General introduction

1.1 PROBLEM STATEMENT

1.1.1 The starting point of thought: the 'trolley dilemma'

The famous 'trolley dilemma' was first introduced by Philippa Foot (1967) and then extended by Judith Thomson (1976, 1985) as follows:

> A trolley is running on the railway. Ahead of the trolley, there are merely two directions (or tracks): five skilled workers are working on one direction while one skilled worker is working on the other direction. The trolley by schedule should be headed down the track where five men are, but if someone pulls the lever, the trolley will be headed down the track where the one man is. Supposing that the trolley could not stop and you were next to that lever, what would you do and what is the right action?

The choice you made, either pulling the lever or not, could be justified by fairly persuasive arguments from two classic ethical theories: Consequentialism and Deontology (e.g. Kantianism[1]). The debate between these two distinct schools of thoughts is long and historical, which has greatly affected the kind of public policies that governments enact (Table 1.1).

Table 1.1 Two paths to right action and implications for public policy

Two paths	Trolley dilemma	Basic points	Implications for public policy
Consequentialism	Pull the lever to generate a greater positive effect on society	Value the consequences of acts Pursue 'the greatest good for the greatest number' (Mill, 1863)	A policy can be justified if, all things considered, it promotes the overall goal of maximising the utility In some cases, the interests of the minority may be given less weight
Kantianism	**Not** pull the lever regardless of how appealing the results might be	Some acts are intuitively right while some are intuitively wrong People are ends-in-themselves and should not be treated as merely means to ends	Respecting and protecting human rights should be the basis grounding all kinds of public policy The interests, goals and values of every individual human being deserve to be equally respected

Consequentialism values the consequences of acts and treats intentions as irrelevant. The paradigm case of consequentialism is utilitarianism. In the eye of utilitarian, pulling the lever is the right thing to do because it is a way of maximising the utility, that is, saving five lives rather than merely one life is likely to generate a greater positive effect on society. Reflected in public policies, if implementing certain policies could benefit the majority of the society,

1 Deontology is an ethical theory that focuses on assessing the rightness or wrongness of choices themselves, rather than the consequences of choices. Immanuel Kant's moral philosophy is considered a deontological theory. For detailed introduction of deontology, please refer to Stanford Encyclopedia of Philosophy via https://plato.stanford.edu/entries/ethics-deontological/#DeoTheKan (last accessed 24 March 2019).

it is morally permissible to ignore or even sacrifice the welfare of the minority. From this perspective, public policies should be designed and implemented with the aim of producing 'the greatest good for the greatest number' (Mill, 1863).

Kantianism criticises consequentialism by stating that the welfare of the minority is equally important because people are ends-in-themselves and should not be treated as merely means to ends. To treat people as ends-in-themselves means to recognise the humanity of them, that is, to realise that every individual human being has his or her own goals, values and interests that deserve to be equally respected. Furthermore, according to Kant, telling the rightness from the wrongness of an action is to assess whether this action conforms to the universal moral law (i.e. a *categorical imperative*[2]). Kant (1785, p. 37) argued that "act only in accordance with that maxim through which you can at the same time will that it should become a universal law." Accordingly, Kant would be highly unlikely to pull the lever regardless of how appealing the result might be because he would not wish 'pull the lever' to be a *categorical imperative* followed by people when they have to make this trade-off. Reflected in public policies, respecting the autonomy and rationality of human beings should always be the fundamental principle of policymaking no matter what the policy is about.

Seemingly, there is no single right answer to the trolley dilemma because the arguments given above have their own merits with different priority settings for public policy: either pursuing 'the greatest good for the greatest number' (Mill, 1863) or prioritising the autonomy and rationality of each individual human being. Actually, these priorities are at the two extremes of the spectrum of desirable policy goals, neither of which can be regarded as a policy panacea because of the changing conditions influenced by diverse socio-economic and cultural factors. Yet, it is this uncertainty that leaves us with an interesting question to be considered:

> ***In a given context, how do we achieve an optimal balance between protecting individual rights and benefiting the overall population in the long run, when hard choices are inescapable?***

1.1.2 The trolley dilemma in healthcare

Healthcare is an important public policy issue in which tough questions are often raised in a close relationship with the trolley dilemma and its modifications. For instance, Leonard Fleck (2009, p. 72) once referred to the trolley dilemma when he argued about the inescapability of healthcare rationing:

> "This case (i.e. the 'trolley dilemma') does present well at least one dimension of healthcare rationing – namely, the inescapability of the need to make rationing decisions with life and death consequences for different individuals or different groups of individuals."

