

Appendix I

Mental Health Resource Map of India																					
Sl. No.	State (1)	Population (2)	Density/sq km (3)	Estimated case load (4)		Existing facilities Hospital beds (5)		Manpower resources (6)													
				Major mental disorders	Minor mental disorders	Govt. sector	Pvt. sector	Psychiatrists			Clinical psychologists			Psychiatric social workers			Psychiatric nurses			Dist. wise distribution of psychiatric facilities	
								Available	Ideal req.	Deficit	Available	Ideal req.	Deficit	Available	Ideal req.	Deficit	Available	Ideal req.	Deficit		
1.	A & N	356265	43	3562	18810	10	-	1	4	3	-	6	6	-	8	8	-	3	3	1	1
2.	Andhra Pradesh	75727541	275	757275	3766375	1020	210	180	757	577	8	865	857	3	1154	1151	Nil	123	123	NA	NA
3.	Arunachal Pradesh	1091117	13	10911	54555	10	-	1	10	9	-	15	15	-	20	20	-	1	1	1	12
4.	Assam	26638407	340	266384	1331720	500	-	29	266	237	5	450	445	1	564	563	1	50	49	23	17
5.	Bihar	82878796	880	828787	4143935	-	-	28	828	800	13	1214	1201	NA	1656	**	NA	**	**	NA	NA
6.	Chandigarh	900914	7903	9009	45045	57	-	31	9	+22 (surplus)	14	14	-	10	18	8	1	6	5	1	-
7.	Chhattisgarh	20795956	154	207959	1049795	10	3	15	207	192	1	304	303	2	414	412	-	2	2	1	15
8.	Daman & Diu, Dadra & Nagar Haveli	158059, 220451	1411, 449	3785	18925	10	-	1	4	3	-	6	6	1	8	7	4	1	+3	1	3
9.	Delhi	13782976	9294	137829	689145	329	113	155	137	+18 (surplus)	43	207	164	13	274	261	172 **	32	+140 (surplus)	7	7
10.	Goa	1343998	363	13439	77195	210	-	26	14	+12 (surplus)	2	21	19	3	28	25	2	21	19	2	-
11.	Gujarat	50596992	258	505969	2529845	853	326	97	505	408	12	753	741	12	1010	998	-	118	118	20	5
12.	Haryana	21082989	477	210829	1054145	89	98	39	210	171	2	315	313	-	420	420	1	19	18	9	10
13.	Himachal Pradesh	6077248	109	60772	303860	14	3	8	61	53	2	90	88	-	122	122	-	6	6	3	9
14.	Jharkhand	26909428	338	269094	1345470	1173	145	50	270	220	15	405	390	10	540	530	NA	135	**	3	15
15.	J & K	10069917	99	100699	503495	120	-	4	100	96	1	150	149	1	200	199	-	12	12	2	12
16.	Karnataka	52733958	275	527339	2636695	1341	1113	198	527	329	69	762	693	56	1052	996	175	245	70	18	9
17.	Kerala	31838619	819	318386	1591930	1937	1539	238	318	80	42	477	435	40	636	596	14	348	334	13	-
18.	Lakshadweep	60595	1894	605	3025	-	-	-	1	1	-	2	2	-	4	4	-	1	1	-	-
19.	MP	60388118	196	603881	3019405	592	NA	12	603	591	-	905	905	-	1206	1206	1	60	59	6	39
20.	Maharashtra	96752247	314	967522	4837610	6073	652	486	967	481	33	484	451	44	1934	1890	117	672	555	17	18
21.	Manipur	2388634	107	23886	119430	10	-	6	24	18	1	36	35	2	48	46	-	1	1	2	6
22.	Meghalaya	2306069	103	23060	115300	70	-	5	23	18	-	35	35	-	46	46	2	7	5	1	6
23.	Mizoram	891058	93	8910	44550	14	-	4	9	5	1	13	12	1	18	17	2	2	-	2	6
24.	Nagaland	1988636	120	19886	99430	25	-	5	20	15	-	30	30	-	40	40	1	3	2	3	5
25.	Orissa	36706920	236	367069	1835345	118	-	19	367	348	5	550	545	1	734	733	-	11	11	4	26
26.	Pondicherry	973829	2029	9738	48690	44	20	15	10	+5 (surplus)	1	5	14	13	20	7	20	7	-(+13)	4 (surplus)	-

Table Continued...

i	ii	iii	iv	v	vi	vii	viii	ix	x	xi	xii	xiii	xiv	xv	xvi	xvii	xviii	xix	xx	xxi	xxii
27.	Punjab	24289296	482	242892	1114460	580	267	89	242	153	18	363	345	21	484	463	10	85	75	11	6
28.	Rajasthan	56473122	165	564731	2823655	627	110	75	565	490	12	798	786	4	1130	1126	-	74	74	16	16
29.	Sikkim	540493	78	5404	27020	20	12	2	5	3	-	7	7	-	10	10	-	3	3	2	2
30.	Tamil Nadu	62110839	478	621108	3105540	1800	NA	262	621	359	7	910	903	21	1242	1221	-	180	180	30	-
31.	Tripura	3191168	304	31911	159555	16	-	9	31	22	-	45	45	-	62	62	-	2	2	1	3
32.	Uttaranchal	8479562	159	84795	423975	-	-	6	84	78	-	126	126	-	168	168	-	-	-	1	12
33.	Uttar Pradesh	66052859	689	1660528	8302640	1750	275	115	1660	1545	20	2490	2470	35	3320	3285	-	202	202	10	60
34.	West Bengal	80221171	904	802211	4011055	1471	210	83	802	719	28	1204	1176	-	1604	1604	4400*	1604	+4258 (surplus)	20	-
	Grand Total			10270165	51251625	20893	5096	2219	9696	7477	343	13259	12926	290	19064	17118	** (6527)	4036	**	219	311

Notes

* Figures unreliable: Nurses with some psychiatric training but without a Diploma in Psychiatric Nursing (DPN) appear to have been included.

