:

A Study Report

Knowledge. Voice. Democracy.
PRIA

GURUGRAM UNIVERSITY

SHLC
Centre for Sustainable, Healthy and Learning Cities and Neighbourhoods

UKRI UK Research and Innovation

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Abbreviations

AFHC	Adolescent Friendly Health Clinic
CHC	Community Health Centre
FGD	Focus-Group Discussion
HIV/AIDS	Human Immunodeficiency Virus Infection/ Acquired Immune Deficiency Syndromes
LMIC	Low- and Middle- Income Country
MFF	Martha Farrell Foundation
PR	Participatory Research
PHC	Primary Health Centre
PRIA	Society for Participatory Research in Asia
RKSK	Rashtriya Kishore Swasthya Karyakram
SBCC	Social and Behavioural Change Communication
SDG	Sustainable Development Goals
SDH	Sub-District Hospital
SHLC	Centre for Sustainable, Healthy and Learning Cities
SRH	Sexual and Reproductive Health
WASH	Water, Sanitation and Hygiene

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Executive Summary

'Our Health, Our Voice' is a Participatory Research (PR) study that explores the relationship between urbanisation, migration and health in low-income communities in India. The study with the adolescents living in urban informal settlements of Gurugram, Haryana has provided rich insights into the lived realities primarily drawn from the perspective of adolescents. Drawing on a mix of participatory research methods, the study has attempted to involve adolescents as 'co-researchers' in every step of the research process, thereby developing a model that emphasises on active participation in knowledge generation. A unique feature of the study has been the building capacities of adolescents to review, analyse and subsequently influence the public health policies.

The achievement of SDG 3 – "Ensure healthy lives and promote well-being for all at all ages" – globally is much dependent on how India aligns national priorities as well as allocates resources to achieve the target. India has the largest adolescent population in the world, 254 million and every fifth person in the country is between the age of 10 to 19 years. For adolescents to contribute productively to the development trajectory of the country, their transition to adulthood should be marked by sensitive handling of emerging physiological and psychological changes. Lack of information regarding the phenomenon of adolescence was found to be one of the biggest impediments to seeking preventive health-care among the adolescents, along with design of the health systems insensitive or non-receptive to health needs of the adolescents.

The study identified three critical barriers impairing health outcomes among adolescents in the context of Gurugram:

- Poor knowledge of adolescent health needs and demands in the local context
- Lack of participatory spaces or avenues for adolescents to talk about their health issues
- Inadequate participation of adolescents in planning, implementation and monitoring of health policies, especially the flagship scheme for adolescents, Rashtriya Kishore Swasthya Karyakram (RKSK)

The objectives of the study were as follows:

- To enquire, from the perspective of marginalised adolescents, the health needs and health education necessary for transition into healthy adults.
- To examine existing government funded health policies and programmes for the adolescents; this includes identifying the right tools and techniques as well as the right triggers and incentives for engaging the adolescents in the planning, implementation and monitoring of adolescent specific health services.
- To offer practical proposals for national and state policy and programmes, based on existing successful models of engagement and knowledge exchange.

Adopting a participatory approach to developing interventions, the following participatory activities were used to address the gaps that emerged during the course of study:

- **Generating awareness and evidence regarding adolescent health:** Co-creation of local knowledge and evidence regarding adolescent health with active involvement of community and multiple stakeholders like public health officials, elected representatives and frontline health workers enabled the study team to identify the priority health areas where adolescents lacked knowledge.

Through using mixed-method data collection techniques (Surveys and FGD), conducting data dissemination sessions and designing locally relevant Social and Behavioural Change Communication (SBCC) materials, the study addressed the gap in information deficit prevalent among adolescents in urban informal settlements.

- **Creating a safe space for adolescents:** Participatory 'visioning exercise' was conducted with adolescents to create a space for adolescents to come together and learn from each other about adolescent health through skits, poetry, painting and games. The study demonstrated the effectiveness of engaging adolescents to gain agency over their life issues through participatory methods in under-resourced settings. Such spaces would be critical in engaging adolescents, not as recipients of top-down service delivery, but as active citizens capable of engaging with governance institutions to demand rights commensurate to their aspirations.

- **Incorporating adolescent voices into policy:** A consultation with city-level health officials was organised to bring adolescents closer to the health policy space. Adolescents were capacitated to evaluate the prevailing health systems in Gurugram and to recommend policy changes to design facilities and services responsive to demands and aspirations of adolescents. The consultation also served as a space for building capacity of district level health officials to conceptualise frameworks for institutionalising adolescent participation in RKSK implementation.

At the onset , the study was conceptualised to institutionalise adolescent participation in health policy.

- For adolescents to transition to healthy adulthood, it is important that they get access to right information and practices regarding health and well-being. Social and Behaviour Change Communication (SBCC) materials were designed by identifying the priority areas of adolescent health through Surveys and FGD, in local language. The materials, adapted to the local context, would address information deficit among the adolescents.

- Through participatory exercises, adolescents were facilitated to take the promotive route to health-seeking by educating them about its benefits as well as by providing information on available health facilities in the vicinity of the community.

- The consultations were successful in getting recognition of adolescents as active influencers of health policy if engaged through participatory activities. This would enable the district health administration to train adolescents as peer educators and would lend credibility to their role in the community and enable more adolescents to volunteer thereby ensuring sustainability of adolescent participation.

- The methodology and results of the study will be disseminated in the form of a report, academic journal and blogs and will be made available in public domain. This would ensure replicability of the study in similar settings.

Introduction

"Every adolescent wants to be relevant" remarked one of the speakers during the national consultation on institutionalising adolescent participation in improving their health and well-being organised on 3 September 2021 under the aegis of the research study on "Our Health, Our Voice – A Participatory Research with Adolescents Living in Urban Informal Settlements in Gurugram, India". The study was undertaken by Participatory Research in Asia (PRIA) in partnership with Gurugram University, Haryana and supported by the UKRI funded Centre for Sustainable Health and Learning City at the University of Glasgow, UK. The remark by the speaker summarises the core philosophy behind the participatory research study. It also brings forth a fresh perspective in adolescent health research; that of viewing adolescents as 'citizens' and people with agency instead of mere recipients of elderly and 'expert' wisdom. The recognition of adolescents and youth as active participants in knowledge creation has been key to achieving PRIA's objective of mainstreaming youth voices at the forefront of driving policy changes and social impact.

In the last decade of accelerating progress towards achieving Sustainable Development Goal (SDG) 3 that aspires to ensure "health and well-being for all', it is important to identify hitherto vulnerable, marginalised and excluded sections of the population to target evidence-based intervention towards formulating inclusive health policies that guarantee accessible and affordable healthcare. Among the most vulnerable sections of the population are India's adolescents in the age group of 10-19 years[1]. India has the largest cohort of adolescents in the world (UNICEF, 2012)[2] and their participation in nation-building is expected to significantly contribute to determining its development trajectory.

Reaping the benefits of India's demographic dividend will be central to India's economic development, but the largest generation of young people in human history face enormous challenges towards realising their potential to be effective human resources. The Lancet Commission report titled, 'Our Future' had identified 'adolescence' as a 'critical phase in life for achieving human potential' but suffering from need of potential investments to improve health and well-being of present as well as future generations (Patton et al. 2016)[3]. It is well-established that adolescents exert a larger pressure on health systems due to multiplicity of demands owing to transition to puberty, physiological, psychological and behavioural changes, and influence of societal factors. In such a scenario, the health systems and public health machinery are expected to be competent, responsive as well as capacitated to address such context-specific adolescent health issues.

Yet, adolescents and youth living in Low-and-Middle Income Countries (LMIC), or under-resourced settings continue to be susceptible to several preventable and treatable health problems like unintended pregnancy, sexually transmitted diseases due to unsafe sex, nutritional disorders like malnutrition and anaemia, and substance abuse, besides the huge burden of mental health disorders. Adolescents are generally perceived to be 'healthy' and general demands on their health and well-being do not receive the warranted attention that it deserves at three levels – individual, caregiver and health systems. A

[1] The flagship scheme of Ministry of Health and Family Welfare (Government of India), Rashtriya Kishore Swasthya Karyakram defines adolescents as those belonging to the age-group of 10-19 years. Refer https://nhm.gov.in/index1.php?lang=1&level=2&sublinkid=818&lid=221

[2] UNICEF: Progress for children: a report card for adolescents.; 2012.

[3] Patton, G. C., Sawyer, S. M., Santelli, J. S., Ross, D. A., Afifi, R., Allen, N. B., Arora, M., Azzopardi, P., Baldwin, W., Bonell, C., Kakuma, R., Kennedy, E., Mahon, J., McGovern, T., Mokdad, A. H., Patel, V., Petroni, S., Reavley, N., Taiwo, K., Waldfogel, J., … Viner, R. M. (2016). Our future: a Lancet commission on adolescent health and wellbeing. Lancet (London, England), 387(10036), 2423–2478. https://doi.org/10.1016/S0140-6736(16)00579-1

centralised policy-making machinery, as the one that exists in India, excludes adolescents from participating in public policy.