2 "The categorical imperative would be that one which represented an action as objectively necessary for itself, without any reference to another end." Kant I. (1785). p. 31.

Interpreting Fleck's argument, it is impossible to satisfy the healthcare needs of every individual patient, especially when it relates to some limited healthcare resources such as ICU beds and artificial hearts. Put differently, there exists an inevitable conflict between protecting individual rights (e.g. satisfying the unlimited patient needs) and sustaining healthcare resources when taking the scarcity of healthcare resources into account. Thus, the interesting question raised in the above section can be modified as follows:

> ***Given that healthcare resources are often limited, how do you achieve an optimal balance between protecting individual rights (e.g. satisfying patient needs) and sustaining healthcare resources?***
>
> ***Or***
>
> ***Given that healthcare resources are often limited, how should the conflict between the protection of individual rights (e.g. satisfying patient needs) and the sustainability of healthcare resources be mitigated?***

This is precisely the fundamental problem at stake that underlies this thesis.

1.2 TWO PROBLEM-SOLVING PERSPECTIVES: PERSONAL RESPONSIBILITY AND STATE ACCOUNTABILITY

From all relevant studies on dealing with the problem raised above, scholarly literature largely builds arguments on addressing state accountability in protecting and promoting individual right to health – namely, securing the 'accessibility, acceptability, availability and quality (AAAQ)'[3] of healthcare resources for patients. The rationale underlying this argument is the pricelessness of human life. Needless to say, limiting a patient's access to certain medical services is counterintuitive when it relates to a concrete single case. However, such behaviour may become acceptable if we take a systematic point of view because sustainability, as another key consideration, will come into play.

In the field of health and healthcare where individuals have great control over their own health,[4] encouraging every individual human being to play a more active role in taking care of their own health – namely, to be more responsible for one's own health – is likely to be a plausible way to respond to the sustainability concern. In this regard, not only can

3 For more information about AAAQ, please refer to https://www.who.int/gender-equity-rights/knowledge/AAAQ.pdf?ua=1 (last accessed 24 March, 2019)

4 Scholarly literature has proved that there exists a causal relationship between disfavoured habits (e.g. excessive smoking, eating disorders and alcoholism) and several chronic diseases (e.g. cardiovascular diseases, lung cancer, and overweight). For detailed discussion, please refer to Watson and Conte (1954); Rehm et al. (2009); Brownell and Walsh (2017).

the health condition of every individual human being benefit from responsible individual behaviour but also, it will in turn contribute to the sustainability of healthcare resources. Thus, addressing personal responsibility in protecting and promoting one's own health has been raised as another problem-solving perspective.

Hitherto, two problem-solving perspectives that are often used to mitigate the conflict between protecting individual rights and sustaining healthcare resources have been mentioned. In order to provide a deeper understanding, relevant studies concerning personal responsibility and state accountability are discussed separately below.

1.2.1 Personal responsibility

By and large, personal responsibility means letting people be responsible for their own choices. In health and healthcare, it can be identified in many ways and it is important to acknowledge that different ways of identifying personal responsibility will result in different, or even conflicting, reform strategies for promoting the healthcare system. That is, if one considered personal responsibility in health and healthcare as an excuse to blame or punish patients, then reform strategies would turn to limiting, rather than increasing, the accessibility of healthcare. On the contrary, if one identified the core value of personal responsibility in health and healthcare as taking good care of one's own health, such as developing a healthy lifestyle and being active in preventive healthcare, then reform strategies would be more likely to reflect the common conceptual basis of a decent society that we owe to each other in matters of healthcare distribution.

Thus, throughout this thesis, personal responsibility in health and healthcare is identified as follows: *people should play a positive role in managing their own health*. In the Chapter 3 of this thesis, a specific interpretation on what constitutes 'a positive role' is provided.[5]

In practice, reform strategies addressing personal responsibility for health have already been taken by some countries; for instance, the bonus policy in the German healthcare system (Schmidt, 2008), and the West Virginia Medicaid State Plan in the United States (Steinbrook, 2006). Behind these reform measures, there are several philosophical foundations, including liberal egalitarianism, luck egalitarianism and communitarianism.[6] How to justify the role of personal responsibility in healthcare distribution is a key question attracting attention from these philosophical traditions.