** Figures unreliable

Column 2. The population figures have been taken from the Census of India-2001 as published in **Provisional Population Totals** (Registrar General Census Commissioner, India).

Column 3. Population density per square kilometre together with geographical terrain is a useful input in planning deployment of mental health resources.

Column 4. Case-load in respect to major mental disorders has been calculated at the rate of 1% of the population and that of minor mental disorders at the rate of 5% of population.

Column 6. (a) While the exact requirements of mental health personnel have not been definitively prescribed, the ideal required number of mental health professionals has been calculated as under:

Psychiatrists: 1.0 per 100,000 population Clinical Psychologists: 1.5 per 100,000 population
 Psychiatric Social Workers: 2.0 per 100,000 population Psychiatric Nurses: 1.0 per 10 psychiatric beds

(b) District-wise data in respect of psychiatric facilities are not available for the states of Andhra Pradesh (total districts—23) and Bihar (total districts—40).

Total number of psychiatrists trained in the country during 2000-2001

Qualification	Male	Female	Total
MD	36	9	45
DPM	15	6	21
Grand Total			66

Source: National Survey of Mental Health Resources carried out by the Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India, during May and July 2002 in Goel et al, 2004, pp.15.

Appendix II

Reasons for investing in mental health

Promote human rights and inclusion	Reduce the human impact of mental health	Prevent premature death	Reduce the economic costs to society	Reduce poverty and social disadvantage	Put knowledge of cost effective treatments into practice
<p>People with mental health problems are more likely than others to experience social exclusion, violent victimization and human rights abuse.</p> <p>Access to evidence-based treatment and care would have a direct positive impact and would greatly promote human rights and the chances of recovery and inclusion.</p>	<p>There is no health without mental health. Mental health problems lead to extremely distressing symptoms for the affected person and burden for family members. In addition, they are closely associated with physical health problems.</p> <p>There is a high level of co-existence of non-communicable diseases and mental health problems which compromise treatment and prevention efforts.</p>	<p>People with severe mental health problems die up to 20 years earlier than people without mental health problems, even in high-income countries.</p> <p>Excess mortality is due to suicide, unhealthy lifestyles such as high smoking rates, poor physical health, and poorer physical healthcare for people with mental health problems.</p>	<p>In 2010, the global economic costs of mental health problems were estimated at US\$2.5 trillion and are projected to rise sharply to US\$6.0 trillion by 2030.</p> <p>Around two-thirds of these costs are related to lost productivity and income - the consequences of untreated mental health problems.</p>	<p>Poverty, social disadvantage and mental health problems are intimately related to one another.</p> <p>Mental health interventions can help improve the social and economic well-being of people affected by mental health problems.</p>	<p>The treatment of mental health problems is as cost effective as other health treatments such as antiretroviral treatment for HIV/AIDS.</p> <p>The returns on investments in mental health are considerable. Every US\$1 spent on programs such as early intervention for psychosis, suicide prevention and conduct disorder leads to a benefit or cost saving of US\$10.</p>

(Source: Patel and Saxena 2013, p,7-8)

Appendix III

Mental Health Problems

Mental health problem	Description	Life course stage
Developmental disorders	A group of conditions characterized by impairments in intellectual, movement, sensory, social, or communication abilities (e.g., autism, intellectual disability and cerebral palsy).	Infancy onwards
Anxiety disorders	A group of conditions featuring excessive worrying, tension and fear, and physical symptoms such as palpitations, headaches and	Childhood onwards
Child behavioural disorders	A group of conditions characterized by impairments of attention and disruptive behaviour (e.g., attention deficit hyperactivity	Childhood onwards
Alcohol use problems	A group of conditions characterized by the consumption of alcoholic drinks to the level of causing harm to the person's health and social/personal relationships.	Adolescence onwards
Depression	A condition characterized by low mood, loss of interest and enjoyment, fatigue and reduced energy, and sleep and appetite disturbances.	Adolescence onwards
Drug use problems	A group of conditions characterized by regular use of substances such as opioids, sedatives or cocaine causing harm to the person's health and social/personal relationships.	Adolescence onwards
Self-harm and suicide	Intentional self-inflicted poisoning or injury which may lead to death.	Adolescence onwards
Schizophrenia	A condition characterized by distortions of thinking and perception (e.g, hallucinations and delusions), behavioural abnormalities and emotional disturbance.	Adolescence onwards
Bipolar disorder	A condition characterized by episodes of elevated or lowered mood and activity levels, often with complete recovery between episodes.	Adults
Dementia	A condition characterized by a progressive deterioration in mental functions, such as memory and orientation, leading to behavioural problems and loss of the ability to care for oneself and, ultimately death.	Late life
<p>This list of mental health problems is based on those prioritized in the World Health Organization mhGAP Intervention Guide for Mental, Neurological and Substance Use Disorders in Non-Specialized Health Settings. 2010, Geneva: Switzerland.</p>		

Source: (Patel and Saxena, 2013,p,40)

