INTRODUCTION
CHAPTER 1: INTRODUCTION

“Making systems work is the great task of my generation of physicians and scientists. But I would go further and say that making systems work — whether in healthcare, education, climate change, making a pathway out of poverty — is the great task of our generation as a whole...Having great components is not enough, and yet we’ve been obsessed in medicine with components. We want the best drugs, the best technologies, the best specialists, but we don’t think too much about how it all comes together.”


This statement poignantly raises the complexities we face in developing multifaceted systems that meet their goals. The main goal of a health system is to achieve good health outcomes, which includes wellbeing in the case of mental health. Yet many health systems have failed to provide accessible mental health care that is equitably distributed and upholds the rights of persons with mental illness. The aim of this thesis is to expand our understanding of the mental health system in India. The primary objective is two-fold: first, to focus on the problem of fragmentation including the structural causes and realizing an accessible, integrated, rights-based system, and second, to analyse the mental health system in India and present potential strategies that could facilitate the delivery and integration of an accessible, integrated rights-based mental health system.

Why is mental health important? The global picture

Globally, mental illness affects about 450 million people at any given time (Von Korff & Goldberg, 2001; World Health Organization, 2010). Mental health conditions rank as the leading cause of disability-adjusted life years (DALY’s) worldwide, and account for 37% of healthy life years lost out of all noncommunicable diseases (Bloom et al., 2011). By 2020 depression alone will be the second largest contributor to disease globally and by 2030 will be the largest contributor — greater than heart disease, stroke, and HIV/AIDS (Omar et al., 2010; World Health Organization, 2004). In 2010, the cost of mental health conditions globally amounted to US$2.5 trillion, and is expected to increase to US$6 trillion by 2030 (Bloom et al., 2011). If left untreated, mental illness can lead to substantial disability, suffering and economic and productivity loss (World Health Organization and World Organization of Family Doctors, 2008).

The importance in addressing mental health issues extends beyond economic loss to considering health in a broader context inclusive of the social, cultural, political and economic factors that impact it. For example, mental illness affects, and is affected by, other illnesses such as HIV/AIDS, diabetes, and heart disease and can be exacerbated by socioeconomic conditions, as associated disability can lead to unemployment, poverty,
deplorable living conditions, human rights violations, and homelessness (Jenkins, Baingana, Ahmad, McDaid, & Atun, 2011; Miranda & Patel, 2005). While no mental health system is immune to these systemic issues, low and middle-income countries (LMICs) may be impacted to a greater degree because of resource and infrastructure limitations (Saxena, Thornicroft, Knapp, & Whiteford, 2007). The inability for LMICs to provide access to mental health care for its citizens (World Health Assembly, 2013) is evidenced by the startling treatment gap, which is highest in LMICs (Jacob et al., 2007; Saxena et al., 2011); highlighting the discrepancy between need and capacity to provide. Furthermore, globalization, economic development, changes in epidemiological patterns and behaviours, and shifts in service delivery models (World Health Organization, 2007) impact this discrepancy.

Inherent in every health system are challenges in resource availability and allocation (Knapp, McDaid, & Parsonage, 2011): how to efficiently provide more with less. Within this economic climate, it is important that there is appropriate governmental, institutional and legal, policy, financing and service arrangements to meet individual needs, promote wellbeing (World Health Assembly, 2013) and deliver affordable equitable care. To address these constraints in the system, governments need to rely on innovative ways to engage with and harness the efforts of the private sector and communities (World Health Organization, 2007). Successful leadership and governance has well-formulated policies/laws, plans and programmes in place, that enshrine the human rights of persons with mental illness and mandate access to much needed care.

Fragmentation in the mental health system is created when there is a lack of leadership and governance which can result in poor regulation of incentives and behaviours of key players in the health system (Lagomarsino et al., 2009), poor strategic policy direction, a poor fit between policy objectives and structures and cultures, and a lack of accountability (Travis, Egger, Davies, & Mechal, 2002). Although these issues are present in both high-income countries and LMICs, health systems in LMICs often face substantial inequities in mental health services and distribution, further weakening access to care (Saxena et al., 2007). Lack of leadership and governance in LMICs is particularly a problem due to the substantial political, administrative and information constraints (Lagomarsino et al., 2009), and in the case of India, poor regulatory mechanisms in place to monitor services and public private actors (Patel, Kumar, Paul, Rao, & Reddy, 2011).

A responsive and integrated public health system is the necessary backbone to support an effective mental health care system. Integrated health systems have been discussed as one efficient way of improving access and continuity of care, particularly for people with complex and chronic needs (Valentijn, Schepman, Opheij, & Bruijnzeels, 2013) including those with mental illness. The capacity for an integrated system to overcome systemic

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1 The treatment gap represents the proportion of people who require care compared to the proportion who actually receive care. (Kohn, Saxena, Levav, & Saraceno, 2004)
issues, such as resource (both human and financial), governance and policy constraints and the dominant myopic allopathic approach to treating mental illness, creates fragmentation both within and between the health and mental health systems. Fragmentation is further created by continued focus on specialisation and compartmentalisation in both the health and mental health systems. While specialisation is inherently good, it creates pockets in the treatment system where specializations do not exist and expands the disconnect between sectors and services. Failure to reduce fragmentation in the health system impedes the ability to achieve the primary goals (improved health status), and intermediary goals (accessibility) without compromising safety and quality (World Health Organization, 2007).

This thesis specifically focuses on the mental health system in India where mental illness affects approximately 55-70 million people and the treatment gap is estimated to be approximately 90%, similar to other LMICs (Patel, 2009). There is a limited overview (Peters et al., 2002) and limited knowledge about the mental health system in India and the processes and dynamics that shape it. This oversight hinders the ability for actors to understand the direction that the mental health system is heading, barriers to change in the system and the drivers or catalysts for change in the system. Insight into the mental health system can allow stakeholders to anticipate the change processes or contribute to the development of strategies to strengthen the system to provide more rights-based, integrated, accessible care to those who need it. Only by understanding the current mental health system, as well as the broader contextual factors explaining and influencing it, will identification of strategies that could potentially result in a paradigm shift be possible. Ultimately, understanding and learning about the shifts and dynamics within the mental health system requires analysis of different elements of a mental health system, and identifying different learning opportunities.

To this end, I hypothesise that the mental health system in India has not been able to adopt an integrated approach to improving mental health, which has hampered its ability to provide accessible care to the population. I also hypothesise a potential way to address fragmentation within the mental health system in India may be through different forms of integration, at multiple levels within the system. Thus, based on these hypotheses, the overall research question guiding this thesis is:

*How can the mental health system in India be further described and understood, and what opportunities and strategies can be identified to move towards a more accessible, integrated, rights-based system?*

In the following chapters, I describe the theoretical concepts and research design guiding this thesis.
CHAPTER 2: THEORETICAL CONCEPTS

This chapter will delineate the theoretical concepts referred to throughout this thesis that guide the sub-questions arising from the main research question. The chapter begins with an exploration of the definitions and functions of a health system, followed by capturing the debate on the ‘ins and outs’ of health systems strengthening. Next, I define what a mental health system is, what impacts it, and what hampers its ability to improve well being and mental health of the population, followed by a brief snapshot of the mental health system in India. Then, I define integration, rights-based approaches as well as describe the hampering factor (fragmentation) delaying the shift to an integrated mental health system. Finally, I present the multi-level and multi-phase perspective, originally adapted from other domains (e.g. water management, agriculture) and apply it to capturing changes in the mental health system in India.