From the perspective of liberal egalitarianism, people should be held accountable for their health-related choices, but not necessarily the consequences of their choices (Cappelen & Norheim, 2005, p. 478). According to liberal egalitarianisms, health policy should take two principles into account: holding people accountable for their own choices (i.e. 'the principle

5 Please refer to page 67 of this thesis.

6 Chapter 2 of this thesis includes a detailed introduction of each theory of justice and their potential implementations for reform policies. Please refer to page 55 of this thesis.

of responsibility') and people who make the same choices should be treated equally regardless of the resulting consequences (i.e. 'the principle of equalisation') (Cappelen & Norheim, 2005, p. 478). The reason why liberal egalitarianism separates choices from consequences is that they believe the same choices may not lead to the same consequences. For instance, the chance of developing lung cancer may be increased by excessive smoking. If A and B are both highly addicted to cigarettes but only B develops lung cancer and needs healthcare badly, liberal egalitarianism would argue that a just healthcare system should hold A and B accountable for their excessive smoking behaviour but not for the consequences (i.e. A is healthy but B has lung cancer). With regard to policy implications, liberal egalitarianism is in favour of using the tax mechanism to hold people accountable for their health-related choices (Cappelen & Norheim, 2005, p. 479). Reflected in the case above, imposing progressive taxation on cigarettes is a recommended way to hold A and B to be responsible for their choice to smoke.

Whether choices are free or not is the core value of luck egalitarianism. Applied in health and healthcare, its basic standpoint implies that a just healthcare system cannot let people be responsible for inequalities caused by factors that are out of their control (Segall, 2009). That is, limiting people's access to healthcare can be justified if people's unhealthy condition resulted from their 'option luck'[7] (e.g. lifestyle choices). For those people, luck egalitarianism argues that health insurance is a way to protect themselves from bad consequences (Dworkin, 1978).

Different from the above two theories of justice, communitarianism values the common good of the society (Ezioni, 2010). People need to contribute to foster common good by taking responsibility for their own health (Callahan, 2003, p. 496). Communitarianism does not care about the diversity of healthcare needs (Houtepen & Ter Meulen, 2000, p. 360). Accordingly, weighting public health over healthcare for rare diseases is justified in the eye of communitarianism.

Overall, personal responsibility in health and healthcare, if suitably interpreted, should be adopted as a key consideration in balancing individual interests (or rights) and the sustainability of healthcare resources.

1.2.2 State accountability

Drawn from literature, addressing state accountability is another perspective that is employed fairly often in discussions concerning how to achieve an optimal balance between protecting individual rights and sustaining healthcare resources. Roughly, there are two prominent aspects guiding the majority of discussions.

7 Ronald Dworkin distinguished 'brute luck' and 'option luck'. For a detailed introduction, please refer to Chapter 2 of this thesis on pp. 53-54. Also, please refer to Dworkin (2000), p. 73.

Social determinants of health

Given that in certain situations where individual patient's access to healthcare is impeded by factors that are out of their control (Figure 1.1), it is reasonable to assign responsibility to the state for the sake of empowering people to claim their denied medical needs and other dissatisfactions.

Apparently, not all determinants demonstrated by Figure 1.1 can be controlled by the state, for instance, the individual lifestyle factors. Nevertheless, the state is still assigned with a major responsibility to correct the injustice of some structural determinants, such as 'poor social policies and programmes, unfair economic arrangements, and bad politics' (Commission on Social Determinants of Health 2008, p. 26).

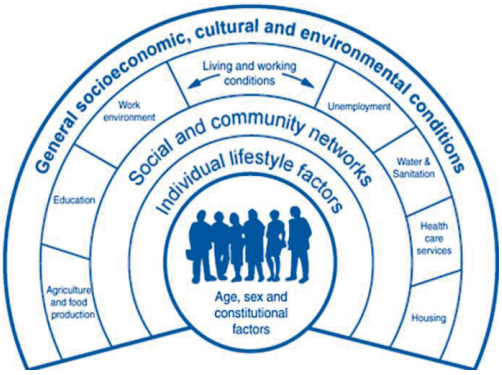

Figure 1.1 The main determinants of health
Source: Dahlgren & Whitehead (1991), p. 11.