Appendix IV

Difference in physical illness and mental illness		
	Physical illness	Mental illness
1	Symptoms are mostly visible. There may be a group of symptoms but each distinct from the other.	Invariably symptoms are of invisible nature. Cluster of symptoms which, many times, being concurrent with others, diagnosis takes time and becomes difficult which, in turn, lengthens treatment.
2	Tests are available for diagnosis and for understanding changes in progression	Objective tests for diagnosis and for course of progression are not available. Thus diagnosis being primarily subjective, it can vary from doctor to doctor. This leads to greater stress & frustration for the shubharthi and the shubhankars.
3	Much information about these illnesses is available not only with the doctors but also is available in the public domain (print, media).	Very little information is available even with the new doctors and much less in the public domain for the families. Families have to rely on psychiatrists.
4	Working and malfunctioning in the physical illness is well understood by the medical science	Working and malfunctioning of the brain and nervous system are still in exploratory/research stages even for the medical scientists.
5	Effective treatments are available more widespread and with various options to the patients.	Effective treatments are not available for various reasons such as * diagnosis is delayed because of overlooking initial warning signs by families * acute shortage of whole range of MH professionals in towns/cities & non-availability in rural areas * non-accessibility to medicines in rural areas * ignorance about MH issues at the family level.
6	Variety of treatments (medicines/non medicines) having varying side effects, recovery period, duration of effect are available	Treatment options backed with hospitalisation are very limited. E.g. hospitals treating MI with homoeo-pathic/ayurvedic/unani are almost non-existent. So in acute state, treatment to allopathic has to be switched & face consequences.
7	Substantial research has been done with significant breakthrough in anatomy, physiology and pharmacology of the illness	Comparatively limited research in different aspects of mental illness seems to have been done.
8	Effective treatments are available for last several decades	Effective treatments are available, relatively in recent times.
9	Premature mortality is possible in major/complicated illnesses/accidents.	Premature mortality is a possibility in small percentage of suicidal cases.

Table Contd...

10	Due to spread of knowledge and visible nature of illness, self-stigma is not a problem. At times, others may come forward to help e.g.rushing to help a person with crutches to cross the road/offer a seat in a bus.	Due to misunderstanding and myths, society have stigma towards MI, which acts as a barrier towards availing treatment. Also in case of an emergency, hardly anyone will come forward to help for fear of violence by mentally ill.
11	Affected persons of chronic illnesses and disabilities receive sympathy and help	Due to invisible nature and other factors affected persons may be avoided or teased or ridiculed.
12	Services –govt. Or private are being developed for last several decades.	Due to limited knowledge and effective treatments; services-govt. Or private are much below the huge requirement in the society.
13	HH have higher response rate(in availing services) to the needs of PMI	HHs have lower response rate(in availing services) due to several barriers

Appendix V

Difference in New and Veteran caregivers		
	New caregivers	Veteran caregivers
1	Limited or no knowledge about the illness/symptoms and future course. Hence likely to give incomplete/incorrect information	Significant knowledge. Well informed. Hence likely to give adequate/accurate amount of information.
2	Since, still novice, are likely to experience emotional problems during the interview, affecting quality of feedback	Long experience of illness has made them tough, even being sensitive to the problem. Can share personal information not only without hesitation but will appreciate how their sharing Can help the cause of MI persons/their families.
3	Relatively young in age i.e in forty's or early fifty's.	Senior in age. In their sixty's or seventy's. Because of high costs of treatment male caregivers have to go out to earn while caregiving becomes the responsibility of female relatives. Consequently, if the lady caregivers are less educated/read, they may not realise value of sharing for this survey.
4	Factors like social stigma and one's own stigma are dominant	Due to years of experience, CGs have adjusted to feeling/handling issues of stigma
5	Treatment, medicines are changing.	Treatment, medicines have reached stability for last several years.
6	PMI is still in active age. CGs are hoping to experience full recovery and return to normal life.	PMI is at a advanced age and CGs are aiming for objective of independent living of PMI or lifelong residential care

Codebook					
Variable	Code	Variable	Code	Variable	Code
PT Current Age		PT Occupation Group		MRD Upto 12 Mon.&above	
1 to 25	0	Unemployed	0	Upto 12 Months	0
26 to 35	1	Lesser Public Contact	1	13 Months & above	1
36+	2	Greater Public Contact	2	MNPT Zero & Above	
CG Sex		CG Occupation Group		No NPT	0
Female	0	Unemployed	0	1 & above	1
Male	1	Lesser Public Contact	1	MNPT Upto 3 Mon.&above	
PT Sex		Greater Public Contact	2	Up to 3 Months	0
Female	0	Family Income		4 Months & above	1
Male	1	Up to 5000	0	MNPT Upto 6 Mon.&above	
Marital Status		5001 to 10000	1	Up to 6 Months	0
Unmarried	0	10001+	2	7 Months & above	1
All Others	1	Diagnosis		MNPT Upto 12 Mon.&above	
Religion		Schizophrenia	0	Upto 12 Months	0
Hindu	0	All Others	1	13 Months & above	1
All Others	1	Age Begin. Sym.		District	
Caste		1 to 25	0	Pune	1
SC	0	26 to 35	1	Ahmednagar	2
All Others	1	36+	2	Beed	3
Type of Family		FT District Pune & Else		Aurangabad	4
Nuclear	0	Pune	0	Jalna	5
Joint	1	Else	1	Latur	6
PT Education		FT District		Parbhani	7
No Education	0	Pune	0	Nanded	8
1st to 4 th	1	Adjoining Pune	1	Usmanabad	9
5th to 10 th	2	All Others	2	Solapur	10
11+	3	Distance		Satara	11
CG Education		0 km to 50 km	0	Sangli	12
No Education	0	51 km to 100 km	1	Nasik	13
1st to 4 th	1	101+ km	2	Buldhana	14
5th to 10 th	2	Place of Residence		Mumbai	15
11+	3	Urban	0	Others	16
Relation with Patient		Rural	1		
Father & Mother	0	MRD Zero & Above			
All Others	1	No MRD	0		
YFT B&A 2000		1 & above	1		
Before 2000	0	MRD Upto 3 Mon.&above			
After 2000	1	Up to 3 Months	0		
PT Occupation		4 Months & above	1		
Unemployed	0	MRD Upto 6 Mon.&above			
All Others	1	Up to 6 Months	0		
CG Occupation		7 Months & above	1		
Unemployed	0				
All Others	1				

Appendix VII

Respondent No-

Questionnaire for Primary Caregiver of Person with mental illness.