How is a health system defined?

A health system, according to the World Health Organization (WHO), consists of “organisations, people and actions whose primary intent is to promote, restore, or maintain health” (World Health Organization, 2007: pg. 2). There are also certain aims, targets and goals that a health system strives to attain. Primarily, a health system is concerned with improving health and equity, ensuring this occurs in a financially fair way, while simultaneously efficiently using resources (World Health Organization, 2007). Intermediary goals of the health system consist of access and coverage, which should be achieved without compromising quality and safety (World Health Organization, 2007). Access, according to this model put forth by the WHO, is conceptualized as having access to benefits, services, or universal access to a specific package of health benefits (World Health Organization, 2007). Coverage refers to the proportion of the population in need that receive an effective intervention (World Health Organization, 2007). Conceptually, a health system is said to consist of six main building blocks (Figure 1), each of which are described in Box 1. These blocks illustrate what a health system is expected to do and their ideal attributes (World Health Organization, 2007). In reality, health systems are recognised as far more complex, which has led to the more recent recognition that health systems are in fact complex adaptive systems (Marchal, Cavalli, & Kegels, 2009) wherein these building blocks (Figure 1) are all interconnected and interact in a dynamic, iterative way. It is therefore more relevant to look at the interaction between building blocks as opposed to their individual contribution to the overall health system. For the purposes of this thesis, I will focus on the interactions between these building blocks, and in particular, focus on two components: service delivery and leadership/governance within the Indian
context, relating these two building blocks to the broader health system in the conclusions/discussion section of this thesis.

**Box 1: Building blocks of a health system** (World Health Organization, 2007)

Service delivery: A well functioning health system with appropriate service delivery in place would deliver safe, high-quality, effective, timely health interventions to the population in need with minimum waste of resources (or duplication).

Health workforce: A ‘good’ health workforce consists of one that works to achieve optimal health outcomes for the population and provides care in a responsive, fair and efficient manner, and works within available resources and circumstances (e.g. mix of different types of health workers, differing yet complementary skillsets, etc).

Information: A ‘good’ information management system collects and disseminates systematic and robust data on health outcomes, health system performance, and determinants of health.

Medical products, vaccines and technologies: A well functioning health system would provide medical products, vaccines and technologies which are safe, high-quality effective, affordable, and equitably distributed to those who need them.

Financing: Ensure that there are adequate funds for health, and that catastrophic spending at the household level due to health care is abolished, as well as ensure that incentives are in place for providers and users to be efficient with care.

Leadership/Governance: Involves strategic policy frameworks to be in place, combined with effective regulations/legislations, accountability mechanisms in place, system-design, coalition building and oversight.

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**Figure 2.1 Health Systems Framework** (World Health Organization, 2007)
A second purpose of a health systems framework is to explain how systems can be strengthened. There has been much debate on how to enable health systems to attain their goals and improve population health. The strategy to do this has been referred to as health systems strengthening (HSS). There has been rhetoric about health systems strengthening within the global health literature, however a clear definition of what and how is still avidly discussed (Frenk, 2010). The WHO, for example, defines health systems strengthening (HSS) as

“improving these six health system building blocks and managing their interactions in ways that achieve more equitable and sustained improvements across health services and outcomes” (WHO, 2007: pg. 4).

The WHO, in this same report, defines a more recent approach to HSS, the diagonal approach, defined as “addressing health systems bottlenecks in such a way that specific health outcomes are met, while system wide effects are achieved and other programmes also benefit” (World Health Organization, 2007, pg. 27). Some definitions are even broader, such as “any array of initiatives and strategies that improves one or more functions of the health system and that leads to better health through improvements in access, coverage, quality or efficiency” (Islam, 2007, p.1). Marchal and colleagues (2009), however, warn that using the term health systems strengthening liberally to apply to any capacity building initiative at the health system level will render the term irrelevant. They critique the WHO definitions of HSS, advocating for a more concise, specific definition of HSS that can be shared among global health actors accordingly (Marchal et al., 2009). For the purposes of this thesis, I will refer to HSS in relation to the mental health system, and adapt the WHO definition of HSS. Therefore, I define mental health system strengthening as strategies that improve one or more functions of the mental health system, and that lead to better health through improvements in access, while upholding rights and without compromising quality.

A closer look into mental health systems

Conceptualising a mental health system

Over the past few decades there have been several notable shifts in mental health systems worldwide. These can be categorized as: deinstitutionalization - shifting from institutionalized to community-based forms of care, movement towards a rights-based approach that focuses on inclusion and promotion of rights as opposed to protectionism and discrimination (Drew et al., 2011); and shifts from specialist care to primary care via task shifting or integrating services at the primary care level (Jenkins et al., 2011; World Health Organization, 2003a). These shifts arose out of a demonstrated urgency to protect
and promote the rights of persons with mental illness, evidenced by the gross human rights violations occurring worldwide in mental health facilities (Drew et al., 2011); as well as evidence showing the startling treatment gap, particularly present in many low and middle-income countries, which urged policymakers and actors (both at the national and international level) to call for the development of strategies on how access could be improved in under-served settings (Prince et al., 2007). Thus, in the case of mental health systems, the ‘ultimate’ goal of improving mental health and wellbeing has not been achieved in many LMICs, including India, nor have the intermediary outcomes of providing access while upholding rights and maintaining quality.

In India’s pluralistic health context (Reddy et al., 2011) a series of separate systems of medicine each provide solutions and care for mental health problems in isolation from one another. Persons with mental illness often consult practitioners from different systems simultaneously - for example, an allopathic psychiatrist and a homeopathic practitioner, or a faith-based practitioner and an allopathic psychiatrist. There are also substantial service differences between the public and private allopathic systems in India and a perception that the public system provides services of lower quality than the private sector. The challenges facing the public health system are largely related to human resources, providing care at the village and community level, whereas the private sector access is dictated by capacity to pay. Both systems provide mental health care therefore it is relevant to think about the “mental health system” as a series of independent, yet related health systems that share common elements. In this pluralistic mental health system, fragmentation between systems, services, and professionals often arises, creating substantial barriers to achieving an integrated health system that can provide accessible mental health care in the country.

Realising a rights-based approach to mental health

Broadly speaking, human rights cover civil, political, economic, social and cultural rights, and fulfilling and protecting these rights are a prerequisite to health and wellbeing (Gruskin, Mills, & Tarantola, 2007). Central to a rights based approach (RBA) to health is the right to health, which forms the legal basis for the majority of the work completed in health and human rights. There is disagreement in the literature as to what a RBA means and entails (Gruskin, Bogeche, & Ferguson, 2010) but the most comprehensive definition, adapted for use in this thesis is an approach that “supports better and more sustainable development outcomes by analysing and addressing the inequalities, discriminatory practices, and unjust power relations which are often at the heart of development problems” (Holmes, 2012). A RBA recognises that the underlying determinants of health (potable water, sanitation, food, housing, education, gender equality) are integral to
ensuring the right to health and provision of appropriate care (Gruskin et al., 2007; Holmes, 2012) and emphasises the interaction between care provision and determinants of health. It is important that there is inter-sectoral action and coherence among approaches to ensuring the right to health (Holmes, 2012), for example, ensuring the right to health may also mean focusing on education, transportation, and economic sectors (Gruskin et al., 2010).