The social determinants of health (SDH) are often argued as key factors causing health inequalities (Sage, 2017, p. 10). Defined by the World Health Organization (WHO, 2008), SDH are the conditions 'in which people are born, grow up, live, work and age, and the systems put in place to deal with illness.'[8] In real-life situations, SDH are not always the same but de facto shaped differently within and between countries due to a wide range of forces (Box 1.1) and the interactions between those forces.

Box 1.1 The solid facts (driving forces underlie SDH)
In the booklet, Social Determinants of Health: The Solid Facts (Richard Wilkinson and Michael Marmot eds., 2nd ed., 2003), ten solid facts that greatly impact SDH have been summarised: (1) the social gradient; (2) stress; (3) early life; (4) social exclusion; (5) work; (6) unemployment; (7) social support; (8) addiction; (9) food; (10) transport.

8 Retrieved from https://www.who.int/social_determinants/thecommission/finalreport/en/ (last accessed 24 March 2019). For more information on the social determinants of health, please refer to http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/ (last accessed 24 March 2019)

Uncovering these solid facts helps to develop a richer understanding of SDH and thereby suggests clear directions for addressing state accountability in healthcare (Marmot, 2005).

Health and human rights

Addressing state accountability plays a central role in the widely employed human rights-based approach to health (Potts & Hunt, 2008, p. 7; Yamin, 2008). According to this human rights-based approach, all health policies must integrate – or at least answer to – the principles of human rights (i.e. 'universal and inalienable', 'interdependent and indivisible', 'equal and non-discriminatory', and 'both rights and obligations').[9] The close relationship between health policies and human rights principles can be best justified by the treaties and instruments of international human rights law. Among these documents, Article 12 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR, Box 1.2) and its General Comment No. 14 clearly stipulate that 'States Parties to the present Covenant' should be assigned with prime duties in protecting and promoting the health of its citizens – namely, to respect, protect and fulfil the right to health in line with the AAAQ standards for its citizens.

In most cases, states have committed to achieving AAAQ standards through implementing policies on expanding accessibility (e.g. achieving the goal of universal health coverage) and improving the quality of healthcare (e.g. the goal of 'building high-quality and value-based service delivery'[10]). Some countries, such as Costa Rica, even adopt health rights litigation and let the Supreme Court play a key role in assuring more fairness in access to healthcare for people (Norheim & Wilson, 2014).

Box 1.2 Article 12 of ICESCR: The Right to Health

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

The steps to be taken by the State Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:

(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
(b) The improvement of all aspects of environmental and industrial hygiene;
(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

9 Retrieved from https://www.ohchr.org/EN/Issues/Pages/WhatareHumanRights.aspx (Last accessed 24 March 2019)

10 'Building high-quality and value-based service delivery' is the goal of deepening healthcare system reform in China. For detailed information, please refer to Healthy China: deepening health reform in China. Retrieved from http://www.wpro.who.int/china/publications/2016-health-reform-in-china/en/ (last accessed 24 March 2019).

Overall, studies either addressing personal responsibility or in favour of state accountability all seem to be plausible and have convincing arguments. However, I agree with what Martha Nussbaum once put, 'a good analysis will attend both to personal and to structural factors' (Nussbaum, 2011, p. xii). Thus, for the question concerned, the state should be assigned 'a certain degree of responsibility' (Schmidt, 2008, p. 200; Schmidt, 2016, p. 219) in securing the health of its citizens while citizens, in return, should also take personal responsibility seriously. Holding a similar standpoint, this thesis is designed to give equal weight to personal responsibility and state accountability in exploring the problem at stake.

1.3 SETTING THE CONTEXT: HEALTHCARE IN CHINA AT A GLANCE

1.3.1 General background

China is a populous nation with 1.379 billion people living in mainland China in 2016.[11] The average life expectancy at birth was 76.09 years in 2015, which showed a tremendous increase compared with 1949 (i.e. average 35 years).[12] As a rapid ageing nation, nearly 10% of the general population was older than 65 years in 2016 which is expected to increase to 18.2% by the year 2030.[13] Furthermore, the ratio of urban/rural residents changed from 1: 2.3 in 1993 to 1: 1.43 in 2016 along with urbanisation and industrialisation.[14]

The above factors and their interactions together contribute to a significant change of the disease spectrum in China: from communicable diseases to non-communicable diseases (NCDs). Data for 2012 demonstrate that cardiovascular diseases, diabetes, cancer, chronic respiratory diseases and other kinds of NCDs accounted for approximately 85% of all deaths and 70% of the total disease burden.[15] As a consequence, the Chinese healthcare system, especially the scope and content of health services and the method of delivery, needs to be reformed in order to meet the changing health needs.