According to Census 2011, of the total urban population in India, 36 percent (135.5 million) were children (0-9 years of age) and adolescents (10-19 years of age). Adolescents constituted around 19.23 percent (72.52 million) of the total population of youth living in cities. The huge population of adolescents living in urban India highlights the need to direct exclusive focus towards treating adolescent health as an exclusive area of healthcare and not as a peripheral stream within the broader realm of healthcare.

Photo 1 – Urban informal Settlements in Gurugram

In order to make health care accessible to adolescents, India has been at the forefront of designing interventions and corrective policies to integrate adolescents into the fold of preventive healthcare. The Adolescent Reproductive and Sexual Health (ARSH) policy of 2006 was an important policy milestone towards achieving sustainable adolescent health, which was followed by Reproductive Maternal New-born Child and Adolescent Health (RMNCH+A) Strategy of 2013, and the *Rashtriya Kishor Swasthya Karyakram* (RKSK).

In the context of the current study, the emphasis is on RKSK, which was launched by the Government of India in 2014 to cater to its adolescent population. The implementation guidelines of the scheme have incorporated the following key initiatives:

- Adolescent Friendly Health Clinics: Adolescent Friendly Health Clinics are to be established as part of the RKSK scheme to provide preventive, promotive, curative and referral services to adolescents in the age group of 10-19 years.

- Peer Educators: The Peer Educator Approach to community intervention embodies the participatory component of RKSK scheme. It aims to ensure that adolescents in the age group of 10-19 years benefit from regular access to information surrounding adolescent health. Peer Educators conduct

meetings with adolescent boys and girls in the community to generate awareness on health issues. They also refer the adolescents to Adolescent Friendly Health Clinics being run at district hospitals, Community Health Centres (CHC) and Primary Health Centres (PHC).

- Weekly Iron Folic Acid Supplementation Programme (WIFS): Administration of weekly Iron Folic Acid supplementation (WIFS Tablet) to eradicate anaemia in adolescent girls is an important mandate under RKSK. The distribution of Iron Folic Acid Tablets is done through schools and through the front-line health worker for out-of-school children.

Photo 2 – Urban informal Settlements in Gurugram

Gurugram (erstwhile Gurgaon) is an important commercial city in the state of Haryana. Earlier known as one of the satellite cities of New Delhi (India's national capital), Gurugram has since grown to become an important IT hub in North India earning the sobriquet 'millennium city'. The development trajectory of Gurugram displays striking similarities to that of Mumbai, another prominent commercial city in India. According to Census 2011, Gurugram has a population of nearly 15 million.

While Gurugram houses the headquarters of multi-national companies, the contradictions of urbanisation are to be seen in the landscape, where high-rise buildings at the forefront dwarf the informal settlements, known as slums or bastis, and residential complexes with bare minimum amenities and living conditions at the fringes. Residing in the informal settlements are persons employed in informal professions such as security guard, gardener, office assistants, domestic workers and contractual construction labourers. Most of the families residing in informal settlements have migrated from states like Uttar Pradesh, Bihar and West Bengal. The economics of the city dictate the migratory patterns in Gurugram. The infamous mass exodus of migrant families in the wake of the COVID-19 pandemic in March 2020, due to inability to find work, reveals the pathetic livelihood conditions of the population inhabiting informal settlements. Education and health needs of adolescents can only be met as long as the parents or caregivers have access to opportunities to earn income. Absence of opportunities to develop, for parents as well as adolescents, affect the transition of adolescents into healthy adults and productive individuals.

In the present study on "Our Health, Our Voice: Participatory Research With Adolescents in Gurugram", majority of the adolescents surveyed belonged to migrant families, with the highest percentage having migrated to Gurugram from West Bengal. Source of income for most families was through employment in informal sector work. The population density in such informal settlements is very high, with as many as 4-5 family members sharing a dingy room which houses a kitchen and, in some cases, a toilet. The settlements also lack access to adequate sanitation facilities and clean drinking water. The residents were also placed under surveillance of high-definition CCTV cameras that monitored their movements and daily life.

Photo 3 – Inside an Urban Informal Settlement in Sikanderpur, Gurugram

It is against this backdrop of below-average living conditions, constant surveillance, inadequate Water, Sanitation and Hygiene (WASH) facilities and restricted freedom that the lives of adolescents and their health-seeking have been analysed as part of the study. The participatory action research study is an attempt to provide agency to the adolescents living in under-resourced settings to take charge of their health and health-seeking behaviour. At all stages of the research process, adolescent and community participation was integrated. The present study is also an attempt to document a model of adolescent participation in improving health policy and systems, especially in the context of low-and-middle income countries.

There are 1.2 billion adolescents in the world, of whom nearly 90 percent live in low- and middle- income countries (LMICs). In many of these countries, collaborative and adolescent-led approaches to health have had an impact[4] and was shown to be effective models in addressing the deficit in health-seeking behaviour. In order to increase the uptake of welfare schemes and services, it is important to secure and facilitate participation of adolescents in generating evidence and designing policy interventions. Considering the burden of diseases among India's 254 million adolescents, it is important to adopt a participatory approach to health planning. To demonstrate the effectiveness of community engagement in generating evidence, PRIA and Gurugram University with support from SHLC, collaborated with

[4] Clark, Helen, Awa Marie Coll-Seck, Anshu Banerjee, Stefan Peterson, Sarah L. Dalglish, Shanthi Ameratunga, Dina Balabanova et al. "A future for the world's children? A WHO–UNICEF–Lancet Commission." The Lancet 395, no. 10224 (2020): 605-658.

adolescents living in urban informal settlements in Gurugram, Haryana to conduct Participatory Research (PR) into health-seeking behaviour and to suggest health policy changes.

Box 1. PRIA and work on empowerment of communities

The larger vision for PRIA is to promote people-centred development using an inclusive model where even the most marginalised stakeholder can represent their stake and not go unheard. All efforts of PRIA point in one direction that is 'deepening participation'. PRIA advocates for use of Participatory Research (PR) in conducting research with the communities. PR is a research paradigm within the social sciences that emphasises collaborative participation of trained researchers as well as local communities in producing knowledge directly relevant to the stakeholder community. The guiding vision for PRIA has been that of spreading knowledge and giving access for the marginalised sections is a path to empowerment, in short 'knowledge is power'.

Closely linked to this objective is training, which holds the promise to actualise the potential of the chosen participant group to assert their rights in the public domain – which in this case is the adolescent group. Researchers involved in using participatory methodology tend to use a blend of participatory learning and action methods such as games, play and drama with audio-visual tools being integrated into the training sessions. In the present study, capacity building workshops for conducting digital survey and training sessions on participatory techniques like aspirational envisioning workshop were conducted to further the stakes of adolescents in improving their health and well-being.

Methodology

Participatory Research (PR), unlike classical research emphasises the active participation and involvement of community over the generation, utilisation and elaboration of knowledge. Participatory Research maintains that the actors in the situation are not merely objects of someone's study but are active influencers in the process of knowledge-creation. In the process, they not only emerge as 'sources of data or knowledge' but also earn their place as its legitimate owners of new knowledge[5]. However, the success of an effective Participatory Research would require a lot of facilitation within the community.

The aim of Participatory Research is to provide the catalyst to bring forth initiative among people in the community in a way that they collectively act to improve their existing situation. The role of the outside researcher is crucial in bringing information to the community from different contexts and from other avenues in similar situations. The researcher, however, facilitates the process of research in a manner that the communities directly involved have a critical voice in determining the direction and goals of change.

The study titled 'Our Health, Our Voice' was implemented as a collaborative process with the adolescents, university, community, policy makers and grassroot stakeholders like frontline health workers, elected local body representatives, schoolteachers and district health officials. The entire process of research revolved around using Participatory Research (PR) methodology to enquire into the health and living conditions of adolescents from their perspective and to design a mandate for strengthening adolescent friendly health services from the perspective of adolescents.

The objectives of the study are as follows:

- To enquire, from the perspective of marginalised adolescents, the health needs and health education necessary for transition into healthy adults.
- To examine existing public health policies and programmes for the adolescents; this includes identifying the right tools and techniques as well as the right triggers and incentives for engaging the adolescents in the planning, implementation and monitoring of adolescent specific health services.
- To offer practical proposals for national and state policy and programmes, based on existing successful models of engagement and knowledge exchange.

Even though the guidelines of RKSK scheme have integrated community engagement in its scheme of implementation, the intent has not translated into practice as the experience of the current study has shown. A key point emphasised by adolescent health practitioners is the undue emphasis on implementation of RKSK in rural areas than urban areas[6]. Key informant interviews with representatives of district health administration in Gurugram, also revealed the weak focus of the scheme on adolescents in urban areas as compared to rural and semi-rural areas. Gurugram is designated as a 'non-RKSK' district implying that the provisions of the scheme do not apply to the district, even though certain measures like AFHC, distribution of iron folic tablets and counselling for school-going adolescents are implemented.

[5] Tandon, R. (2008). Participatory research; re-visiting the roots. New Delhi: Mosaic Books.
[6] Ramadass S, Gupta SK, Nongkynrih B. Adolescent health in urban India. J Family Med Prim Care. 2017;6(3):468-476. doi:10.4103/2249-4863.222047

The research uses various participatory tools – transect walk, mobile-based participatory survey, Focus Group Discussions, aspirational mapping of adolescent friendly health services, multi-stakeholder dialogues – with active participation of adolescents in all stages of the knowledge creation and policy advocacy. Their inputs have helped shape the questions used for surveys, analysis of the data that was shared through sharing workshops, their insights in the group discussions that generate community demand for health services, and their interactions with government officials and health workers in multi-stakeholder dialogues. All these have helped find a way forward for action that results in improving adolescent friendly health services.