There is consensus as to key components or ingredients included in a RBA (Gruskin et al., 2007; Holmes, 2012). These include:

- Examining laws and policies
- Systematically integrating core human rights principles into policy and programme responses
- Focusing on key elements of the right to health: availability, accessibility, acceptability and quality. For mental health, it is important to entrench these elements in standards for service provision, especially in LMICs where these four key elements are poor.
- Standards and principles such as participation, equality, non-discrimination, accountability and transparency should be integrated into the health programming process (including in program design and planning, priority setting, implementation, monitoring and evaluation).

To realise a RBA to health, discrimination and discriminatory practices should be eliminated from policy and legislation, duty bearers (those who have the duty to embed and implement human rights into practice) should be trained and competent to meet obligations outlined in International Conventions (e.g. United Nations Convention on the Rights of Persons with Disabilities), and rights holders (e.g. persons with mental illness) should be encouraged to feel empowered and claim their rights (Holmes, 2012).

A lack of coherence and poor leadership and governance among actors and sectors can result in fragmentation and threaten a rights-based approach to mental health from being realised and integrated into laws, policies, and into practice on the ground.

**Integration through a mental health lens**

*How can we define integrated care?*

There has been substantial debate as to what the term ‘integrated care’ means, as it is interpreted in a number of ways depending on the context. At the basic level, integrated
care can be defined as “combining parts so that they work to form a whole, in order to optimise care and treatment to people where fragmentations in care have led to a negative impact on their care experiences and outcomes” (Goodwin, 2013). Another way of defining integrated care is the bringing together of inputs, delivery, management and services related to diagnosis, treatment, care, rehabilitation and health promotion (Delnoij, Klazinga, & Glasgow, 2002; Gröne & Garcia-Barbero, 2001). Integrated health systems, more broadly, have been seen as a means to improve access, quality and continuity of services in a more efficient way, especially for people with complex needs (Valentijn, Schepman, Opheij, & Bruijnzeels, 2013) such as people with mental illness. An integrated mental health system is one that is able to adopt a holistic approach to viewing mental health and wellbeing. Here, we should note the difference between a holistic approach and integration, as they are often used synonymously. The term holistic can have a spiritual or religious connotation to it, though for the purposes of this thesis, I will refer to it as an approach that upholds and addresses the broad spectrum of client needs, which may include spiritual needs as well as others (e.g. physical, mental, social). Integration refers to the mixing or assimilation of different parts once segregated and/or fragmented. In this light, an integrated mental health system could still adopt a holistic approach. This would mean that sectors, policies, services, professionals might be integrated and no longer operating in silos, and the approach within this integrated system is holistic, as it strives to address the broad range of client needs.

The complexities of care that come with many chronic conditions (including mental illness) is thought to require a service delivery that involves “coordinated inputs from a diverse set of health professionals and places patients at the centre, as co-producers of care in order to optimise health outcomes” (Nolte et al., 2012: pg 126). Despite this call for more integrated and coordinated care, services are often fragmented - within and between systems (e.g. faith-based and allopathic), sectors (e.g. mental health and social care sectors), as well as between and within service levels (e.g. primary and tertiary care) (Nolte et al., 2012). Recognising this fragmentation, many countries try to move away from fragmentation by attempting to bridge the gaps between professionals, services, and institutions through integration (Nolte et al., 2012).

In practice, integrated care is often far more complex, and therefore many scholars have had difficulty with conceptualising the process of integration (Goodwin, 2013), as it is a multi-faceted concept. To illustrate, integration has different degrees (i.e. across the spectrum of care, linkages, co-ordination, full integration), dimensions (e.g. organizational, professional, functional), ‘spreads’ (vertical, horizontal), and processes (i.e. cultural, social, structural and systemic) (Goodwin, 2013). Additionally, the path to achieving integration within a health system can be hampered by a number of factors, of which the most
frequently discussed is fragmentation (Valentijn et al., 2013). Fragmentation can result from specialization, differentiation, segmentation and decentralization (Valentijn et al., 2013). The assumption is that a less fragmented health system potentially produces a more effective and equitable allocation of health care (Elhauge, 2010).

**Degrees of integration**

If we picture the spectrum of integration, we can envision segregation on the complete left of the spectrum. *Segregation* refers to the complete absence of any form of integration in care (Ahgren & Axelsson, 2005). Moving up the spectrum towards more integration are *linkages*—referring to linkages between organisations/services—likely involving timely referrals and communication between professionals with the aim of promoting continuity of care (Ahgren & Axelsson, 2005). For example, a cardiologist may have a link to a psychiatrist, where they communicate about a particular client’s comorbid ischemic heart disease and depressive symptoms. Next, *coordination* refers to clients who are managed between organisations or services, whereas *full integration* means that these different organisations or services are merged to form a new, integrated programme—which aims to have services that address the spectrum of needs of clients (Ahgren & Axelsson, 2005). Ahgren and Axelsson (2005) use the term segregation in their conceptual framework of integration—they define segregation as the “absence of any form of integration”. This can be seen as a more extreme form of fragmentation, as with fragmentation, certain elements of an entity may be fragmented while others still left intact and integrated.

In order to explain the dimensions, spread and processes of integration, I will refer to the model of integrated care, adapted from Valentijn et al. (2013). Although Valentijn and colleagues developed their conceptual framework based on primary care, it is equally applicable for integrated mental health care and will be applied to mental health in this thesis. The conceptual framework is shown in Figure 2 and 3. Broadly, the conceptual framework organizes the dimensions of integration (mentioned above) according to three main levels: the macro (system) level, the meso (organizational) level and the micro (clinical) level. For the purposes of this thesis, we adapt the model proposed by Valentijn and colleagues (2013) by modifying the terminology denoted at the macro level. They suggest that macro level integration consists only of systems integration; however, we argue that systems integration can occur at the macro, meso, and micro level. For example, an organisation or an institution (meso level) can also conceptualise integration by taking a systems-perspective. Therefore, we further specify systems integration at the macro level to looking at integration from the policy and legislative angle (reflected in Figure 2.3).
Macro level: A look at health systems from a policy and legislative angle

System integration refers to the alignment of rules and policies within a system (Valentijn et al., 2013), and integration at this level is thought to contribute to increased efficiency, quality of care from the systems perspective, and increased quality of life, well being and satisfaction from the client perspective. Figure 2 is meant to illustrate that population-based care and person-focused care (client-oriented) lie at the core of the integration process, and illustrates that both vertical and horizontal integration are required in order to shift the system. The differentiation between vertical and horizontal integration can be seen as a focus on client (individual-level, vertical) versus the population level (horizontal integration). To illustrate, vertical integration may involve integrating diabetes care for the service user by linking tertiary, secondary, and primary care approaches for diabetes. Conversely, horizontal integration may include integrating diabetes prevention by linking up with the medical sector, food industry, and the social sector – in order to prevent diabetes at a population level. The combination of both types of integration can improve the degree of integration (e.g. push for entire integration). Both of these spreads of integration are needed in order to tackle the fragmentation of services in a health system (Valentijn et al., 2013).