1.3.2 The Chinese healthcare system

Generally, there are three essential dimensions of the Chinese healthcare system: delivery, financing and supervision (Meng et al., 2015, p. 14). In this section, these three dimensions will be briefly introduced through discussions on healthcare delivery system, health insurance schemes, and health governance and legislation.

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11 Data source from the World Bank, please refer to https://data.worldbank.org/indicator/sp.pop.totl?end=2016&name_desc=false&start=1960 (last accessed 24 March 2019).

12 Data source from the World Bank, please refer to https://data.worldbank.org/indicator/sp.dyn.le00.in?end=2015&start=1960 (last accessed 24 March 2019).

13 Please refer to http://www.sic.gov.cn/News/455/5900.htm (in Chinese, last accessed 24 March 2019).

14 Please refer to http://www.stats.gov.cn/tjsj/sjjd/201702/t20170228_1467357.html (in Chinese, last accessed 24 March 2019)

15 Ministry of Health, *China National Plan for NCD Prevention and Treatment (2012-2015)*, retrieved from http://www.chinacdc.cn/en/ne/201207/t20120725_64430.html (last accessed 24 March 2019).

Healthcare delivery system

In China, the healthcare delivery system has been established with a three-tier structure (Figure 1.2). Patients are allowed to choose from those medical institutions for healthcare (i.e. both outpatient and inpatient services) freely which means there is no mandatory gatekeeping in healthcare in China. Although lower level medical institutions are designed to undertake primary medical services (e.g. 'health education, prevention, rehabilitation, family planning, and treatments for common diseases'[16]) for people, they do not play a gatekeeping role in healthcare delivery in China (Meng et al., 2015, p. 203).

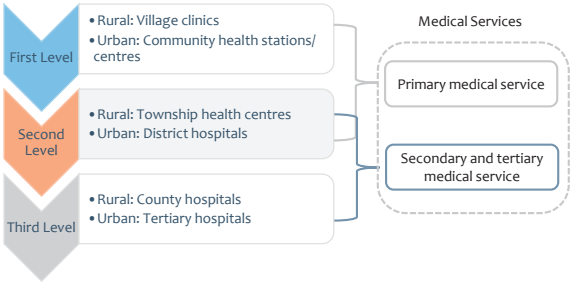

Figure 1.2 Three-tier structure and medical services on three levels
Source: Meng Q., Yang H., Chen W., Sun Q., & Liu X. (2015). People's Republic of China: health system review. *Health Systems in Transition*, *5*(7): 1-246. p. 133.

With regard to patient pathways, they are likely to choose medical institutions on lower levels as their first contact for diseases even though they are aware that the higher the level of the medical institution, the better facilities it will have. Furthermore, data show that there has been no big change in this preference from 2008 to 2013 (Figure 1.3).

However, medical institutions on the lower level, especially village clinics and community health stations, generally fall short of advanced medical facilities and qualified healthcare professionals. Such deficiency results in an awkward situation where healthcare services are indeed easy to access but the quality of services cannot be guaranteed. In some cases, patients have to go to higher level medical institutions for their unhealed diseases. Due to a poor referral system, patients often need to take certain medical tests for a second time in order to provide reliable information for doctors' new diagnosis. During that period, not only will patients suffer more from extra medical tests and aggravated diseases but also, they will have to pay a higher medical bill with out-of-pocket money. The weak primary medical services and the poor referral system generate far-reaching consequences for healthcare in China

16 Examples of primary medical services are summarized by Meng et al., 2015, p. 20. Retrieved from https://iris.wpro.who.int/bitstream/handle/10665.1/11408/9789290617280_;jsessionid=6F183D3886BA2F4E81B8A9996E64F036?sequence=1 (last accessed 24 March 2019)