Name of the Interviewer:

Place:

Date:

Background Information about the family		
1		
1.1	Religion	Hindu -----1 Muslim-----2 Christian-----3 Sikh-----4 Buddhist/Neo Buddhist---5 Jain-----6 Others-----7 -----Specify-----
1.2	Caste	SC-----1 ST-----2 NT-----3 OBC-----4 OPEN-----5 Others—(specify)-----6
1.3	Type of family (At the time of Beginning of Illness-BOI and current)	BOI- Joint ---1,Nuclear --2 Current: Joint ---1,Nuclear ---2
1.4	No of members in the family (At the time of Beginning of Illness-BOI and current)	BOI- Current:

2 Information about primary caregiver and patient									
		Name	Relations With the patient	Age	Sex M/ F	Marital status	Education and qualification	Occupation	Income of the family
2.1	Information about primary care giver								
2.2	Information about the patient								
Codes for occupation- 1.Cultivator (large farmer) 2.cultivator (small/marginal farmer), 3.Agricultural labourer, 4. Non-agricultural labourer, 5. Government service, 6. Private Service, 7. Business, 8. Self-employed 9. Pensioner, 10. Home maker, 11.Others (specify).									

Age & Education in completed number of years.

पालकांसाठी अनुमती पत्र

प्रिय सहभागी,

आपण आपल्या कुटूंबातील जाणकार अशा व्यक्ती आहात. आम्हाला आमच्या सर्वेक्षणासाठी आपली मुलाखत घ्यावयाची आहे. हे सर्वेक्षण विद्यावचस्पती (Ph.D) या पदवीसाठी आवश्यक असणाऱ्या संशोधनासाठी असून 'गोखले अर्थशास्त्र संस्थे'मध्ये या विद्यार्थ्याची नोंदणी झाली आहे. ही मुलाखत प्रशिक्षित मुलाखतकर्त्याकडून घेतली जाईल. या मुलाखतीसाठी साधारणपणे 45 मिनिटे ते 1 तास लागेल.

तुम्हाला जे प्रश्न विचारले जातील त्याचे स्वरूप खालीलप्रमाणे असेल –

1. तुमच्या कुटूंबातील सदस्यांची सामाजिक आर्थिक इ. माहिती
2. मानसिक आजार (अथवा शारीरिक आजार) यांच्या उपचारांविषयी आपण घेतलेले निर्णय आणि हे निर्णय घेताना त्यावर प्रभाव पाडणारे घटक

आपण जी माहिती द्याल त्याचा उपयोग कुटूंबाचे आरोग्यविषयक अग्रक्रम कसे असतात आणि आरोग्यावर खर्च कसा केला जातो हे समजून घेण्यासाठी होणार आहे. आपण देत असलेली माहिती गोपनीय ठेवली जाईल आणि इतर कोणालाही ती उपलब्ध होणार नाही. आपण देत असलेल्या माहितीचा उपयोग फक्त संशोधनाच्या कामासाठी केला जाईल. आपले नाव, पत्ता आणि इतर व्यक्तिगत माहिती प्रश्नावलीतून काढून टाकली जाईल आणि तुमचे नाव व उत्तर दर्शविण्याकरिता कोड नंबरचा वापर केला जाईल. आपली मुलाखत पूर्ण होण्यासाठी अत्यंत आवश्यक असेल तरच किंवा अधिक माहितीसाठी भविष्यात आपल्याशी संपर्क साधला जाईल.

या सर्वेक्षणातील आपला सहभाग पूर्णपणे ऐच्छिक असेल आणि मुलाखतीस सुरुवात झाल्यानंतर केव्हाही आपण आपला सहभाग काढून घेऊ शकाल. प्रश्नावलीतील कोणत्या प्रश्नांना उत्तर द्यायचे अथवा नाही याचे पूर्ण स्वातंत्र्य आपल्याला असेल. या सर्वेक्षणाविषयी आपणाला कोणतीही शंका असेल तर आपण माझ्याशी संपर्क साधू शकता. (अनिल वर्तक avartak@yahoo.com, 020-24483650(R) & 9503710859 (M))

3	We are going to ask you questions that are related to several years in (Name)'s past life. You can take time to answer each question. If you remember anything later, do not hesitate to bring it to our notice. Now, we would like to ask you about the psychiatric treatment that (name) is taking currently (past).	
3.1	Is/was (name) taking psychiatric treatment for mental illness?	
3.2	What is the nature of the current (last) treatment?	MedicationA CounsellingB Day care centre.....C Hospitalisation.....D ECT.....F Any other (Specify).....