This section outlines the key processes involved in conducting participatory action research with adolescents. Inspired by the ideals of Participatory Research approach developed by Tandon (2002)[7], the diagram (Figure 1) highlights the key process involved in the current research study. The Participatory Research study was conducted from January 2021 to October 2021 in five urban informal settlements in Sikanderpur, Nathupur, Chakkarpur, Ghata and Harijan Basti located in Gurugram.

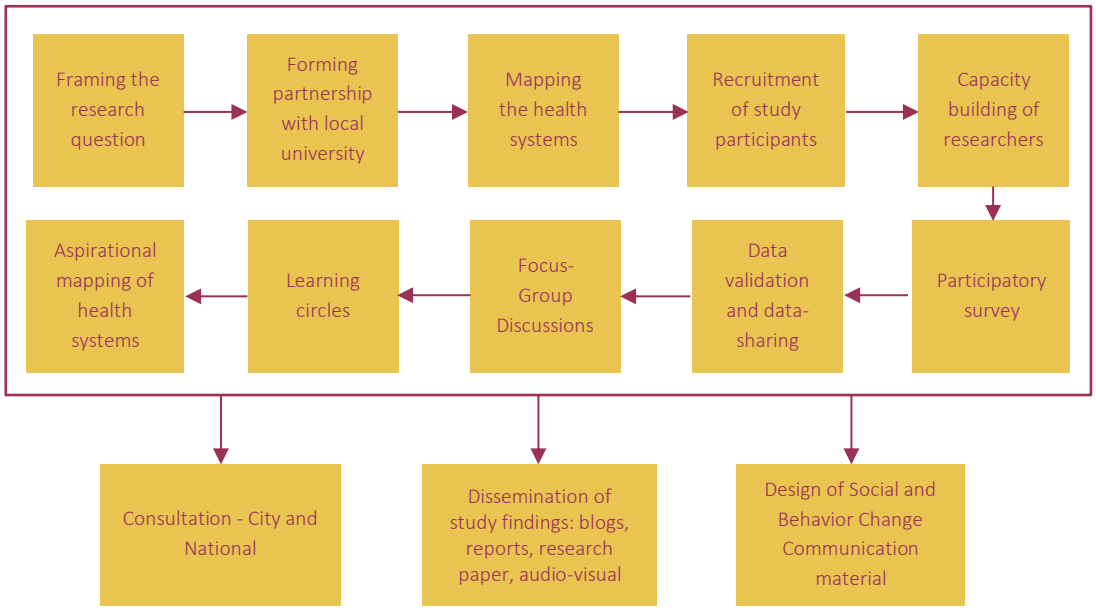

Figure 1 - Steps in Participatory Research Followed in the Study

Framing the research question

In the initial stage of the research process, a team of researchers at PRIA conducted a literature review to understand the phenomenon of 'adolescent health'. Global and Indian studies related to adolescent health, urban adolescents' health, and adolescent health systems were reviewed to identify the gap in literature and a set of key research questions were formulated. It was gathered that there is a paucity of studies using PR methodology to conduct research on adolescents in LMICs and in the context of under-resourced settings.

Mapping of community resources and health systems

Based on synthesis of available literature and evidence, a transect walk of the community was undertaken to develop a contextual understanding of physical conditions and available community

[7] Tandon, R. (2008). Participatory research; re-visiting the roots. New Delhi: Mosaic Books.

resources in five urban informal settlements in Gurugram. Mapping of existing health systems was also undertaken to identify relevant systems catering to adolescents and to the population, in general.
Forming partnership with the local university

The Participatory Research study was initiated as a partnership with a local public university, Gurugram University to strengthen community-university engagement. The purpose of forming partnership with the local university was to build capacity of the university faculty members and students in conducting participatory health research. University students were trained on community engagement as well as conducting surveys using smartphones.

Development of study tools and instruments

Before conducting the survey, a survey instrument had to be designed that was culturally, geographically and scientifically relevant to the communities living in urban informal settlements. The survey questionnaire was adapted from the Indian Adolescent Health Questionnaire (IAHQ) developed by Long et al (2013)8. After assessing for emerging adolescent health issues through transect walks and informal interactions with the community, the IAHQ tool was adapted to the local context. The participatory survey was administered through a smartphone.

In addition to the questionnaire, an informed consent form was also administered to all the participants indicating their willingness to participate in the survey under conditions of anonymity and confidentiality.

Capacity building workshop for the community group as co-researchers

A Participatory Research methodology training workshop was organised for the student researchers and community animators, as part of the study. The workshop was conceptualised with the objective of acquainting the researchers as well as animators associated with the study towards using PR methodology as well as making them proficient in conducting and administering digital survey, besides community engagement and group work.

In addition to recruiting student researchers, hiring and training local community members to conduct the survey contributed to accuracy of the data due to trust. It helped in removing apprehensions of the community in opening up to 'outsiders' on matters of confidentiality as related to health. Detailed survey guidelines were prepared and distributed among the data collection team to guide them through the process during the COVID-19 pandemic. The field staff was advised to maintain physical distancing and were provided with hygiene kits.

Recruitment and enrolment of study participants

The potential participants of the study were briefed about the participatory research study and the objectives. Informed consent was sought from the participants before formally enrolling them in the study.

8 Long KN, Long PM, Pinto S, Crookston BT, Gren LH, Mihalopoulos NL, Dickerson TT, Alder SC. Development and validation of the Indian Adolescent Health Questionnaire. J Trop Pediatr. 2013 Jun;59(3):231-42. doi: 10.1093/tropej/fmt006. Epub 2013 Feb 16. PMID: 23418132; PMCID: PMC3693506.

Participatory survey

A participatory survey was conducted with 330 adolescents (141 boys and 189 girls) living in urban informal settlements in Gurugram to understand the attitudes and practices followed by the participants including their health-seeking behaviour in the month of February (1-18 February 2021). The data was collected by the student researchers and community animators through smartphones.

Stratified sampling was used to recruit the study participants. The study population was chosen based on their age group, which is 10-19 years, as identified by the Government of India under the RKSK scheme. Further, since certain parameters like health-seeking behaviour, consumption of drugs and substance and menarche vary considerably among the people in the mentioned age-group and according to gender, the study population was divided into two age groups, i.e.,10-14 years and 15-19 years and gender groups (participants who identify themselves as 'male' and 'female') to elicit age and gender specific responses.

Data validation and data sharing

Post the analysis of data, the preliminary survey findings were validated with the actors in the problem situation, in this case adolescents. In classical research, dissemination and use of survey findings is considered as a task to be addressed after surveys are completed. However, reciprocity (gathering knowledge from the community and ensuring that the knowledge benefits the community) includes sharing data with the participants. This also includes stating that the survey information would benefit the adolescents as well as their caregivers in exercising in responsible behaviour with regard to health.

In the current study, the data was disaggregated at the level of settlements to ensure context-specific insights to be presented. Adolescents were presented an opportunity to understand the research findings and to raise an objection if there was disagreement with the data. A total of four such meetings were held in all five settlements in the month of March (8,16 and 19 March 2021). Post the validation of data, data was shared with the wider community and stakeholders related to the informal settlements to generate awareness about the prevalent situation of adolescent health and to decide the future course of action and policy change through participation.

Focus group discussions

Focus Group Discussion is a qualitative research method in which a trained moderator facilitates a guided discussion with a small group of people, often 6-8 participants, who have personal or professional experience with the topic being studied. The Focus Group Discussions (FGD) offer the advantage of group communication to gain insight into the participants' attitudes, feelings, beliefs, cultural norms, experiences and reactions regarding a specific topic of interest.

Four FGDs were conducted during the course of the study with the adolescents as well as the caregivers or female guardians of adolescents. As the second wave of pandemic struck during the course of study, FGDs were conducted online as opposed to face-to-face sessions. The participant groups, namely the adolescents as well as their mothers participated in the FGD through the virtual platform. For adolescent or women participants, who reported not owning or having access to a smartphone, they were encouraged to share a device with their co-participants, if they lived in the vicinity following COVID-appropriate behaviour.

Learning circles

Learning circles are intellectual spaces created to explore a particular phenomenon from a multi-stakeholder perspective. The research team conducted two online learning circles aimed at carrying forward the discussion on adolescent health with adolescents and representatives of civil society and academia. The Learning Circles offered the benefit of engaging stakeholders adept at different thematic areas within adolescent health, such as SRH, nutrition, mental health, drug and substance abuse and health systems, to explore a topic through different perspectives. It also provided an interface for adolescents to engage with participants keen to learn about adolescent health.

Aspirational mapping of health systems

Aspirational mapping is a participatory 'envisioning' exercise where adolescents were facilitated to visualise the design of adolescent friendly health clinics from their perspective and to articulate their vision for improved health policies centred around their needs and demands. Different activities like skit, play and poetry were used by adolescents to design the health system.