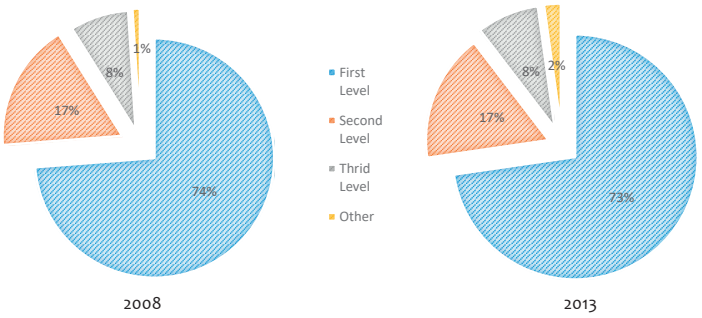

Figure 1.3 First contact medical service (2008 vs. 2013)
Source: Developed by the author with data from the 5th National Health Service Survey in 2013 (Centre for Health Statistics and Information, 2013 p. 39)

which are well expressed by a short phrase: '看病难，看病贵' (to see a doctor is difficult, to see a doctor is expensive).

Another issue that cannot be overlooked is the rapidly growing private sector in healthcare in China. By the end of 2016, the number of private medical institutions (PMIs) was increased to 16,432 which accounted for 56.39% of all medical institutions. Although the average size of PMIs is relatively small in China, they still took care of approximately 12.8% of total patient visits in 2016 (Meng et al., 2015, p. 112). The increasing involvement of the private sector in healthcare in China not only will make the healthcare delivery system more efficient, but it will also contribute to diversifying health services and thereby expanding the accessibility of medical services and protecting patient rights. Nevertheless, negative effects will also be generated if countries lack related advanced technical and administrative capacity (Roberts et al., 2008, p. 254).

Health insurance schemes

In China, health insurance schemes are roughly divided into social insurance schemes and private insurance schemes. Social insurance schemes include three basic types: Urban Employee Basic Medical Insurance (UEBMI), Urban Resident Basic Medical Insurance (URBMI), and New Rural Cooperative Medical Scheme (NRCMS). Easily observed from their names, enrolling in which insurance scheme is mainly based on the registered residence of people and their status of employment. Furthermore, UEBMI requires mandatory enrolment. URBMI, NRCMS and private insurance are voluntary insurance schemes. Contributions to social insurance schemes are designed differently in China. For example, UEBMI is relying on the employee and the employer; the contribution to URBMI is mainly made by individuals with limited government subsidies; NRCMS is financed by individuals, collectives and government (Meng et al., 2015, p. 86).

By the end of 2015, over 95% of the general population had been protected by one of these three social insurance schemes in China.[17] Staying over 95% coverage contributes greatly to protecting and promoting the right to health, especially in terms of expanding the accessibility of healthcare by making services affordable for patients in China.[18]

Nevertheless, difficult issues still exist, such as the reimbursement problem of seeking healthcare in places other than the patients' place of residence. For example, taking migrant workers,[19] they are rural residents but working in the urban areas of China. Due to their registered place of residence, they can only enrol in NRCMS which may limit their access to healthcare in their working places for two reasons: (1) NRCMS has a relatively lower benefit coverage than URBMI and UEBMI; (2) migrant workers have to go back to their place of residence to get reimbursement (Yu, 2015, p. 1149). Such reimbursement problems do not merely block migrate workers' access to healthcare; people who want to seek better healthcare in a place other than their place of residence will also have to face this difficult issue. In most cases they have no choice but to bear unaffordable, out-of-pocket medical costs, which ultimately bankrupts many families in China.

Health governance and legislation

In China, healthcare is governed by a complex set of policies, government agencies (central and local) and legislation.

On the state level, healthcare issues are mainly administrated by the National Health and Family Planning Commission (NHFPC) and the State Administration of Traditional Chinese Medicine (SATCM). On the provincial level, city level, and county/district level, these two governance bodies have their own affiliations to assume and fulfil their responsibilities (Meng et al., 2015, p. 21). Other departments of government, such as the Food and Drug Administration (FDA), the Ministry of Education (MOE), the Ministry of Finance (MOF), the Ministry of Human Resource and Social Security (MOHRSS), and the National Development and Reform Commission (NDRC), are assigned with their own responsibility in relation to healthcare (Meng et al., 2015, p. 21).