3.3	What is the name of the treating doctor?	
3.4	Will you specify his/her diagnosis?	
3.5	How long is he/she taking this treatment at this center?	
3.6	What is the frequency of your visit to the treatment centre?	
3.7	How much on an average you have to spend per month on this treatment (out of pocket)?	Items of cost
		Consultation charges
		Medication
		Transport
		Total expenses
		Any other (specify)

4 (Name) is taking treatment for psychiatric problems for some time. We will like to know about his/her journey towards psychiatric treatment. First, we will like to know your experience of treatments other than psychiatric treatment. If he/she has not taken any treatment other than psychiatric treatment, then please go to next section.			
4.1		Nature of Intervention (treatment)	Additional information
	Did you give (name) any other treatments?*,**	Tantric/mantric/tradioanl herbal treatment (vaidu)/fortune teller/spiritual persons/any other.....1 Medical treatment from other pathies- ayurvedic/ homelpathy/unani/any other.....2 Alternative treatment –naturopathy/massage /panchkarma/yoga/meditation/any other....3 Any other (Specify).....	
	When was this treatment given for the first	Yearand month	
	How long was this treatment given ?	Yearand month	
	What symptoms caused the decision to take this treatment?	Odd behaviourA Discontinuation of education or job.....B Troublesome at home and to others.....C Violent behaviour.....D Physical problem.....E Any other (specify).....	
	Was the treatment given for physical problem or mental problem? Give details.		

	What was the problem that		
	Distance from residence? NPT ---- District place --		
	How old was (name) then?		
	What was his/her education then?		
	How did (name) occupy himself/herself then?		
	What was his income then?		
	Did anyone suggest to give this treatment?	Suggestion from Family member/community leaders.....A Patient.....B	
	Why do you think that the decision to follow that suggestion was taken?	We have faith in itA Due to personal experience.....B Stigma.....C Non acceptance by the patient.....D Will be of help.....E Available in the vicinity.....F	
	How will you compare these expenses of the past to expenses on treatment by other service providers?	Treatment at YMH(VsV NPT) --Very high/high/almost same/lower/much lower Treatment at Private Trt. Centre (VsV NPT) --Very high/high/almost same/lower/much lower	

**If you have given any other treatment even after or along with psychiatric treatment, fill this section.
 ** (if there is more than one treatment or overlapping treatment then pl. give the details of each treatment
 Separately in the order in which they were taken*

Recognition delay, (consultation delay) and treatment delay

5	For treating someone with mental illness, it is necessary for families to recognise early the symptoms of mental illness in the patient. Now, we would like to ask you some questions about how you recognised that these symptoms are related to psychiatric problem.	
5.1	What is the nature of the current (last) treatment?	Medication.....A Counselling.....B Day care centre.....C Hospitalisation.....D ECT.....E Any other
5.2	When was the psychiatric treatment started for the first time?	Year and month ...
	What was the distance from your place of residence?	
5.3	What symptoms caused decision to give this treatment?	Odd behaviourA Discontinuation of education or job ...B Troublesome at home and to others ...C Violent behaviorD Other treatments did not workE Let us try this oneF Aggrevation of the symptomsG Any other (specify).....H
5.4	Now, when you look back, do you think that (name) 's symptoms/problem has started even before you started any treatment (Psychiatric treatment or non-psychiatric) for the first time?	Yes1 No2
5.5	If yes, how much time did it take? If no, then proceed to next question.	Years..... and months.....
5.6	What may be the explanation for time taken to recognise that something is wrong?	Lack of informationA Thought that this is a physical problem/ some other problemB Thought that this is a problem in the development phase of the patientC Thoughtdue to addictionD Thought due to shocking incident .. E Any otherH

5.7	Do you think it took some time for you to consult someone even after recognising that something is wrong with (name)?	Yes.....1 No.....2
5.8	If yes, how much time did it take? If no, go to next question.	Years..... and months.....
5.9	Do you think there are reasons for not consulting any one immediately? Give details.	Confusion due to myths-(since when, what was the nature of myth) A Could not decide B Did not know where to goC Lack of cooperation from the patient (any specific event)E Thought will-self helpF Services were not available in the vicinityG Feeling of stigma- to the patient, to the family members (since when, any specific event/opinion)H Any other reason. (Specify)
5.10	Do you think that it took some time for you to start treatment (or routinely) even after consulting someone?	
5.11	How much time did it take?	Year and month
5.12	Do you think there are reasons for not starting treatment immediately? What are those reasons?	Feeling Stigma (to the family members, patient)A Did not know where to goB Services were not availableC Thought/found that treatment is expensiveD Thought treatment will be of no use.....E Thought patient will improve over timeF Any other
5.13	Will you specify your overall experience of delay in receiving treatment?	

Discontinuation of the treatment –

6	Discontinuation of treatment is a common phenomenon in mental illness. Several reasons are given by families. Now, we would like to know about your experience of discontinuation of treatment.		
6.1	After starting initial treatment, were their instances of discontinuation of the treatment?		
6.2	Which was the first instance?	Yearand month....	
6.3	How did (name) occupy him/her self then?		
6.4	Why do you think that treatment was discontinued?	Side effects.....A Expensive treatment.....B No improvement from the treatment.....C Lack of cooperation from the patient.....D Any otherE	
6.5	When did you start treatment again?	Month..... and year.....	
6.6	Do you think someone suggested you to start treatment?		
6.7	Were there symptoms due to which did you start treatment again?	Aggressive behaviour from the patient.....A Cooperation from the patient...B Uneasiness of the patientC Eruption of the symptoms.....B Deterioration in his/her condition Any otherD	