Multistakeholder dialogues

Multi-stakeholder dialogues in the form of consultations were organised to connect with policy makers, academicians and health professionals with interest in adolescent health to communicate the research findings and to contextualise it from a pan-national perspective. Two consultations were organised, at the city and national level. Adolescents presented their demands for improved health services to the stakeholders present.

Dissemination of study findings

The key findings of the study and the participatory research process were disseminated both by the adolescents and the research team. While the research team published blogs, articles, reports and academic papers, the adolescents facilitated by the research team engaged with the policy makers and different stakeholders working on adolescent health through city and national level consultations to communicate their demands and aspirations as informed by the evidence generated by them.

Designing SBCC material to effect behaviour change

Social and Behaviour Change Communication (SBCC) material were prepared and distributed to the adolescents as well as their parents on important topics such as nutrition, sexual and reproductive health and drug and substance abuse, besides a booklet on RKSK.

Box 2. Informed consent and COVID-19 protocols

Due diligence procedures were followed by the team in ensuring safety of the researchers as well as the participants. Informed consent was sought from the participants of the survey. They were recruited to the study after informing them of the study objectives, the purpose of data collection as well as the mode of dissemination of the study findings. For participants who reported inability to read or write, the informed consent was administered orally. All participants were given the option of choosing not to answer questions that they did not want to answer and to drop out from the study. Throughout the duration of the study, the research team ensured adherence to WHO COVID-19 protocols.

Processes, Engagements and Outcomes

Mapping Health System in Gurugram

In order to understand health-seeking behaviour of adolescents and to create awareness about the available health facilities in the city of Gurugram, we mapped the health system in and around the city, especially the Adolescent Friendly Health Clinics (also known as '*Mitrata* Clinics' in Haryana).

The health system in Gurugram district is under the administrative control of the Health Department, Gurugram. The director of health systems in the city is the Civil Surgeon, who is bestowed with administrative powers to implement health related welfare schemes. The Deputy Civil Surgeon is tasked with the administration as well as implementation of *Rashtriya Kishore Swasthya Karyakram* (RKSK).

Photo 4 – AFHC Facility at the Community Health Centre in Gurugram

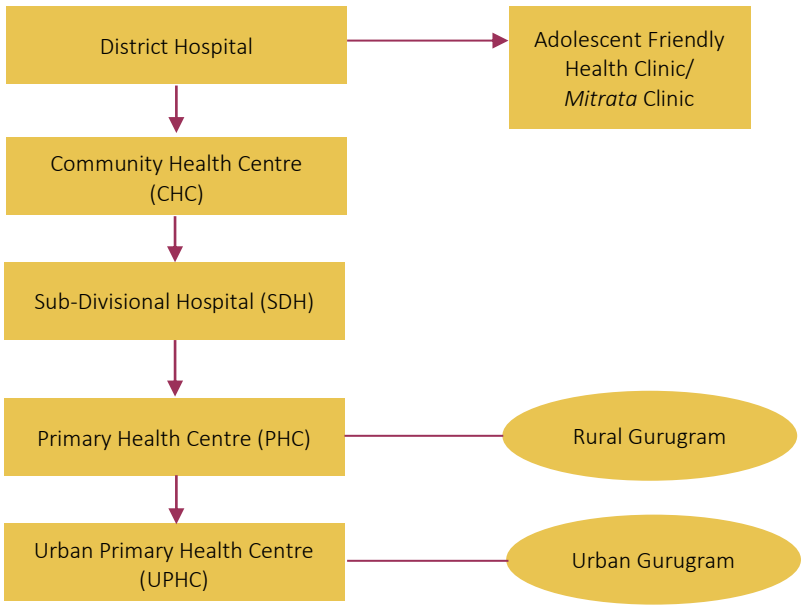

Figure 2 –Health Systems Structure in Gurugram

Community Health Centres and Primary Health Centres are headed by Senior Medical Officers and Medical Officer in-charge respectively. In Gurugram, AFHC is located at the district hospital in Sector 10, Gurugram District. In addition to that, AFHCs are established in 10 PHCs across Gurugram, even though a dedicated counsellor and room is not allocated to the facility. However, no AFHCs are set up in Urban Primary Health Centres. The RKSK scheme mandates health care professionals to provide medical services to adolescents ensuring complete anonymity and the frontline health workers to provide door-to-door service delivery, especially watching out for symptoms of anaemia, providing awareness about menstrual health practices, enquiring about infections and ensuring regular supply of iron folic tablets for adolescent girls.

Even though RKSK guidelines mandate the establishment of AFHCs in the district hospital as well as CHC, PHC and UPHC, there is only one such facility currently at the district hospital, with a dedicated room and full-time counsellor. Adolescent health-seeking in community health centres and Urban Primary Health Centres is part of Out-Patient Department (OPD) and not delivered as separate adolescent friendly health facilities.

Photo 5 – Adolescents Outside the Adolescent Friendly Health Clinic Facility in Gurugram

Findings and Insights from the Participatory Digital Survey (L2)

The participatory survey was conducted to quantify the prevalence of adolescent health issues in the community and to inform evidence to drive the participatory research process forward. The survey was conducted by a research team, comprising of university students from Gurugram University, community animators and the PRIA research team. In February 2021, with strict adherence to COVID-19 safety protocol and norms, the survey was conducted in five urban informal settlements in Gurugram – Sikanderpur, Chakkarpur, Nathupur, Ghata and Harijan Basti. All of them are low-income informal

settlements inhabited by the migrant families. Due to their 'migrant' status, many households do not possess identification or verification documents, which restrict their access to public welfare schemes and programmes. Access to health care was also observed to be impaired.

Informed consent forms were administered to all the participants who had volunteered to take part in the study. They were given the option to drop out of the study at any point of time with the assurance that their identity would be kept strictly confidential. For the participants who reported inability to read or write, the data collection administered the informed consent form verbally. In addition to participation in the study, all participants as well as members of the data collection team were encouraged to maintain COVID-19 appropriate behaviour. Strict monitoring of the data collection team as well as the process of quality control was followed.

The study instrument was divided into seven sections:

- Socio-economic and family characteristics
- Source of information and awareness regarding SRH
- Knowledge of HIV/AIDS and sexually transmitted diseases
- Nutrition
- Use of cigarette, tobacco, alcohol and drugs
- Violence (gender-based violence), domestic violence, abuse and unintentional injury
- Adolescent health- seeking behaviour

To be eligible to participate in the survey, the participants had to belong to the age group of 10-19 years. They should also be a resident of the five settlements as identified. Status of education, marital status, migrant status and gender was no bar in becoming eligible to be a study participant. Data was collected by student researchers enrolled in Gurugram University and community animators, drawn from the communities where the survey was conducted.

Photo 6 - Digital Survey of Adolescent Health in Urban Informal Settlements

Socio-demographic profile of adolescents

Age and family background

330 adolescent boys and girls in the age group of 10-19 years participated in the survey. 141 participants (42.7 percent) were males, and 189 participants (57.3 percent) were females. Further disaggregation of the study participants based on age was done for the purpose of analysis.

Adolescents in the age group of 10-14 years were identified as being in 'early adolescence', while those in the age group of 15-19 years were put in the category of 'late adolescence' 45.2 percent of the participants (n=149) belonged to the 10-14 age category and 54.8 percent (n=181) of the participants (n=181) were between the ages of 15 and 19. The mean age of the participants was 14.6 (±2.4). Only a small proportion (less than 1 percent) of the participants were married (at the time of the survey).

Education, housing and water facilities in the settlements

93 percent of the adolescent boys and girls have received their education in formal educational institutions.

31.2 percent of the participants have completed primary education.

60 percent of the households had access to a shared tap facility to meet their daily needs related to water.

67.2 percent of the participants only had access to a shared toilet facility

Out of the 189 adolescent girls, who participated in the study, 149 participants (78 percent of the participants) reported to entering menarche. In the community we observed high levels of awareness among adolescent girls (n=149) regarding menstrual hygiene.

The mean age of menstruation among adolescent girls was 12 years. Majority (73.15 percent) of the girls used commercially available menstrual hygiene products, like branded sanitary napkins, easily available in the local shops in their settlements

The mother, being the primary caregiver of the adolescent boys and girls, was the preferred source of information on matters related to Sexual and Reproductive health for majority of the adolescents (42 percent), which was followed by the teacher (41 percent).

Enquiry about knowledge of STI symptoms was done by presenting four common and physically recognisable signs of infection, like discharge from vagina/penis, pain during urination, burning sensation in genital organs and ulcer in genital organs to the adolescents. Around 89 percent of the participants could not identify even one symptom and only a small proportion of the participants could identify two symptoms.

Majority of the participants (55.76 percent) rated their ability to initiate discussion on issues related to sex with their parents as 'very difficult'. 80 percent of adolescents reported not receiving training on issues related to sexual and reproductive health.

92 percent of the participants admitted to never having attended any training session on the benefits of a nutritious diet on their health. Awareness in the community regarding specific nutrition needs of adolescents was found to be poor.

91.2 percent of the participants reported lack of awareness regarding Adolescent Friendly Health Clinics.

97.8 percent of the participants reported not visiting a health facility to receive services or information related to STD/ Contraception/ pregnancy/abortion.