17 Please refer to http://www.mohrss.gov.cn/SYrlzyhshbzb/dongtaixinwen/buneiyaowen/201612/t20161214_261978.html (in Chinese, last accessed 24 March 2019)

18 World Bank Group, World Health Organization, Ministry of Finance, National Health and Family Planning Commission, Ministry of Human Resources and Social Security. (2016). *Deepening Health Reform in China: Building High-Quality and Value-Based Service Delivery*. p. xxvi. Please refer to https://openknowledge.worldbank.org/bitstream/handle/10986/24720/HealthReformInChina.pdf (Last accessed 24 March 2019)

19 In 2016, China had over 281 million migrant workers (National Bureau of Statistics, 2016). Data is available online, please refer to http://www.stats.gov.cn/tjsj/zxfb/201704/t20170428_1489334.html (in Chinese, last accessed 24 March 2019).

Table 1.2 Special health laws in China

Laws	Date of Issued and Effective	Concerns
Frontier Health and Quarantine Law (2009 Amendment)	Issued and Effective: 27/08/2009	Public Health
Law on Maternal and Infant Health Care	Issued: 27/10/1994; Effective: 27/08/2009	Women and Children
Law on Population and Family Planning (2015 Amendment)	Issued and Effective: 27/12/2015	Public Health and Reproductive Rights
Law on Prevention and Treatment of Infectious Diseases (2013 Amendment)	Issued and Effective: 29/06/2013	Public Health
Law on the Prevention and Control of Occupational Diseases (2011 Amendment)	Issued and Effective: 31/12/2011	Public Health and Occupational Health
Law on Traditional Chinese Medicine	Issued: 25/12/2016; Effective: 01/07/2017	TCM
Law on Practicing Doctors of the PRC (2009 Revision)	Issued and Effective: 6/26/1998	Medical Professionals
Law on Blood Donation	Issued: 29/12/1997; Effective: 01/10/1998	Public Health
Law on the Red Cross Society (2009 Amendment)	Issued and Effective 27/08/2009	Humanitarian and Public Health
Mental Health Law	Issued: 26/12/2012; Effective: 01/05/2013	Mental Health
Pharmaceutical Administration Law (2015 Amendment)	Issued and Effective: 24/04/2015	Drug

Source: Developed by the author with data from pkulaw, please refer to http://en.pkulaw.cn/

Similar to many other countries, China has not yet enacted an 'umbrella' health law (Meng et al., 2015, p. 18). Nevertheless, there were eleven special health laws in China by 2017 (Table 1.2). Besides these special health laws, other health-related legislations are stipulated in legal fields such as administrative law, contract law or even criminal law, which implies a characteristic of fragmentation of effective health-related legal rules. Lawmakers in China are now drafting an 'umbrella health law'[20] to connect the Constitution; eleven special health laws, and health-related legislations in other legal fields.

1.3.3 Other considerations

Other considerations, especially cultural and political contexts, have a particular relevance to healthcare because they demonstrate the uniqueness of healthcare in certain countries. Therefore, those cultural and political considerations cannot be downplayed or overlooked when studying the Chinese healthcare system.

20 The 'umbrella health law' is named as 'Basic Healthcare and Health Promotion Law of People's Republic of China'. It is still in its 'drafting, discussing, and revising' process. The first draft was discussed on December 2017 and the second draft was discussed on August 2018. For more information, please refer to http://www.npc.gov.cn/npc/lfzt/rlyw/node_33534.htm (in Chinese, last accessed 24 March 2019)

Confucian tradition and Chinese bioethics

Confucian ethical tradition attaches great importance to the virtue of '仁' (benevolence) and '孝' (filial piety).[21] From a Confucian viewpoint, the individual human being is incomplete without belonging to a family (Chen & Fan, 2010, p. 577). Confucian societies (e.g. Singapore and China) therefore value close family ties and attach great importance to the role of the family when drafting social policies (Wong et al., 2009, p. 53). To a large extent, this viewpoint decides the family-based character of the healthcare system in these societies, such as emphasising the role of the family in healthcare decision-making.