7	Sometimes patient has to undergo treatment other than pharmacological treatments. Now, we will like to ask you, your experience of such treatments. If (name) has not taken any such treatment then go to next section.
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7.1	Which are the other treatments that were suggested to you earlier by your psychiatrist?(or you came to know about it through other sources) If answer is no, then go to next section.	Day care.....A ECT.....B Hospitalisation.....C long stay home.....D Any other.(specify).....
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7.2	If have not availed it or with significant delay what are the reasons for it?				
Treatment 1	Reasons for not availing or delay in it	Treatment 2	Reasons for not availing or delay	Treatment 3	Reasons for not availing or delay in it
	No available in the vicinity.....A Do not know where it isB Expenses were too highC Patient was not violent. Hence, thought that it is not necessaryD Patient was not ready to comeE Stigma- what others will thinkF Nobody was there to accompany him/herG B Thought, it will not be of helpH Thought he will improve over time ..I Any other		No available in the VicinityA Do not know where it isB Expenses were too highC Patient was not violent. Hence, thought that it is not necessary.....D Patient was not ready to comeE Stigma- what others will think.....F Nobody was there to accompany him/her.....G Thought, it will not be of help.....H Thought he will improve over time ..I Any other		No available in the VicinityA Do not know where it isB Expenses were too high.....C Patient was not violent. Hence, thought that it is not necessary.....D Patient was not ready to comeE Stigma- what others will think.....F Nobody was there to accompany him/her.....G Thought, it will not be of help.....H Thought he will improve over time..I Any other

8	Sometime patient or someone in the family may have undergone treatment for chronic physical illness like TB, Ashtama or any other. We will like to ask you questions about it. If your answer is yes, then go to next question. Otherwise go to next section.		
8.1		Information about (name)	Information about other family members
8.2	Who was affected by any chronic illness?	Name	Name
8.3	What was the illness?		

8.4	Can you tell when did you start treatment for this disease?	Year and month...	Year and month...
8.5	What was the nature of treatment? Give details.	Pharmacological treatment.....A Surgery.....B Any other treatment. (specify).....	Pharmacological treatment.....A Surgery.....B Any other treatment. (specify).....

8.6	How did you come to know about (name)'s illness?		
8.7	What were the symptoms of it? Give details.		
8.8	How old was he/she then?		
8.9	How did he/she occupy himself/herself?		
8.10	What was his/her income then?		
8.11	Is(was)he/she taking continuous treatment since then? If yes, then go to 12.		
8.12	Has the treatment been terminated as per the advice of treating physician? If yes, then go to 12.		
8.13	Was it discontinued for some time?		
8.14	How many times and how long?		
8.15	Is (name) suffering from this illness even now?		
8.16	What is the nature of treatment and how frequently (name) has to take it?		
8.17	How much do you have to spend per month?		
8.18	Do you think that it is significant expenditure for you?	Significant/moderate/insignificant	Significant/moderate/insignificant
8.19	Do you think that there was any delay in recognition of symptoms?		
8.20	How long was the delay?	Years..... And months	Years..... And months
8.21	If yes, what is the reason?		

8.22	Do you think that there was delay in consultation and treatment of the (name)'s physical illness?		
8.23	How long was the delay?	Years..... And months	Years..... And months

8.24	If yes, what are the reasons for that?		
8.25	Do you think that, you have given treatment for physical illness much timely as compared to treatment for mental illnesses?		
8.26	If yes, what factors might have contributed such decision?	Visible illnessA Effective treatment is availableB Absence of stigma.....C Acceptance of the illness by the patient.....D Pain to the patientE Cooperation from the patient.....F Quick recovery is possibleG Any other.....	Visible illnessA Effective treatment is availableB Absence of stigma.....C Acceptance of the illness by the patient.....D Pain to the patient.....E Cooperation from the patient.....F Quick recovery is possibleG Any other.....

9	You have taken treatment for physical illness and mental illness and you have experienced barriers while taking treatment for each of the illness. Now, we will like to ask you questions about these barriers.	
9.1	Now, we will like to know from you –how will you differentiate between nature and treatment of physical illness as well as that of mental illness.	
9.2	How do you compare barriers -while recognising and availing treatment for mental illness Vis a vis physical illness? Pl. substantiate your argument.	
9.3	What measures will you suggest to do away with these barriers? Pl. suggest measures barrier wise.	

Name:-		Address :-
Contact No.		

Appendix VIII

Interview Guide for Veteran Caregivers¹ at YMH

How do caregivers (CG) understand or conceptualise mental illness (MI)?

How do CGs come to know about the mental illness of their family member?

What are the symptoms of MI?

What are the symptoms which generally make CG realise that there is some problem?

What is their reaction once they notice symptoms?

What are the symptoms that CG generally find alarming? Do they understand gravity of the symptoms?

How much time is passed in recognising symptoms as mental illness since its onset?

Do they consult someone once they think that symptoms are alarming? Who are these persons?

How much time do they spend once they notice symptoms till consultation or treatment?

What is the advice usually do they get?

How do they work on it? What is their response? What action do they take?

What are the pathways patients usually follow before reaching a psychiatrist?

Do they find relief during Non-psychiatric treatment? Do they continue with such treatment? How long?

How much time do they spend to initiate psychiatric treatment once they notice symptoms?

Do you think that this pattern is same across all socio economic and demographic groups?

Do people with different socio/eco./demographic back ground show change in such pattern?

¹ A veteran caregiver is a caregiver who is not only informed by MI of his/her family member but due to his/her experience, education and overall alertness have enough knowledge to talk about conditions of PMI in general, pathways that PMI take before taking psychiatric treatment and delay in the process.

Appendix IX

Interview Guide for staff at YMH

How many patients visit OPD of YMH per day and per month?