![Figure 2.2. Model of integration (Valentijn et al., 2013)](image)

Meso level: organizational integration

At the meso level of a health system, the literature refers to organizational integration most frequently (Delnoij et al., 2002; Valentijn et al., 2013) (Figure 3). This form of integration has two sub-categories: institutional (organisations) integration, and
professional integration. Organisational integration describes the extent to which services are linked to each other. Institutions and the professionals within them either adopt this new integrated approach, or continue to operate in silos. Organisational integration is crucial to provide population-based care, such as public health, and is particularly important for reaching socially disadvantaged populations. This is based on the assumption that organisations should work together in an integrated way to respond to client needs. However, within a system, when you have multiple actors forming organisations, and embedded structures, cultures, and practices within these organisations, integration can be difficult. Organizational integration can be achieved through hierarchical governance structures, market-based governance structures between organizations, or through establishing networks (Valentijn et al., 2013).

Professional integration relates to the partnerships of professionals within and between organisations, and partnerships can be part of vertical integration or horizontal integration. For example, one could have a partnership between a specialist and a primary health care doctor (Generalist), or between a social worker and a primary care doctor. The idea here is that professionals have a ‘collective responsibility’ to ensure the wellbeing of the population, and in order to ensure wellbeing, professionals from diverse sectors and domains need to come together and adopt a shared responsibility for this integration of services. There are two potential factors compromising integration at this level, and those are unclear roles and a loss of professional autonomy (due to blending of responsibilities, task-shifting, and the client-centric nature of integration). Divergent belief systems can be a problematic aspect at this level of integration, however, this should not exclude the possibility of embarking on the path to integration.

Micro level (clinical integration or service integration)

Clinical integration refers to the coherence in service delivery for clients, as well as the degree to which care is coordinated across professional, institutional and sectorial boundaries within a system (Kodner & Spreeuwenberg, 2002; Valentijn et al., 2013). Although the idea of clinical integration is meant to be client-centric, in practice, often two approaches to disease management are integrated (e.g. integrating diabetes and depression care) which distances the client from the integration process, as the focus here is on the disease (driven by professionals) rather than client needs.

Functional and normative integration

Finally, two additional levels of integration are functional and normative integration. Both of these levels of integration link the macro, meso and micro level together (accordingly, they link up systems, organisations, services/clinical integration together). Functional
Integration involves the key support functions and activities (financial management, human resources, strategic planning, quality improvement, information management), which are centred on service delivery. At this level of integration, these functions and activities should help with coordination, supporting accountability structures, and in decision-making (both between organisations and professionals) and add value to the system (Valentijn et al., 2013). It should be noted that this level of integration adopts a flexible approach that takes into account the changing environment and changing needs of the population (Valentijn et al., 2013). Normative integration, however, focuses on coherence between value systems of actors, organisations, and the clinical system (Valentijn et al., 2013). Thus this level of integration focuses more on streamlining norms across individuals, professionals and organisations (e.g. shared values, culture, goals). Ways of achieving normative integration include a clear mission and vision reflecting the local population, defining mutual shared goals, and emphasising leadership at the professional and management level (Valentijn et al., 2013).

Figure 2.3. Integrated care modelled on functions of primary health care (Adapted from Valentijn et al 2013)
Making sense of transitions: how can we model change in the mental health system?

Changing the mental health system: Responding to persistent problems

Persistent problems exist in every societal system, characterised as systemic issues rooted in existing institutions in a system (Loorbach, 2007, p.25). More specifically, a persistent problem can be defined as:

“A systematically (re)produced enduring problem. In other words, a persistent problem comprises the features underlying an enduring problem, as well as the pathways and mechanisms through which production/reproduction is effected. These pathways and mechanisms exist because agents act out rules, regulations, financial structures, etc” (Schuitmaker, 2010, p. 35)

Based on this definition, persistent problems involve multiple actors coming with multiple perspectives (which may reflect their own roles and interests within a societal system), and these actors are often grounded in various societal domains and levels (Loorbach, 2007). Relating to mental health, examples of persistent problems can include poor access to care, a paucity of human resources to address mental health needs, or rising costs of care despite stagnation of funds. Thus, persistent problems often have multiple layers and angles, making them difficult to address and solve. Resolving them requires actors to reflect not only on cultures, structures and practices in health systems, but on the underlying foundations of a health system as well. This reflection process must then drive the urgency or need to change the system—this urgency to address a persistent problem can prompt system innovation (Essink, 2012).

Effectively addressing persistent problems in health necessitates structural system-level changes; also referred to as a transition. Structural systems change is a complex, long-term, non-linear, multi-level process, involving multiple actors aiming to solve persistent problems and transform the system (Loorbach, 2007, pg.23). Even when levels of integration are clarified and hampering factors are identified, modelling transitions in a complex adaptive system, such as a mental health system, may prove to be a difficult task. A health system (including mental health) is one of the most interdependent systems known (Kodner & Spreeuwzenberg, 2002), and reductionist approaches to improving health systems (including mental health systems) have been found to be inadequate to both address persistent problems as well as anticipate future challenges (Swanson et al., 2012).

A transition can be thought of as a “major shift, or change in societal system, where a system transitions between equilibrium states of social systems, as a result of a co-
evolution of economic, cultural, technological, ecological, and institutional developments occurring at different levels” (Rotmans et al., 2000, p.19). To better understand transitions in health systems, I apply the multi-level perspective (to understand where transitions occur, and at what level) and the multi-phase concept (to understand the development of a transition over time). Both frameworks have been applied in agriculture, technology, engineering and more recently, health (Broerse & Bunders, 2010; Essink, 2012; Schuitmaker, 2010; Van Raak, 2010).

**Structuring elements within a complex system: Culture, structures and practices**

Theories focusing on transition posit that within a system are structures, cultures and practices, which form a cluster known as a constellation. These constellations are a set of interrelated practices and structuring elements that define and fulfil a specific function in a societal system (Van Raak, 2010). Actors are the individuals or organisations in the system, governed by the collective choices made in a system.

Culture refers to the dominant value systems, ways of thinking, perceptions, and mental frames that actors in a system hold. Structures entail the “physical, economic, legal, financial, organisational, and power structures that facilitate and/or constrain the behaviour of involved actors with regard to the system” (Van Raak, 2010). Practices are the operations and tasks that actors carry out within a system which contribute to the system's overall functioning.

These three concepts are all inter-related within a constellation. For example, practices are outcomes of an actor’s behaviour and can shape cultures and structures; however, structures and cultures in a system can also constrain or enable certain practices. Together, a constellation contributes to defining the role a societal system will have, and shapes the outcomes and/or products of that system. In order to progress towards a transition to a different state of the system, structures, cultures and practices must fundamentally change (Rotmans & Loorbach, 2010).