The survey highlighted the need to approach adolescent health from a preventive perspective than formal health-seeking delivered through secondary and tertiary health facilities.

Some of the key lessons from the survey:

- Adolescents lack awareness and knowledge regarding sexual health practices as well as information related to contraception, sexually transmitted diseases and pregnancy.
- Lack of knowledge about AFHCs or the services provided through AFHCs is impacting health-seeking behaviour of adolescents.
- Adolescents expressed the need as well as desire to be part of information dissemination sessions or workshops related to sexual and reproductive health as well as nutrition.
- Poor outreach by community workers or frontline health workers in the community was a major reason for adolescents to seek information on critical health issues from peers or internet.

The detailed survey report and survey audio visual document can be accessed here.

Data Validation and Sharing

Photo 7 – Data Sharing Sessions in Progress

Post the participatory survey, data validation and data sharing workshops were held in five settlements with active participation from community members. Data, disaggregated at the level of informal settlements, was communicated to them in simple language and subsequently validated with adolescents in all the survey locations. Post the validation, data was shared with multiple stakeholders within the community like parents and caregivers of adolescents, urban elected officials and municipal representatives, frontline health workers, local schoolteachers, local adolescent champions and NGO representatives. It was observed that these workshops provided a space where adolescents could be mobilised to discuss various health issues related to health, education, family and livelihood with their peers. During one such workshop, the adolescents spoke about creating a 'safe space' within the community exclusively for adolescents.

The data validation and sharing workshops also provided an opportunity to the community to interact with the elected representatives of local government, local schoolteacher, frontline health workers and representatives of local civil society organisations with regard to collectivising towards improving health outcomes among adolescents. Members of the community also raised important concerns of everyday life with the elected representatives like municipal ward councillors. There was a rampant problem of water shortage in the area which was affecting children. Similarly, parents were confronted with challenges of providing smartphones to their young children to continue with online education during the lockdown. These issues were raised with the principal of the local school. The frontline health workers were also invited to the workshops to enable them to interact with the adolescents to promote positive health-seeking behaviour and to reach out in the event of emergency or counselling.

The workshops, in addition to providing an overview about the prevalent state of adolescent health in the informal settlements, also connected them to stakeholders. It also proved to be a safe space where adolescents could interact with each other as well as the team of researchers.

Photo 8 – Data Sharing Sessions in Progress

Photo 9 – Adolescents Referring to the SBCC Materials on Nutrition

Design of Social and Behaviour Change Communication (SBCC) Materials

In order to create awareness among adolescents regarding the phenomenon of adolescent health, Social and Behavioural Change Communication (SBCC) materials were prepared and distributed to adolescents in Hindi and Bangla, two dominant languages spoken in the informal settlements. In addition to generating awareness, the idea was also to create locally relevant material for the community to spread awareness on issues like nutrition, sexual and reproductive health, drug abuse, all of which were identified by adolescents as subjects they lacked information on.

The SBCC material was developed from open-source material developed by the Ministry for Health and Family Welfare, Government of India and modified in accordance with the socio-economic conditions of the community that we were working with. A pamphlet was prepared by the research team focusing on the provisions in RKSK and distributed to the adolescents in the community, which carried salient details of the government scheme as well as the contact details of the local AFHC and medical practitioners.

Click here to access the RKSK pamphlet and SBCC material.

Focus-Group Discussions

Photo 10 – Celebrating International Women's Day

In order to identify the social determinants behind adolescent behaviour in urban informal settlements, it was important to explore the care-giver perspective. In the context of urban informal settlements, the survey identified the mother or female guardian as the primary source of information for adolescents on matters related to important adolescent health issues. Along with the mother or female guardian, adolescents were also involved in Focus-Group Discussion (FGD). Since data to inform evidence around sexual and reproductive health and access to health systems was gathered through the survey, it was

decided to explore aspects of nutrition and safety from the perspective of caregiver and adolescents respectively.

Four FGDs were held with adolescent boys and girls and their caregivers. The online FGDs were recorded after seeking the verbal consent from the participants at the onset. Convenient sampling was used to recruit participants for the FGDs, since community mobilisation was not possible due to pandemic related lockdowns. All participants were explained the rationale for conducting the FGDs after contacting them personally. All participants were given the option of withdrawing from the FGD at any point without the need for explanation.

The FGDs were transcribed by the lead researcher and translated into English from Hindi, which was the medium of conversation between the facilitator and the participant. Two facilitators were involved in the process. While one facilitator moderated the discussion, another facilitator took notes and handled the IT logistics. All responses were manually coded, and thematic analysis was performed to identify the emerging themes.

Box 3. Challenges of organising online FGDs amidst the pandemic

Due to second wave of pandemic and ensuing lockdown in India that ran from April to June 2021, FGDs were conducted online to enable participation from mothers or caregivers and adolescents. Arts-based methods of FGD were used in online sessions to generate discussion around the topics that were discussed. Each FGD was conducted with 7-8 participants. The participants in the discussion were encouraged to arrange their own smart phones with instructions given on using online platforms. Due to the low-income status of the families and considering the digital divide in India, not all participants had access to personal smart phone devices. In case of non-availability, two participants in the neighbourhood were encouraged to share a device with strict adherence to COVID-19 protocols.

Breaking the initial hesitation of adolescents to get the conversation flowing, encouraging adolescents to open up in the presence of family members, and allowing time for participants to feel comfortable enough to speak were some of the challenges faced by the facilitators while conducting online FGDs.

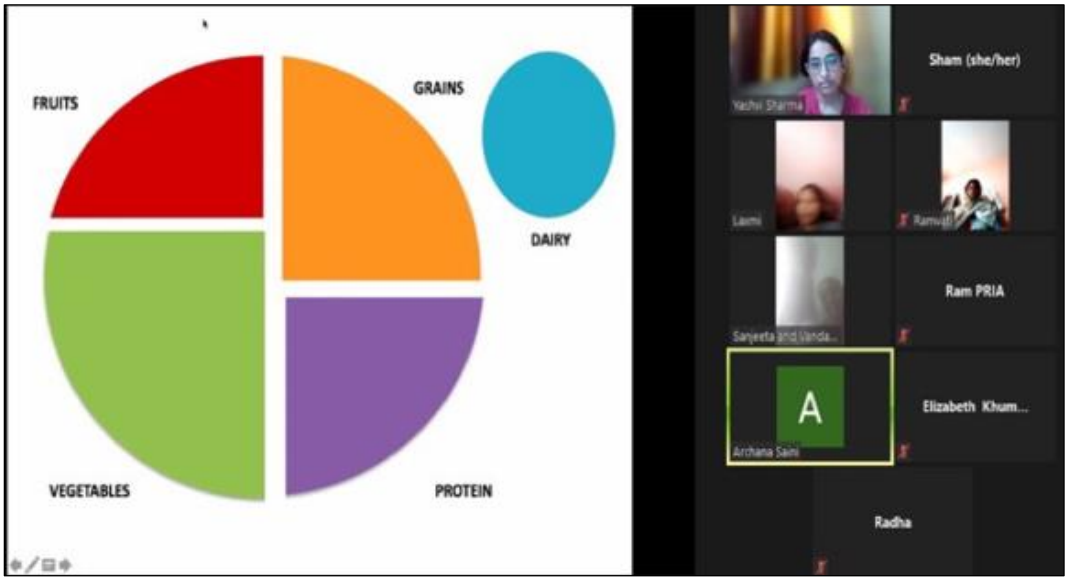

Photo 11 – Online FGDs with the Caregivers

An 'ideal serving plate' consisting of fruits, grains, vegetables, protein and dairy products was presented through online platform to the participants. Mothers were encouraged to list down the food items that they include as part of the daily diet of adolescents, where they listed food items like saag (green leafy vegetables), seasonal vegetables, eggs and some non-vegetarian items.

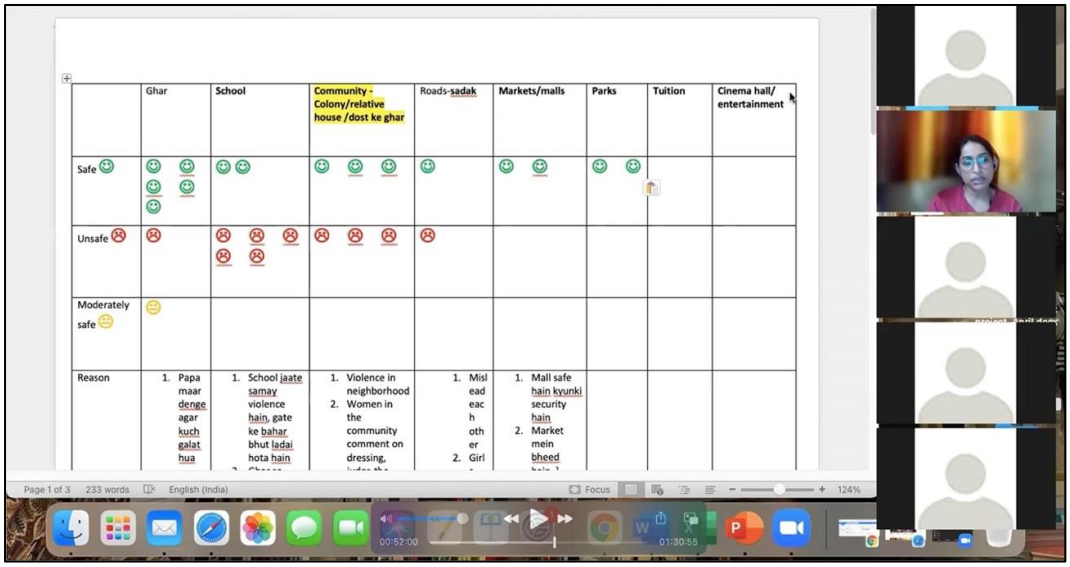

Photo 12 – Online FGD with the Adolescents

A safety mapping of the community was conducted to explore the perception of safety among adolescents in the community. Adolescents were facilitated to identify the spaces that they frequently visited. The adolescents identified home, road, school, market, malls, parks and cinema halls as the places they frequented. Perception of safety in these spaces was marked by the facilitator using 'smiley' stickers' (☺ for safe, ☹ for unsafe and 😐 for moderate safety)