What is socio-economic and demographic background of such people?

What is social background of these people? Caste/religion/family type

What is the economic back ground of these people? income group/ occupation/type of farmer?

What is demographic background of such people? District/distance

How do they conceptualise mental illness?

What is idea of mental illness of patients and caregivers?

How do people come to know about their mental illness?

What are the symptoms which generally make people realise that here is some problem?

What do they do before such symptoms become visible?

What is their reaction once they notice such symptoms?

Do they understand gravity of the symptoms?

Do they consult some one? Who are these persons?

What is the advice usually do they get?

How do they work on it? What is their response? What action do they take?

What are their pathways?

Do they find relief? Do they continue with such treatment?

How much time do they spend once they notice symptoms till consultation or treatment?

Do you think this pattern is same across all socio economic and demographic groups?

Do people with different socio/eco./demographic back ground show change in such pattern?

Appendix X (10.1)

Mental Hospitals in India

The mental hospitals in India have evolved over time. There is a record of an institution for mentally ill patients in Muhammad Khiljis time in 15th century (Krishnamurthy, Venugopal, & Alimchandani, 2000). Prior to this, patients were kept in temple and religious places. Mental hospitals i.e. asylums, as they were called earlier, is a British conception. They were started in England to provide custodial care to patients in 16th century. The first asylum in India was started in Calcutta in 1787 called as lunatic asylum. In India, these asylums were started mainly for European soldiers posted in India at that time. European and Indian patients were segregated in separate wards or institutions (Krishnamurthy, Venugopal, & Alimchandani, 2000; Weiss, 1983). The purpose of these hospitals was to separate mentally ill persons from mainstream society. There were hardly any medicines and treatment that was given was basically of opium, hot baths, leeches to suck blood and sometimes music to calm patients down (ibid).

In 1858 Lunacy Act was passed which provided guidelines for establishment of asylums and admission procedure. From 20th century onwards, development of mental hospitals started from a humanitarian angle. Hospitals which were under inspector general of Police were now put under charge of civil sergeant (Banerjee, 2001). During two wars, efforts were to made raise the standard of treatment and care. During this period, asylums were renamed as mental hospitals. The importance of occupational therapy and rehabilitation received importance gradually. Bhore Committee which was set up in 1946 surveyed all the hospitals and gave several suggestions for improvement. From 1947 onwards, number of hospitals increase and in 2008 their number was 37 (NHRC and NIMHANS, 2008) Conditions prevailing in mental hospitals deteriorated over time due to inadequate resources, inadequate staff and general neglect towards mental health.

The available beds in all hospitals in India are 26,989 (20,893 in government and 5096 in private hospitals). In India, psychiatric beds per 10,000 population is only 2.5 as compared to 3.9 in Australia, 7.7 in USA and 1.08 in China. In India, majority of these beds

i.e. 80 per cent of them are in mental hospitals rather than being in general psychiatric units, private hospitals or community based hospitals. Considering the need for long term care and hospitalizations of PMD, the availability of total beds in private and government hospital is very low.

Lack of updated infrastructure, overburdened staff and doctors, very few rehabilitation programmes, etc are the major problems faced by mental hospitals in India. Additionally, mental hospitals are stigmatized in society at large. People shudder while passing them; mental hospitals are the butt of jokes. Restricted access, high and barbed walls, lack of visibility for the outsider, secluded location in the city, contributes further to the marginal position of mental hospitals.

The first modern mental institutional care as we see it today was established in India during the colonial times. The first mental hospital was started in Calcutta in 1787. Over the years, several mental hospitals came up, yet there remains a huge gap between the capacity of public mental hospitals and the need. There exists a huge gap between number of beds available in mental hospitals and the actual requirement of inpatients. The ratio of number of psychiatrists to the total population is also disproportionate.

Human right violations are noted to occur in mental hospitals. Erwadi fire incident which happened in 2001 is an example of this. 28 inpatients of the Erwadi mental hospital died in a fire. They were chained and hence they could not escape. Later a lot of abusive practices were discovered. Human Rights Watch has noted human right violations in case of inpatients.

Several conferences, workshops were held in the last two three decades in order to improve the quality of service and human right standards in these hospitals. However, little has changed so far. NHRC 1999 and 2008 have done audit from the point of view of quality of services and human rights for all the mental health hospitals and made several suggestions to improve their functioning.

National human rights commission (1999) in their finding says -

“The findings reveal that there are predominantly two types of mental hospitals, The first type do not deserve to be called ‘hospitals’ or mental health centres. They are ‘dumping grounds’ for families to abandon their mentally ill member, for either economic reasons or a lack of understanding and awareness of mental illness. The living conditions in many of these settings are deplorable and violate an individual’s right to be treated humanely and live a life of dignity. Despite all advances in treatment, the mentally ill in these hospitals are forced to live a life of incarceration. The second kind are those that provide basic living amenities. Their role is predominantly custodial and they provide adequate food and shelter. Medical treatment is used to keep patients manageable and very little effort is made to preserve or enhance their daily living skills. These hospitals are violating the rights of mentally ill persons to appropriate treatment and rehabilitation and a right to community and family life”.

However, conditions at mental hospitals have not changed much in a decade after 1999 (NHRC and NIMHANS, 2008). A recent trend is towards deinstitutionalization of mental hospitals, admission of voluntary patients, creation of general hospital psychiatry units rather than building more mental hospitals and reliance on community based rehabilitation alternatives.