**The multi-level perspective**

The multi-level perspective distinguishes between three levels of social organisation influencing transitions (Broerse & Bunders, 2010; Geels & Kemp, 2000; Loorbach, 2007; Rotmans, Kemp, & van Asselt, 2001): the regime, the niche and the landscape.

The **landscape** includes the entire societal context in which transitions occur. Broadly speaking, the landscape encompasses economic structures, environment, societal norms
and values. The landscape develops independently, outside of the regime, yet nevertheless considerably influences both the niche and regime levels.

A *regime* of a system (in this case, the mental health system) is made up of multiple actors that interact with each other through a dominant structure, culture and practice. The regime has a stabilising function by guiding the actions and ways of thinking within a system.

At the *niche level*, individual actors hypothesise and develop and test innovations, including technological, social, or policy innovations, thus experimenting with novel structures, cultures and practices. Niche level experiments occur because actors want to solve problems or seize opportunities unable to be realized within the dominant structure, culture and practice of the regime. Experiments at the niche level therefore divert from the dominant culture, structure and practice and introduce new ways of thinking, acting and organizing.

This model is useful in this thesis for several reasons: First, it helps us in understanding what developments are happening at the different levels (niche experiments, changes in cultures or practices institutions at the regime level, changes in policies/ regulations at the landscape level). Second, it helps us better understand whether a transition in the mental health system is likely. The regime is often the stabilising factor in the multi-level model, meaning that it is rigid and resistant to change; thus changes at the regime level require significant pressure and efforts in order to have enough critical mass to reach a transition. Trends at the landscape level and successful niche experiments provide such pressure.

Building on the multi-level perspective is the multi-phase concept, which describes how a transition sequentially evolves over time. Theoretically, transitions proceed through four stages: the pre-development phase, the take off phase, the acceleration phase and stabilisation phase - these stages are represented by an S-shaped curve (Loorbach, 2007).

The *pre-development phase* is characterised by a variety of developments and experiments at the niche level, which does not have move away from the status quo. This is often attributed to the fact that these niche experiments lack a clear direction and do not significantly impact the regime enough to change it. Changes considered successful in niche experiments at this level include optimising existing cultures, structures and practices. Conversely, the *take-off phase* marks the beginning of societal change, where changes at the niche level and results from niche experiments begin to scale up in such a way that the regime level is affected. However, the direction of change at this stage is still unclear, and not all components of the system are affected by this initial change. It is only in the *acceleration phase* when real structural change occurs and when momentum builds
up through an accumulation of socio-cultural, economic, technological, environmental and institutional changes which are interrelated and interdependent. In this phase, the direction of change (positive or negative) becomes clear, and is marked by a number of collective learning, diffusion and embedding processes, which leads to a fundamentally different approach in changing the system. After the acceleration phase, the societal changes begin to gradually decrease speed and stabilise (*stabilisation phase*), resulting in a new state of equilibrium – thus, the new culture, practices and structures become fully embedded in the new regime.

*Anticipating the direction of a transition*

Steering notions have an influence on both the direction and the speed of a transition (van den Bosch & Rotmans, 2008), and are essential for system innovation, including health system innovation. These mechanisms can open up space for learning processes to take place while simultaneously facilitating interactions between niche experiments and the context, or embed new practices to increase the scale and impact of the niche experiment (van den Bosch & Rotmans, 2008; Van den Bosch, 2010). These steering notions consist of deepening, broadening and scaling up.

![Figure 2.4. The multi-level model (Broerse and Bunders, 2010)](image-url)
Deepening is a process placing emphasis on learning as much as possible within a specific or given context, which can steer a shift in the culture, structures and practices between the new and old regime. This steering mechanism also focuses on, in an interactive way, obtaining or developing knowledge on competences, norms and values. Deepening can lead us to develop best practices or proof of principle and better understand whether a social innovation works, under what conditions, and what the added value of the innovation is. Identifying change agents and aligning them with other actors is also important in this stage, as they are necessary catalysts for system innovation. Broadening involves repeating the experiment or innovation in different contexts, to broaden the applicability, replicability, and generalisability. Finally, scaling up is often the most challenging mechanism, as it requires embedding the innovation in the regime, as well as changing the dominant structures, cultures and practices (van den Bosch & Rotmans, 2008; Van den Bosch, 2010). There are often substantial institutional and attitudinal (i.e. resistance) barriers to overcome.

The combined multi-phase and multi-level conceptual frameworks are helpful in diagnosing the state of a particular system; in this case, the mental health system in India. It also explains why realising accessible, integrated and rights-based care is and will continue to be a challenge in India. The model also allows for mapping out the phase of development that niche experiments may be in (mental health niche experiments in India), as well as in expanding and deepening our understanding of the contextual factors embedded in the landscape in India. In order to expand our view of the mental health system and the capacity for change, it is necessary to understand the contextual factors.
influencing the system, as well as the challenges and opportunities the system faces. The next chapter will cover how this understanding will be fostered through research.

Conditions for transformative change

De Haan (2010) distinguishes between three pathways to change that can lead to a transition: reconstellation (top-down change), empowerment (bottom-up change) and adaptation (self-change) (de Haan, 2010). Reconstellation is a top-down change, where a new or existing constellation/regime gains power from a higher-level constellation (e.g. a new mental health law, or a new international Convention). With the introduction of such a law or policy, change is imposed on the system. Reconstellation may fail when there is a breakdown of the system and actors are unable to adhere to the change imposed on the regime. Conversely, bottom-up change may occur when an existing constellation or regime gains power (either on its own or through coalition building with other constellations). Change in the system may progress to a transition but may fail when the structures, cultures and practices of the incumbent regime are not able to adapt to this new change, resulting in a backlash, where things return to the status quo. Finally, self-change refers to a regime’s internal change, which is gradual and incremental. This change may fail if there is no longer urgency or pressure to change, leading to a ‘lock-in’ where change slows down and stabilises. These patterns can over time form pathways to change, leading to a transition. The pathway to transition depends on the power dynamics between the existing regime, upcoming niches, and tensions at the landscape level (Ferguson, Haan, Brown, & Deletic, 2012).
CHAPTER 3: RESEARCH DESIGN

This thesis consists of five Parts. The first part includes a policy document (Chapter 4) within India’s first National Mental Health Policy, commissioned by the Ministry of Health and Family Welfare, Government of India. This chapter answers the first broad sub-question that will guide subsequent Chapters. The findings from Part 1 set the scene for the proceeding research articles in this thesis. Part 2 of this thesis focuses on mental health legislation and policy at both the international, national, and local level. It includes one analytical review (Chapter 5), two systematic narrative reviews (Chapter 6 and 7) and one exploratory case study (Chapter 8). This Part successively answers sub-questions 2 to 4. Part 3 focuses on a case study of collaboration between the faith-based and allopathic (biomedical) sector (Chapter 9), and answers sub-question 5. Part 4 of this thesis focuses on an emerging health problem in India, comorbidity. This part includes one quantitative screening study (Chapter 10), answering sub-question 6. Finally, Part 5 of this thesis aims to map the way forward for mental health in India and includes one reflection piece (Chapter 11) and successively answers sub-question 7.