In the context of Participatory Research in times of pandemic, it is important to recognise the virtual space as a platform of great convenience, but it is vital to create a space of trust and privacy as is done in face-to-face FGDs. The online sessions provided an opportunity to innovate on methodology to suit the prevalent situation of physical distancing. While use of smart phones is expected to be an inclusive factor in reaching out to communities, it is also a factor of exclusion due to the huge digital divide in India. Using digital means of data collection demonstrates adaptability, but trust and intimacy stands eroded if such methodological changes are routinised and normalised.

The detailed FGD report with adolescents and mothers and audio-visual documents can be accessed here.

Overall, for the adolescents who live in under-resourced urban communities, the spaces that they occupy impact their transition as healthy and 'responsible' adults. However, as the safety and nutrition mapping of the informal settlements reveal, adolescents in urban areas have to navigate multiple challenges like safety concerns in public spaces affecting their education prospects and rising prices of commodities in market affecting the nutritional outcomes.

Learning Circles

Learning circles were organised by the research team to engage with adolescent peer educators, members of civil society and academia to discuss the present situation of implementation of adolescent health programmes. A virtual platform was provided for adolescent health practitioners and members from civil society working on adolescent health to interface with adolescents and to contemplate on new approaches placing the needs and demands of adolescents at the centre. For the learning circle, PRIA and Gurugram University collaborated with three organisations working with the adolescents: Dasra 10 to 19 Adolescents Collaborative, MAMTA and Martha Farrell Foundation.

Learning Circles are intellectual spaces created to explore a particular phenomenon from multi-stakeholder perspective. The first learning circle "The Voices From the Ground: Re-Imagining Working With Adolescents" was organised on 15 July 2021 to identify the challenges of CSOs working with adolescents around the key components of adolescent health, namely SRH, nutrition, child trafficking, mental health and domestic violence. The devastating second wave of COVID-19 has had a severe impact on CSOs, adolescents and communities. In the time period following the pandemic, several knowledge sharing and dissemination initiatives had brought forth the challenges faced by the adolescents and civil society working in the domain of adolescent health. However, it was also important to share the lessons learnt as a result of conducting interventions with adolescents in the midst of a pandemic and to deliberate on the ways in which civil society should realign their operations, programs and interventions to suit the needs of a post-pandemic environment.

Box 4. Key take-aways from the first learning circle

- While working with adolescents, community advocacy, civil society partnerships and capacity building are the strategies that work best, if sustainable outcomes are to be seen as part of interventions.
- Use of digital spaces and how we negotiate with the owners of the spaces, be it parents, schools, communities would be crucial as most communication platforms and organisations move to virtual space.
- Promoting inclusivity within the overall programme design and intervention is key to achieving the programme objectives. Organisations working with adolescents, especially at the level of communities must strive to reduce the power differential.

The second learning circle "Strengthening Facility-Based Intervention to Improve Health Outcomes among Adolescents through Adolescent Friendly Health Clinics" was organised on 29 July 2021 to deliberate on the role AFHCs can play in improving health outcomes of urban adolescents. The role played by civil society in ensuring better outreach about adolescent friendly health services to the under-served and vulnerable sections of the population, like youth living in urban informal settlements was also discussed.

The key focus of the discussion was the role played by the AFHCs in addressing the gaps in health-seeking as identified by adolescents during the participatory survey. While adolescent peer educators highlighted the challenges they face as user groups, civil society and academia presented evidence to highlight why more AFHCs would be needed if the health needs and demands of India's burgeoning adolescent population is to be met.

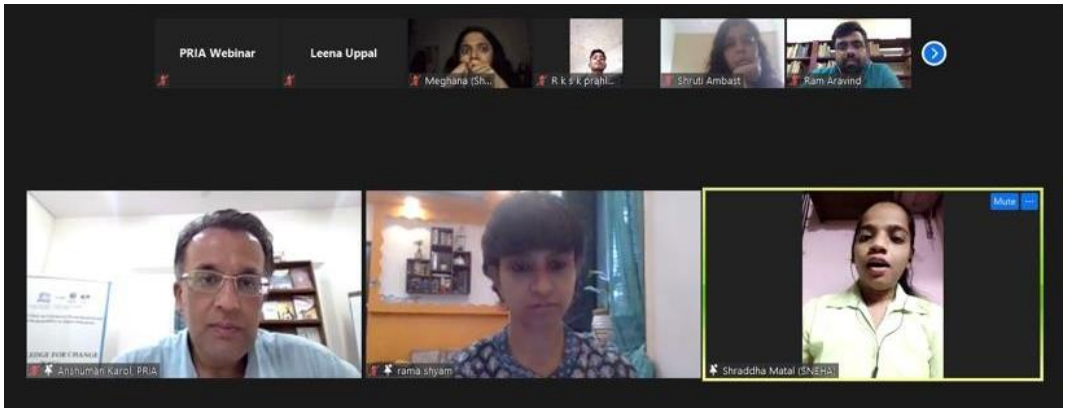

Photo 13 - An Adolescent Peer-Educator from Dharavi, Mumbai Sharing Experience

The evidence presented from different parts of the country highlighted minimal engagement of adolescents with the formal health care system and declining trend of health-seeking especially after the onset of the pandemic. Availing the services provided through affordable and cost-effective public health systems like AFHCs would be critical in addressing the health-seeking deficit if unmet needs of adolescents are to be met. In order to address the rising gaps in health systems and to increase the footfalls in AFHCs and improved health-seeking, the following key points were mooted.

"There were 8000 AFHCs across India by the end of 2019 for 254 million adolescents in the country. That works out to one AFHC for a population of 30,000. The statistics with regard to counsellors is even disappointing. There are only 1700 counsellors for a population of 1.5 lakh adolescents"

- KG Santhya, Population Council

Box 5. Key takeaways from the second learning cycle

- Decentralised planning is essential for effective implementation of RKSK scheme and should be built into the protocol of scheme implementation.
- Lack of human resources has affected effective implementation of the scheme. There is room for innovations to augment the resources. Research has shown effectiveness of training semi-skilled workers to support the health system. Civil society can provide the much-needed capacity building and technical support.
- Considering the over burden on frontline health workers and emphasis of health systems on pandemic management, civil society can work towards or advocate for integrating technology into the protocol of the scheme.
- In addition to targeting behavioural change of adolescents through the RKSK scheme, there is also a need to bring those who influence the adolescents (mothers and peers) into the scheme of things.
- Advocacy with regard to gaps identified, by civil society, could contribute to better health outcomes among adolescents.

Aspirational Mapping of Adolescent Friendly Health Clinics

The participatory action research was initiated with the objective of empowering adolescents to voice their demands in decision-making processes that affect their health and well-being. As was evident from the survey and the focus-group discussions, adolescents are affected by poor health-seeking behaviour as well as lack of awareness about Adolescent Friendly Health Clinics. During the data sharing sessions, adolescents also spoke about the need of forming exclusive spaces led by adolescents where they could discuss problems that affect them. The learning circles highlighted the facilitating role to be played by civil society in supporting the public health systems in identifying the gaps in implementation of RKSK scheme.

A key exercise was to start with AFHCs and explore whether these clinics or the services offered through the clinics were receptive to the needs and demands of adolescents and whether it embodied the spirit of 'friendliness' as was mentioned in the name. Hence, the adolescents visited the nearest AFHC to conduct an audit of available facilities.

Based on the observation of adolescents, a participatory aspirational mapping exercise was conducted with 29 adolescents in urban informal settlements to increase their stakes in planning and to suggest policy changes from the perspective of 'user group.' The adolescents would be enabled through participatory methods to identify the gaps in implementation of RKSK from their perspective.

Photo 14 – Adolescents Participating in Aspirational Mapping Exercise through Role Play

The objectives of the visioning exercise were as follows:

- To identify the reasons behind poor health-seeking behaviour of adolescents
- To explore avenues for seeking medical care during emergencies and the social and cultural determinants of health-seeking behaviour in the community

- To develop an agenda for 'ideal design of Adolescent Friendly Health Clinics' to be presented during city consultation.