In a developing country like India, with vast majority of poor people, public mental hospitals play a crucial role in facilitating access of people to psychiatric care. Use of mental hospitals can be minimized by community based services and general hospital psychiatric units. However, for severely ill patients there is no alternative to mental hospitals. Hence, efforts are necessary to improve their functioning (Krishnamurthy, Venugopal, & Alimchandani, 2000).

Appendix X (10.2)

Yerawada Mental Hospital

Yerawada mental hospital, Pune, is one of the oldest mental hospitals in India. This hospital which was originally established in Colaba in 1889 was shifted to Yerawada, Pune in 1915. Currently it has a capacity of 2400 beds, 1400 for men and 1000 for women.

YMH has very huge campus. YMH, which was located on the outskirts of Pune and near prison, now, due to growth of the city, is a very much part of the city and surrounded by tall software companies. Hospital buildings and other infrastructure is very old and maintenance of building and campus is very poor. YMH has shortages of staff especially in the category of psychiatrists. The hospital receives patients from several districts – Pune, Ahmednagar, Nashik, Satara, Kolhapur, Beed, Jalna, Nanded, Usmanabad, Latur and even from districts outside Maharashtra.

Mental hospitals, due to their inferior conditions, command fear and stigma by lay people. Patients in general or caregivers do not want to visit or utilise services at mental hospitals unless they do not have any option to do so. The researcher due to his work with an NGO had prior contact with YMH. Some of the awareness programs were conducted in YMH in which the researcher took part. However, the students who assisted the researcher in collection of data were under tension due to lack of information and myths about mental illness and mentally ill persons. However, after their first visit their fear subsided and realised that patients are not harmful or violent as it is understood by lay people. They were comfortable in collecting data from caregivers and patients.

Appendix X (10.3)

Debates in Mental Health – Positions and Assumptions of the Researcher

The topic for this PhD thesis stems from my long term academic and activist interests: economics and mental health. I have been an activist in the field of mental health for two decades now, working closely with users, families, psychiatrists and other professionals. Diversity of experiences and reflecting on them have led me to have my own takes on two important debates in mental health i.e. role of family and psychiatry.

Position on the role of the family:

As notes Srinivasan, there are three categories of mental illness patients/users in India: those in or requiring institutional care, those in family care and those on the road i.e. the homeless and hence not on treatment. Majority of the users are within family care. Community care is almost absent, and is extremely expensive. Across categories, even for patients in institutional care, those availing psychiatric treatment in private or public hospitals and clinics and even those who are availing NPT or no treatment at all, family plays an important role in caring, supporting emotionally as well as financially. Family becomes the safety net for the patient.

Thus India, where social security is absent and disabled being a marginalized community, public expenditure is very low and there are hardly any community care centres. Hence, the responsibility of the giving care as well as support lies on the family. Their concern for patients is almost round the clock. One leading caregiver's organisation in India has made an apt comment "Family is the 24X7 care provider. More than 90 per cent of mentally challenged patients live in their families (Srinivasan, 2015)

Users may take help from professionals but for other forms of care i.e., domestic care, rehabilitation care and emergency care, family is the only source to rely upon. In India, family support is the backbone for the users. Thara, Padmavati, & Srinivasan(2004) says

“...This underscores the importance of cultural, social and family factors in service utilisation. In a country like India it is not easy or appropriate for a health care service to bypass the family to reach the potential patient; the family may have to be persuaded first of the need for treatment. More positively, however, this situation reflects the intrinsic coping style of the community and the family in dealing with disability, which may contribute to the better outcome of treated schizophrenia in India”

Care giving by families is recognized at different levels-individuals, professionals and policy makers. National Mental Health Programme of India seeks to deliver mental health care through community based approaches. This programme is based on premises that the locus of care, for persons with serious mental illness, will continue to be natural kin network. The report further says “In India community care often translates in to care by the family”. However, this is not to say that one can glorify the family. In many instances family is the site of coercion, violence, forced institutionalization or even the cause of neglect and ignorance, taking decisions detrimental to the patients’ interests. This has led many activists in India and elsewhere to argue for an individual based approach, for individual rights in decision making. The United Nations Convention on Rights of Persons with Disabilities (UNCRPD) can be taken as a case in point. Advocacy activists in mental health are arguing individual rights to supersede the rights of the family.

My personal position is that in the Indian context family plays an indispensable role in care of the patient. The State is not equipped and will not be equipped in the near future to fully provide for patients’ needs. Instead of attempting to weaken the role of the family, we must recognize its contributions. Rather than aiming to delink the individual from the family, we must try to strengthen the relation of patient, family vis a vis psychiatric care.

Patients, policies, care are contextual. Context needs to be understood for effective policy design and implementation. The immediate context of the patients is family. They are embedded in the values, practices of familial relations. To be effective in terms of reach and use, policies targeted at users, should be targeted towards the family. Caregivers rights cannot be compromised on.

Position on psychiatric treatment:

In the field of mental health, an important debate is on psychiatric treatment itself. Psychiatric drugs have severe side effects and with little guarantee of results. Anti-psychiatry movement has evolved over the last century being particularly strong in the 1960s and the 70s. Psychiatry is seen as oppressive and a tool to repress and subjugate patients. It is seen to create unequal relationship of power between patients and doctors, between 'normal' people and those requiring psychiatric treatment. This line of thinking continues even today, and there are people who oppose psychiatric treatment on these grounds, and valorise non psychiatric treatment.

However, I hold the view that NPT cannot be a substitute for psychiatric treatment. Some forms of NPT can be complementary to PT, but not a substitute. In spite of the side effects, psychiatric treatment does help the patient and set him/her on the path to recovery. This is the underlying assumption of the thesis: that there is no alternative for psychiatric care.