Research questions

As mentioned in Chapter 1, the main research question of this thesis has been formulated as follows:

*How can the mental health system in India be further described and understood, and what opportunities and strategies can be identified to move towards an accessible, integrated, rights-based system?*

In Chapter 1, I hypothesised that the mental health system in India has not been able to adopt an integrated approach to improving mental health, which has hampered its ability to provide accessible care to the population. I also hypothesised that a potential way to address fragmentation within the mental health system in India may be through different forms of integration, which has been posited as a way forward for other health domains, such as primary care (Goodwin, 2013; Valentijn et al., 2013). If these assumptions are correct, a number of questions immediately arise. Where and why is there fragmentation in the mental health system in
India? What developments are occurring to address this fragmentation? What strategies can be developed to facilitate these developments further? Are these developments likely to take off to a transition towards a more accessible, rights-based mental health system? In order to begin to address and answer these questions, more research is needed on the current state of the mental health system in India.

The overview of the literature reveals that there is limited knowledge on mental health systems in LMICs, including India. The aim of this thesis is to fill in this knowledge gap by expanding our understanding of the mental health system in India. The primary objectives of this thesis are two-fold: First, to focus on the problem of fragmentation and realizing an accessible, integrated, rights-based system. Second, to analyse the mental health system in India, and, to present potential strategies that could facilitate the delivery of more accessible, rights-based and quality care; third, to better understand the structural causes of fragmentation in the mental health in India in order to pinpoint ways of achieving integration at different levels.

This main research question can be further specified into 8 sub-questions that will be answered through research and reflections presented in this thesis. The sub-questions follow an emergent design, meaning that each sub-question was developed by taking into consideration the objectives of this thesis, an increased understanding of the Indian context, and reflecting on the theoretical frameworks.

As the first aim of this thesis was to understand the current state of the mental health system in India, a situational analysis was carried out which provided a broad overview of all aspects of the mental health system, as well as the persistent problems in mental health. This led to the following sub-question:

*What are the persistent problems in the mental health system in India?*

Following from the situational analysis and the theoretical frameworks, the first step was to understand the developments and obstacles faced at the macro level (in relation to the integrated care framework in Chapter 2) in mental health. This required an analysis of the obstacles and developments at in mental health law and policy both at the global level and the national level. This led to the following three sub-questions:

*What are the main issues at the mental health law and policy level, both internationally and in India?*

*To what extent are human rights integrated in legislation and policies, both internationally and in India?*
Which obstacles hamper implementation of human rights for persons with mental illness in practice in India?

Building on the analysis of mental health law, policy and human rights at the macro level, it was important to find out how access to mental health care could be strengthened, as well as how quality of care could be ensured through promoting the rights of persons with mental illness. One route to strengthen access and quality is through law and policy, however, an alternative route is through exploring collaborations and developments at the niche level. These niche experiments/pilot programmes could be evaluated to identify strategies for reducing fragmentation in mental health services, as well as identify strategies for increasing access to care. This led to the sub-question:

How can collaboration between professionals and institutions reduce fragmentation of the mental health system in India?

Addressing this sub-question also required an actor analysis – as the institutions and professionals participating in such a collaboration shape the dynamics and success of the collaboration. The collaboration (detailed in Chapter 9) is therefore illustrative of the relationships between the macro, meso and micro levels.

Some niche experiments emerge from regime-level actors as they are confronted with problems they are unable to address using the dominant solution pathways. For example, a diabetes specialist may encounter many instances in their practice where clients with diabetes present with depressive symptoms. This may lead the specialist to wonder whether this is a problem for other diabetes specialists across India, and think about ways to tackle this comorbidity they observe in their client base. This may lead the specialist to the realisation that services and organizations are fragmented, such that mental health care and diabetes care are addressed in isolation from each other, resulting in a desire to take action and obtain a greater understanding of this problem. This shows an example of a niche experiment driven from the regime level, as the problem and desire to experiment and understand emerges from the front line workers experiencing problems in service delivery. Thus, prior to experimentation, it is important to determine first whether there is a need to take action on a particular issue (i.e. is this a problem in the Indian population, and if so, to what extent) before setting up an intervention or pilot programme. This leads us to the following sub-questions:

Are comorbidities a problem at the professional and organizational level in India? If so, to what extent are they recognized and acted upon?

In order to answer this sub-question, we first conducted a prevalence study on the presence of depression in service users with diabetes to assess the magnitude of the
problem, provide visibility on this comorbidity, and then discuss how this comorbidity is addressed by professionals and/or services in India.

In order for a transition to occur, all of these strategies identified and analysed at the macro, meso and micro level need to be implemented by actors in the regime (mental health system). Considering this, one question remains:

*What do stakeholders view as options for changing the mental health system in India?*

In order to answer this, we interviewed key stakeholders in India through exploring the following topics: What strategies can be identified to move towards a transition in the mental health system? What else could be done to progress towards a transition in the mental health system? What are the obstacles to this happening?
Research approach

Location of the research

In addition, given that India is one of the most diverse countries in the world and accounts for nearly 20% of the world’s population, not surprisingly there is substantial heterogeneity in terms of health status, programmes and priorities between states. In order to account for some of this variance, this thesis collected data from three states (Gujarat, Tamil Nadu and Maharashtra) as well as conducted reviews to reflect the situation at the national, and international level.

Methodological approaches

Due to the diversity of sub-questions posed in this thesis, several methodological and research approaches are required. For instance, reviews were appropriate to better understand best practices in terms of what other countries are doing to implement International Conventions into domestic law, or the barriers and facilitators governments face in this process. Subsequently, when implementing a new tool outlined in a policy or law, or describing an innovative mental health collaboration, a case study approach is more appropriate. When assessing the magnitude of a particular problem in society, a quantitative approach is needed that can concisely communicate the scale of the problem to stakeholders. This thesis uses all of these study designs, therefore representing an overall mixed methods design (Teddlie & Tashakoori, 2009).

The individual research articles are grouped in this thesis by theme (i.e. mental health law and policy, collaborations, and multiple care needs) forming three Parts of this thesis (Part 1, Part 2, Part 3). Within each part, there are different methodological approaches and study designs. These are described sequentially (as the study appears in this thesis) below. More details on research design can be found in each of the studies in their respective Parts of this thesis. Table 1 provides a visual map of this thesis.

Study 1: A situational analysis of mental health in India

The first part of this thesis sets the scene for understanding the mental health system in India, through a situational analysis. The analysis was carried out for the National Mental Health Policy Task force, and was a narrative synthesis of data related to mental health in India. The aim of this analysis was to provide a comprehensive overview, or profile, of mental health in India as a preface to the National Mental Health Policy itself. The analysis involved synthesizing research studies and grey literature (e.g. state-level policy documents, annual reports of non-profit organisations, government reports, Census data)
related to a broad range of mental health topics in India. Then, the data and information were organized into themes covering thematic areas related to demographics, burden of disease and elements of the mental health system. Themes were based on the World Health Organization’s PROMIND templates, which provide a comprehensive overview of mental health in low and middle-income countries (WHO PROMind Country Profiles, 2011). The situational analysis was disseminated and peer reviewed by stakeholders on the steering group for the National Mental Health Policy. It should be noted that this is not a research study, but an analysis fitting into a national policy document. This analysis allows us to first understand what the systemic issues in mental health in India are; second, map out the knowledge gaps, and third, pinpoint the drivers for change.