The exercise provided an opportunity to enlighten adolescents on the RKSK scheme and its different components. Through sport-based activities, skit and painting, adolescents were encouraged to explore what constituted 'health' for them. On the second day of the visioning workshop, all adolescents were treated to a healthy and nutritious breakfast. The purpose of providing breakfast to the adolescents was to inculcate healthy eating habits as well as to enable them to identify the nutritional component of food items.

Photo 15 - Adolescents Participating in Aspirational Mapping Exercise through Sports

A brief about some of the key process involved in visioning exercise:

- Adolescents were facilitated to interpret the meaning of 'health'. The responses were used to identify the reasons behind poor-health seeking behaviour of adolescents and to convey the idea that a health-seeking approach in everyday life should be preventive and not just curative.
- With active support from Pro-Sport Development (PSD) (an Indian CSO working on sport for development), PRIA used the medium of sport to emphasise on the need for improved health-seeking behaviour and practices among adolescents.
- In order to identify the factors that inhibit health-seeking among adolescents, all the participants were encouraged to do a group work to recognise instances in everyday life that require medical or clinical attention but are often ignored through the medium of skit, painting or poetry to convey their ideas.
- Based on the activities, all adolescents did an aspirational mapping condensing the factors that inhibit health-seeking as well as the gaps they would like to address in the AFHC that they visited.

Based on the participatory activities, a policy brief was prepared by the adolescents incorporating the following demands:

- Young female as well as male counsellors are to be placed in AFHC to offer counselling services
- Soft skills training should be imparted to the AFHC support staff, especially skills to engage with adolescents and youth
- SRH education should be made available to boys as well and not restricted to girls
- The peer educator component of RKSK needs to be implemented in the district
- Counsellors of young age will encourage adolescents to open up on confidential matters related to adolescent health
- Locally relevant Social and Behaviour Change Communication (SBCC) material should be made available
- Community outreach by frontline health workers need to increase, especially among children and parents from migrant families
- The Adolescent Health Facilities must be situated closer to the informal settlements so that adolescents can minimise the cost incurred on transportation

Why adolescents think AFHCs need to be more 'friendly'……

"When we visited the AFHC, the lady at the reception behaved rudely with us. We were forced to wait for a long time to meet the counsellor, it was tiring to wait after school hours."

- Jyoti, Adolescent champion

"In the clinic, we were told that there would be a counsellor. But instead, the medical doctor was attending to us. We could barely open up about our problems Infront of her."

- Manish, Adolescent champion

The detailed policy brief can be accessed here.

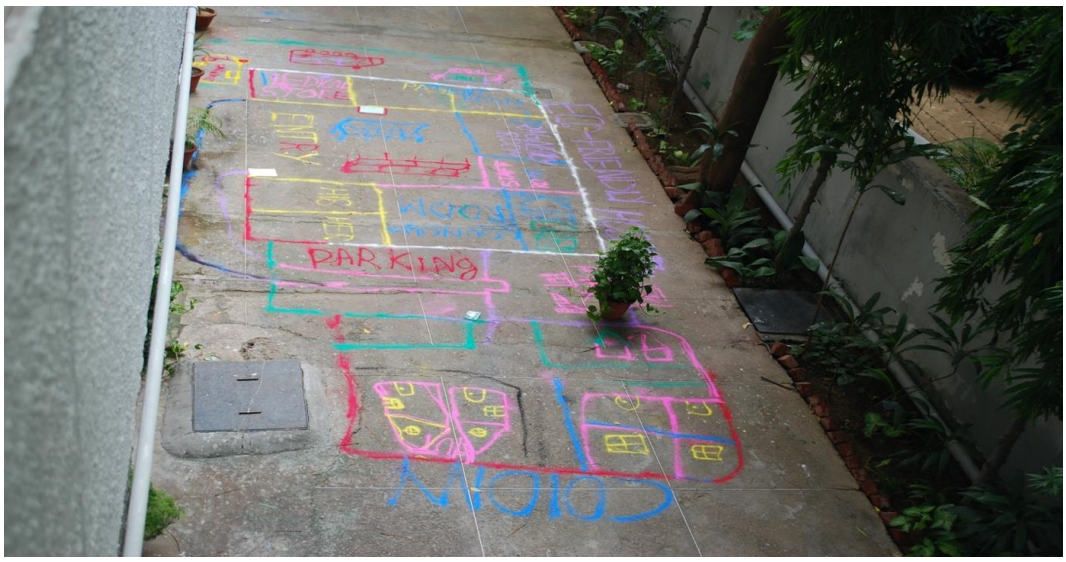

Photo 16 – Aspirational Mapping of the 'Ideal Adolescent Friendly Health Clinic' designed by adolescents

Policy Advocacy

A consultation was held on 18 August 2021 with city-level health officials in the Office of the Civil Surgeon, Gurugram to discuss the findings of participatory survey with adolescents in Gurugram and to present a platform for adolescents in urban informal settlements to present their manifesto for strengthening and re-designing adolescent friendly health systems from their perspective. The consultation provided a platform for bringing adolescents closer to the health policy makers. The consultation also served as a space for building capacity of district level health officials and to sensitise them to conceptualise frameworks for institutionalising adolescent participation in RKSK implementation. The adolescents presented the manifesto/agenda prepared as part of the aspirational mapping exercise to the authorities[9].

Photo 17 - Adolescents Present the Manifesto for Improving AFHC Services

Post the city consultation, a national consultation was held on 3 September 2021 on the topic "Our Health, Our Voice: Institutionalizing Adolescent Participation for Improving their Health and Wellbeing" in hybrid mode (blend of physical and virtual sessions). The national consultation brought together adolescents from the urban informal settlements with adolescent health practitioners from civil society, adolescent health policy makers, representatives from UN adolescent health organisations and civil society leaders with decades of experience working with the youth as well as Government.

The national consultation was conducted to discuss the ways in which adolescent participation for their health and well-being can be enhanced and institutionalised through AFHCs to widen the outreach and penetration of services through active facilitation and involvement of civil society. PRIA' work with adolescents was discussed during the consultation along with evidence from regional and national

[9] Please refer to the 'Summary and recommendations' section to read in detail

context brought forth by panel speakers. Adolescents were presented an opportunity to bring to national attention, their needs and demands for improved health-seeking facilities.

Photo 18 - Adolescents Present the Manifesto for Improving AFHC Services

The panellists were of the opinion that the process of institutionalising adolescent participation in health should begin by decentralising health policy making. Enough emphasis has to be placed on integrating adolescent participation in matters concerning their development. For this, the terminology of 'participation' needs to be popularised, as it is being done currently in government policy guidelines. The RKSK scheme has sought to popularise direct participation of adolescents in health space through envisaging the 'peer educator' initiative. However, the implementation of the scheme is yet to gather steam in many different parts of the country, as is currently the case with Gurugram.

Even though government records stipulate 30 percent of the population to be residing in cities, unofficial figures would peg it at 70 percent. There is migration at a scale that is never imagined. Increasing dependence on the private sector by the people is also driving policy decisions in urban areas. The assumption that the private sector will complement health-seeking; it is necessary that the policy should be pushed in urban areas. There is a need to give agency to adolescents. They have access to information since information vacuum never exists. Implementation agency is ignored.

In order to effectively secure the participation and mobilisation of adolescents, the government machinery has to look for actively securing the co-operation of civil society. Vertical structures of governance (ministries) with the structure and capacity that they have historically are not best equipped to facilitate anybody's participation. It should not be carried out as contracted task, but with other actors rooted in the ground like schools and women's groups. Participation needs to be facilitated.

Learnings and Challenges

The implementation of this study has demonstrated how leveraging the skills and capacities of adolescents can lead to improving health outcomes among adolescents as well as inform the design of adolescent friendly health services. Overall, the study has proved how adolescent boys and girls can be powerful agents of change for addressing existing health concerns as well as other health topics in their communities. Expanding and sustaining this initiative through regular training would offer the opportunity to monitor and assess changes in health-seeking behaviour and health outcomes among adolescent population.

Figure 3 – Framework for Institutionalising Adolescent Participation in Health Policy

Specific lessons learned from this initiative include:

- Adolescents have the potential to serve as active change agents or 'champions' in the community and not just as passive recipients of state-sponsored welfare.
- Investing in participatory approaches that engage young people to strengthen their capacities as leaders, encourage ownership of their communities, and take a positive lifecycle approach to adolescent health issues can yield a myriad of benefits.
- Confidential and private spaces for adolescents should be made available in low-resourced urban settings for healthy peer-to-peer interaction.
- Engaging adolescents as 'responsive citizens' may have a long-term impact on their health and well-being.
- Initiating and implementing community-level groups is key to mobilising adolescents around issues of health

A key policy change advocated by the adolescents to the city level health officials was to revive the defunct peer educator programme in Gurugram. PRIA, as the civil society partner, would facilitate the training of the adolescents in urban informal settlements as 'peer educators' and designate them as community champions, who will motivate youth in the community to exercise responsible health seeking behaviour as well as provide information on the nearest adolescent friendly health clinics. PRIA has also

drawn up plans to ensure sustainability of the 'peer educator' component and to provide periodic trainings in co-operation with the Health Department, Gurugram.

The cadre of Peer Educators, trained by the health department, would serve to link adolescents to the AFHC or referral services. This effort is also expected to benefit out-of-school children as well as children of migrant families who reported requirements of training on sexual and reproductive health as well as nutrition. As part of the project, we are in talks with the Health Department, Gurugram to ensure that peer educators are periodically trained on health issues. Local NGO partner, which partnered with PRIA on the study, would monitor the activities of peer educators and recruit new batches, as and when the existing batches of adolescents complete their tenure or drop-out.

The study findings would be used to advocate for establishing more Adolescent Friendly Health Clinics in the district. The evidence would also inform re-prioritisation of components of RKSK to better reflect the localised needs of health care from the perspective of adolescents. The process would, however, be led by the peer educators and adolescent champions who will be trained to exercise tools of democracy to voice their demands on behalf of adolescents in the informal settlements. PRIA would also do handholding of the city-level health department, to integrate participation into implementation of adolescent specific health services.

The model of engaging adolescents in planning and implementing action research projects has been disseminated at city and national consultations and through conferences to ensure that similar models are replicated and scaled up across the country. The study methodology, findings and learnings would be disseminated as academic articles, popular writings like blogs and working papers in open access journals and platforms to be accessible to academic as well as non-academic audiences.

In the months of April and May, the imposition of national lockdown in India prompted the postponement of several key research and participatory activities planned at the onset of the study. Hence, state and national consultations, participatory visioning exercise as well as learning circles, initially scheduled in the month of May and June, were conducted in the months between July and September resulting in re-visiting time commitments.

The Focus-Group Discussions were conducted virtually with mothers and adolescents. Trust-building through virtual spaces was a major challenge, especially when discussing sensitive and private information regarding young people. Similarly, the data collection team, especially university researchers reported initial hesitation from the community to accept 'outsiders' to collect data, especially demographic information.

The digital divide in India was also an impediment to effectively conducting online FGDs. It was a challenge to identify participants in the community who had access to personal smart phones. In low-income communities in India, the gendered digital divide is glaring with women less likely than men to own a smart phone in the household. Hence, more women participants dropped out.

Due to the COVID-19 scare prevailing in India, the national consultation was conducted as a hybrid event, with physical as well as online attendees. The consultation, if organised with attendance from participants as well as speakers in a physical space would have afforded more opportunities for knowledge sharing, cross-learning as well as networking with professionals working on adolescent health. Activities like survey, data dissemination workshops, capacity building workshops for the data collectors were organised in physical spaces with due adherence to COVID-19 protocols laid down by the World Health Organization.

Recommendations

Based on the participatory action research study, the following recommendations are proposed for improving the health services as well as health-seeking behaviour of adolescents:

Establish Adolescent Friendly Health Clinics (AFHC) following the 4:1000 arrangement

Gurugram has only one Adolescent Friendly Health Clinic (AFHC) in the formal health care facility to cater to the population of adolescents in the age group of 10-19 years. The AFHC, also known as '*Mitrata* Clinic' is anchored in the District Hospital, Gurugram. Even though adolescent health facilities are offered through the Community Health Centres (CHC), Primary Health Centres (PHC) and Urban Primary Health Centre (UPHC), a dedicated Adolescent Friendly Health Clinic with a full-time counsellor and proper signage has not been made operational in rest of the public health facilities. The state government should enforce the implementation guidelines that mandate four AFHCs per 1000 adolescents.

Increase AFHC outreach among adolescents in urban areas

Poor health-seeking behaviour of adolescents living in urban informal settlements can be addressed by increasing uptake of health facilities among adolescents. This can be achieved by engaging and training frontline health workers and by developing locally relevant Social and Behaviour Change Communication (SBCC) materials. The adolescents should be made aware of the presence of *Mitrata* Clinics in the vicinity as well as the services offered through the facility like counselling, distribution of Iron Folic Tablets and sanitary napkins. A printed pamphlet, accounting for linguistic diversity within the locality, mentioning the address of the nearest adolescent friendly health service and the point of contact (medical officer or counsellor) should be made available to the adolescents as well as parents in the community. Monthly meetings by the government health services counsellor should be mandated in under-served communities.

Increase the strength of trained counsellors in the AFHC to one counsellor per 1000 adolescents

The present strength of one adolescent health counsellor to cater to the entire population of nearly 30,000 adolescents in Gurugram highlights the need for increasing the manpower in AFHCs. The public health system should ensure that the AFHC is staffed by a trained counsellor (preferably MA/MSc degree in psychology). The counsellor should also be provided opportunities for capacity building and hand-holding support by either medical professionals or civil society. The role of counsellor should not be delegated to the medical officer, or a physician as was observed in the community medical centres.

Female and male counsellors should be present in each AFHC

At present, in the Gurugram AFHC, there is only one male counsellor to deal with adolescent health problems. However, pan-India evidence points to the need for gender-appropriate appointment of AFHC counsellors, so that adolescents, irrespective of their gender preferences, do not hesitate to reach out when they need to seek referral or counselling. The need to appoint male and female counsellors in the AFHC was highlighted by the adolescents as means to increase their confidence in revealing confidential health issues.

Out-of-school children and children from migrant families should be better targeted through outreach

In order to increase the footfall in AFHCs, counsellor outreach to adolescents should not be restricted to adolescents who have enrolled as 'students' in the local schools. The task of outreach for out-of-school children primarily rests with the over-burdened Frontline Health Worker (FHW), whose performance or outreach to adolescents is not periodically evaluated. The lack of preference among adolescents to reach out to FLWs was evident from the survey and this accounts for one of the major factors in poor health-seeking behaviour of adolescents in the communities. Regular home-visits to homes of migrant and out-of-school children increase the confidence and motivation among adolescents to reach out to community workers.

Bring AFHC out of the formal health systems like hospitals

At present, the adolescent friendly health services are housed in district hospitals and community health centres. Adolescent friendly health services are envisaged to provide counselling and referral services to adolescents and hence, it is important that spaces like AFHCs be disengaged from the formal health systems and brought closer to the community. It is important to ensure that spaces for adolescents be designed reflecting their demands and aspirations and ease of access. This will help in promoting a perspective of health-seeking that is not predominantly medical. Involving adolescents in envisioning spaces for their development through participatory methods ensures a user-centric design.

Holistic emphasis on adolescent health should be placed

A key critique of the RKSK scheme is the high priority accorded to Sexual and Reproductive Health over other important components of adolescent health like nutrition, mental health, drug and substance abuse, safety and injury. It becomes a case for poor utilisation of available resources, thereby jeopardising progress with regard to improving holistic parameters of adolescent health. Adolescent health services should be capacitated to look beyond distribution of sanitary napkins and iron folic tablets and information dissemination towards addressing domestic violence cases, safety concerns, drug and substance abuse issues and mental health. One of the ways in which a holistic emphasis covering the entire life spectrum of adolescents can be ensured is through convergence of government schemes.

Peer Educator component of the RKSK scheme should be brought back into the RKSK Haryana to increase participation of adolescents

There is a need to revive the peer educator component of RKSK in states like Haryana. Currently, the government has scrapped the peer educator initiative across the state. Peer educator models across the country have been found to be cost-effective in terms of delivery of health care, especially among out-of-school adolescent children. While reviving peer educator programmes, it is important to ensure sustainability of the programme by incentivising volunteers and recognising their work. Regular monitoring and evaluation of the peer educator work should be made mandatory so that future scope for improvement can be evidence-based.

Annex.1: Key Documents Prepared As Part of the Study

Publications

- Survey report (methodology and findings): Link to the preliminary findings report
- Focus-Group Discussions (methodology and findings)
  - FGD with mothers on theme of nutrition: Link to the report
  - FGD with adolescents on theme of safety: Link to the report

Blogs

- A Researchers' diary: Is there healthcare for adolescents in the margins: Link
- A Researchers' diary: Is it right to defer conversation about sex anymore? Link
- Adolescent health in Gurugram: Mobile-based survey findings: Link
- From challenge to opportunity: shifting community-based research online: Link
- When health clinics become friendly: adolescents' vision for the future: Link

- Adolescent Health Survey Info-graphics Sheet (Bi-Lingual)
  - Adolescent health survey: Key takeaways (English): Link

- Focus-Group Discussion info-graphics sheet (Bi-Lingual)
  - FGD with mothers on theme of 'nutrition': key takeaways: Link (English) (Hindi)
  - FGD with adolescents on theme of 'safety': key takeaways: Link (English) (Hindi)
- Participatory Visioning Exercise(methodology): Link to the report
- Policy brief (manifesto for improving adolescent friendly health services): Link

Tools Developed

- Adolescent Health Survey Questionnaire
- Social and Behavioural Change Material (Bi-lingual): Link
- Focus-Group Discussion (semi-structured interview guide)

Learning Circles (LC) and National Consultation (NC)

- The voices from the ground: re-imagining working with adolescents: Link to event report Link to recording of event
- Strengthening facility-based intervention to address adolescent health issues: Link to event report Link to recording of event
- City consultation on 'Strengthening facility-based intervention to address adolescent health issues': Link to event report
- National Consultation on 'institutionalizing adolescent participation for improving their health and well-being: Link to event report

Audio-Visual Documents

- Participatory Survey methodology: Link
- Focus-Group Discussion: Link
- Participatory skit: Link
- Participatory Envisioning exercise: Link
- Our Health, Our Voice: Participatory Research with Adolescents: Link