**Study 2: A rights-based review of mental health in Commonwealth countries**

**Study 3: Supported decision-making for persons with mental illness: A review**

**Study 4: A review of barriers to using psychiatric advance directives in clinical practice**

Study 2, 3, and 4 all consist of reviews. The aim of conducting reviews was to systematically map out best practices in mental health law and policy reform internationally, specifically in relation to countries that may have adopted a more rights-based approach to care in their country and updated their legislation accordingly. This is particularly pertinent in light of the introduction of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2006, which, once ratified, mandates countries to reform their legislation to align with provisions in the CRPD. Lessons learned from the reviews were explored for potential adaptation in low and middle-income countries, and specifically, India. This was a helpful exercise for determining whether any elements of these best practices could be adapted or adopted to the Indian context.

The analytical review (Study 2) focused on reviewing mental health legislation in Commonwealth countries (n=45) in order to obtain insight as to how mental health legislation in these countries complies with the CRPD (including India). This review compared each law against CRPD provisions as well as to the WHO Checklist on Mental Health Legislation (World Health Organization, 2005).

Article 12 of the CRPD, Equal Recognition Before the Law, is one of the most celebrated Articles in the CRPD by activists, said to be the ‘beating heart of the CRPD’ (Minkowitz, 2010; Quinn & Stein, 2009). Its main premise, ensuring the right to exercise legal capacity, has been subject to debate among professions, however, due to its implications on modifying guardianship structures embedded in many legislative systems worldwide, and shifting decision-making powers to the person with mental illness. One way to enable a
person to exercise their legal capacity is through supported decision-making. In light of the international debate and importance placed on Article 12, we wanted to explore whether this debate had been channelled into action and changed domestic legislation, or, whether it had been piloted and tested in practice through research. This formed the first systematic narrative review (Study 3) on supported decision-making for persons with mental illness, included a total of 55 papers ($k^2=25$ research papers reviewing the literature on supported and shared decision-making, and $k=30$ in portion of the review focusing on reviewing laws internationally).

After reviewing supported decision-making for persons with mental illness, we found that a number of country laws referred to provision of psychiatric advance directives when referring to guardianship. It was then discerned that psychiatric advance directives were one tool that enables supported decision-making. Given its presence in domestic legislation, we wanted to know: are these tools implemented in practice? If so, where? If not, what are the barriers to uptake and implementation? These questions guided us through the second systematic narrative review (Study 4) of barriers to uptake of psychiatric advance directives, included 30 research studies. Given the qualitative nature of many of the studies included in both of these reviews, a meta-analysis was not possible and therefore a narrative synthesis was conducted instead.

Study 5: Unpacking the psychiatric advance directive in under-served settings: An exploratory qualitative study in Tamil Nadu, India

Study 6: How can mental health and faith-based practitioners work together? A case study of a collaborative mental health programme in Gujarat, India.

Study 5 and 6 use a case study approach. I will first elaborate on the case study as a methodological approach, and proceed to describing the data collection and research design for both of these cases.

Case study approach

The aim of a case study approach is to obtain insight and depth into a particular phenomenon (Yin, 2003) and obtain and in-depth understanding of a single or small number of cases within their real-world contexts (Bromley, 1986). Case studies can describe and analyse policies, institutions, persons, decisions and projects studied holistically by one or more methods (Yin, 2008). Case studies are useful in explaining,

$^2 K$ denotes the total number of studies included in a review.
describing and exploring events in their natural context (Yin, 2009) and are particularly useful for understanding the ‘how’s and the ‘why’s of phenomena, such as how is an intervention being implemented and received on the ground (Crowe et al., 2011).

Inherent in the case study approach is understanding contextual factors shaping this phenomenon as well as its complex conditions. For example, case studies may explore professional attitudes to a new policy initiative or service (Crowe et al., 2011), such as a new mental health law or a new community-based treatment for persons with mental illness.

Cases can be selected based on pre-defined criteria or be theory-driven (Yin, 2003). Cases for this thesis were selected based on their relevance to the main research question, and were selected based on the following criteria: The case should involve aspects related to mental health systems, the case should focus on India or on mental health aspects related to India, the cases should be accessible for investigation, the case studies should represent a diverse set of social phenomena, related to health systems, and the cases should allow one to answer the main research question. The collection of case studies constructs the frame for analysis, and provides a unique opportunity to feature the change processes occurring in the mental health system in India. Within a case study approach, different methods can be applied. In this thesis, a mix of qualitative and quantitative methods was used.
Selected cases

Two cases were selected for analysis in India, diverse in their regional contexts (i.e. one case was located in the state of Gujarat, one in Tamil Nadu), and reflecting two different topics (legislative tool implementation (psychiatric advance directives), and collaborative programmes between faith-based and allopathic mental health professionals). These case studies are described in Chapter 8 and 9.

The two case studies are covered separately (Case Study 1 is covered in Chapter 8 in Part 2, and Case Study 2 is covered in Chapter 9 in Part 3, respectively).

Case Study 1: Exploring the implementation of psychiatric advance directives in Tamil Nadu, India

The first case study in this thesis was an exploratory qualitative study assessing the feasibility of psychiatric advance directives (PADs) once implemented into practice in Tamil Nadu, India. Since one of the major issues of legislative and policy reform is translation to practice, it was important to conduct an exploratory case study among clients and carers to understand whether the psychiatric advance directive, a tool mentioned in India’s new Mental Health Care Bill, could be useful and adapted on the ground in India. This qualitative study was conducted at a non-profit mental health services organisation the state of Tamil Nadu, and included a total of 51 semi-structured interviews with clients (n=39) and carers (n=12), carried out in Tamil Nadu, India. The qualitative analysis of this study followed a thematic approach (Miles & Huberman, 1994).

Case study 2: Describing the Dava Dua Programme in Gujarat, India

This case study was a mixed-methods case study that aimed to shed light on how collaboration between professionals and organisations between two systems (faith-based and allopathic) could be realized, on trajectories of clients and carers accessing this collaborative programme (The Dava Dua Programme), and experience with the programme from different stakeholder perspectives (faith-based and mental health practitioners, carers, and clients). The Dava Dua Programme is a unique case in India, as, to the best of our knowledge; there are no existing sustained collaborations of this nature in India. It was felt that this case study could provide interesting insights on lessons learned.

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3 Allopathic: Also referred to as the biomedical system
4 Carers are family members or friends of a person with mental illness. In India, a family member is often responsible for the ongoing care of their relative with a mental illness. From here onwards, they are referred to as carers.
learned, as well as shed light on the processes that led to this specific niche experiment being a success. To explore this, we conducted 16 semi-structured interviews were carried out in this study (n=3 faith-based practitioners, n=3 allopathic mental health practitioners, n=3 clients, n=7 carers). The quantitative data however, provided information on who accesses the programme, and their corresponding demographic and clinical characteristics. This portion of the study presents data on 3172 clients. This research was carried out in the state of Gujarat, India.

**Study 7: Assessing multimorbidity in the Indian context: A screening study of depression in type-2 diabetes in Pune, India.**

Diabetes and depression independently contribute substantially to the burden of disease in India, however it is unclear to what extent this comorbidity poses a problem in the Indian context, and if it does pose a problem, what can we do about it? The research study presented in Part 4 is a public health screening study to assess the prevalence of depression among patients with type-2 diabetes in Pune, Maharashtra, India. In this study, we included 658 service users with diabetes, selected from a larger study focusing on diabetes and depression, which included service users with type-1 diabetes as well (n=878).

**Study 8: Reflection with stakeholders**

Reflecting on the potential for a transition to a more accessible, integrated rights-based mental health system in India, it is important to obtain the views of key stakeholders in mental health in India to get their perspective on the way forward for mental health in the country. This entailed a qualitative study, where 7 semi-structured qualitative interviews were carried out with key stakeholders who were selected through convenience sampling, based on their roles in shaping mental health structures, cultures and practices in India.

**Research teams**

In this thesis, there were four main research teams, involving a mix of researchers and health care workers primarily from India, as well as several researchers from the Netherlands. The role of the author in the research teams was in conceptualising and designing the research approach, collecting data, analysing the data and writing the results and articles. The author was not part of the implementation team in the case studies (Chapter 8 and 9) or part of the clinical team in Chapter 10, allowing some distance between the research and implementation/service provision.
Ethical considerations

The research presented in this thesis received local ethical approval in India, as all primary data collection was conducted in India. For Chapter 8 in Part 2, ethical approval was obtained from The Banyan Academy for Leadership in Mental Health’s External Ethics Review Committee in Chennai, Tamil Nadu. For Chapter 9 in Part 3, ethical approval was obtained from the Ahmedabad Hospital for Mental Health Ethics Review Committee, Gujarat, India, and finally, for Chapter 10 in Part 4, ethical approval was obtained from the Institute for Treatment and Research in Diabetes and Endocrinology, Pune, Maharashtra, India.

Table 1. Overview of studies covered in this thesis

<table>
<thead>
<tr>
<th>Study</th>
<th>Location</th>
<th>Type of study</th>
<th>Chapter</th>
<th>Part</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Situational analysis</td>
<td>India (national-level)</td>
<td>Needs assessment/situational analysis</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>2. Review of mental health legislation in Commonwealth countries</td>
<td>Commonwealth countries (global)</td>
<td>Analytical review</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>2. Review of supported decision-making</td>
<td>Global</td>
<td>Systematic narrative review</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>3. Review of barriers to using psychiatric advance directives</td>
<td>Global</td>
<td>Systematic narrative review</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>4. Implementing psychiatric advance directives in India</td>
<td>Tamil Nadu, India</td>
<td>Case study approach (niche experiment) – qualitative study</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>5. Mental health and faith-based healers working together</td>
<td>Gujarat, India</td>
<td>Case study approach (niche experiment) mixed-methods study</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>6. Screening study of diabetes in depression</td>
<td>Maharashtra, India</td>
<td>Quantitative study</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>7. Reflection with mental health stakeholders on the mental health system in India</td>
<td>Tamil Nadu and Maharashtra, India</td>
<td>Reflection piece – Qualitative study</td>
<td>11</td>
<td>5</td>
</tr>
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</table>

Furthermore, ethical considerations were addressed throughout the three empirical studies in the following ways: Participants were briefed with information about the study, provided with opportunities for terminating the interview and/or questionnaire without penalty or compromising their care; remaining open as researchers to receiving questions throughout the data collection process; obtaining informed consent (verbal, written, or both, and in case of illiteracy, thumbprint) from every participant prior to participation; assigning unique case IDs to participants to replace their unique personal identification...
details and protect confidentiality; limit the number of research team members and health care professionals with access to the databases with personal identification information; store completed questionnaires and interview materials (e.g. tapes) in locked cabinets with restricted access, available only to core research team members.

**Research validity**

Throughout this thesis, a variety of strategies were built into the research design and process to minimize bias and preserve both the internal and external validity of the results arising from the quantitative and qualitative research, as well as the reviews.

*Validity of the quantitative Data*

External validity within the quantitative research in this thesis attempted to ensure that the findings of the study could be applicable to other people and ensure that the conditions under which the studies were carried out represent other situations (Roberts & Priest, 2006). For example, we paid careful attention to ensure that gender was equally representative across the quantitative study, as well as socioeconomic status.

Strengthening content validity and criterion-related validity helped to strengthen internal validity. To do this, we attempted to pilot questionnaires before administering them, and using a validated screening tool also will help in strengthening criterion-related validity (relevant in Chapter 10).

*Validity of the qualitative data*

To ensure that the methods and analyses for the qualitative studies could be replicated under different conditions (Roberts & Priest, 2006), several checks were built into the research design. First, attention was paid to saturation (conducting interviews until no new data emerged). In terms of selecting participants for interviews, convenience sampling was applied in all qualitative studies (Chapter 8, 9). Convenience sampling likely restricts the diversity of the sample population, however, the researcher attempted to ensure that the sample was representative (That is, to interview relatively equal numbers of males and females and recruit clients from a diverse set of socio-economic backgrounds).

Second, we used two types of triangulation to enhance the credibility of the data. We used investigator triangulation (multiple researchers involved in the data process on each research team), and methodological triangulation (use of multiple methods to collect data, including interviews, questionnaires, and field notes). Cross-checking findings in light of existing published literature also assists in validating findings (Roberts & Priest, 2006).
Third, to anticipate and minimise potential researcher bias, interview data was sent to an independent researcher in order to check the level of agreement among codes and qualitative analysis, in order to increase inter-rater reliability. A third rater was available if disagreements arose around code selection. Furthermore, qualitative data analysis enhances reliability, particularly when entered into a computerised qualitative data package. In this thesis, MAXQDA (version 11) was used to analyse qualitative data. Content analysis helped to augment validity of the data as specific codes were generated and revisited over time to check for stability/agreement.

Additionally, reflexivity was exercised by reflecting on my ability to be unbiased and consider how my presence affects the research settings. In order to help minimise this bias, member checks were in place to review accounts and interviews (in most cases, this was the audio recording of the interview, or a written summary of the respondent’s account) for feedback and accuracy.

**Validity of the data obtained from reviews**

Although a comprehensive systematic review and/or meta-analysis fell beyond the scope of this thesis, we attempted to ensure validity of the reviews by making review questions specific, actionable, and relevant to the audience (e.g. health professionals or service users). Furthermore, the search strategies employed and databases consulted were outlined in methodology sections, and references at the end of articles were cross-checked for additional references that could be included in the review that our search may have missed. Moreover, at least two researchers evaluated each study for inclusion in the reviews and made decisions about inclusion (i.e. selection and assessment). In order to make the selection process systematic rather than arbitrary, inclusion and exclusion criteria, as well as the sifting process, was documented in a sifting strategy.