Decentralised reform on administrative system

Due to three waves of decentralisation reform in China (1958, 1970 and 1978), the administrative powers of central government have been gradually transferred to local governments and specific government agencies for the sake of maximising overall social welfare and satisfying the diverse sets of preferences of local people (Feng, 2016, pp. 13–14). As a consequence, health policies formed by central government are often enforced unevenly across local communities, which inevitably raises several concerns such as the vulnerability of local governments (e.g. local interest groups and private capital investment may greatly influence the autonomy of local governments in fully enforcing health policies) and the enhanced inequity in healthcare (Collins & Green, 1994, p. 465).

Household registration system

The household registration system (户口, *hukou*) has been in operation since 1949 for the administration of China's residents. People born legally in China acquire a personal registration card (*hukou* page) to be added to a household registration record (*hukou* booklet). The household registration record is issued per family; it thus certifies not only the legal residence of a citizen, but, more importantly, the relationships between family members. At the very beginning, the household registration record was designed to identify an individual as a permanent resident of a specific place, either rural (agricultural household registration record) or urban (non-agricultural household registration record). Therefore, it exerts a significant influence on access to social benefits, such as education and healthcare (Qiu, 2014, p. 113). However, the impacts of urban-rural differences regarding registered residence has been partially eliminated since the implementation of the Guiding Opinion of the State Council on Deepening the Reform of the Household Registration System in 2014.[22] Following the Guiding Opinion, the reform focused on the innovation of population management by abolishing classification of the agricultural and non-agricultural household registration records. The ongoing reform of the household registration system is believed to bring more fairness to the Chinese healthcare system.

21 For the English translation of those basic virtues of Confucianism, please refer to Runes (1983), p. 338.

22 The State Council (2014). Guiding Opinion of State Council on Deepening the Reform of the Household Registration System, para. 9. Please refer to http://www.gov.cn/zhengce/content/2014-07/30/content_8944.htm (in Chinese, last accessed 24 March 2019).

1.4 RESEARCH QUESTION AND SUBQUESTIONS

The general aim of this thesis is to develop proper strategies for balancing the protection of individual rights (e.g. satisfying patient needs) and the sustainability of healthcare resources in the context of Chinese healthcare system reforms. Special attention is given to drawing a fair 'cut' between personal responsibility and state accountability in order to make the reforms of the Chinese healthcare system more effective. Therefore, the central question of this thesis is designed as follows:

> ***In the context of Chinese healthcare system reforms, how should the conflict between the protection of individual rights (e.g. satisfying patient needs) and the sustainability of healthcare resources from ethical and legal perspectives be mitigated?***

In order to address and answer this central question, I formulate five subquestions that can be mainly categorised into two major dimensions (i.e. personal responsibility and structural injustice) and three concrete topics (i.e. patient empowerment, healthcare delivery model and a supportive environment). These five subquestions will be explored and answered respectively by five independent but interrelated papers which are also in Chapters 2–6 of this thesis. The first two subquestions are mainly framed from the perspective of addressing personal responsibility in healthcare in China, while questions 3 to 5 are framed with a special concern given to the role of the state in correcting structural injustice in healthcare in China.

Given that healthcare systems worldwide are currently experiencing more pressure posed by the ageing population and the increasing burden of non-communicable diseases (e.g. chronic diseases),[23] reform strategies (e.g. the WHO framework on integrated people-centred health services[24]) tend to suggest that policymakers should pay more attention to the role of personal responsibility in healthcare. Yet, what is personal responsibility in healthcare? How do we address personal responsibility properly to make healthcare reforms more effective in a given context? In order to address these concerns, the first two subquestions have been framed as follows:

> *Q 1. To what extent should personal responsibility be addressed in advancing the reform of the Chinese healthcare system?*

23 World Bank Group, World Health Organization, China's Ministry of Finance, National Health and Family Planning Commission, and Ministry of Human Resources and Social Security. Healthy China: deepening health reform in China, at xv–xvi. Please refer to http://www.wpro.who.int/china/publications/2016-health-reform-in-china/en/ (last accessed 24 March 2019).

24 For more information about integrated people-centered health services, please refer to http://www.who.int/servicedeliverysafety/areas/people-centred-care/en/ (last accessed 24 March 2019).

Q 2. How do we place patient personal responsibility fairly in healthcare in China to make the reform measures (i.e. measures derived from the people-centred integrated care (PCIC) model) more effective?

Before governments embark on any restructure of healthcare systems, especially implementing market-oriented reform measures, questions such as whether those new health measures would actually benefit people's health and whether they are formulated in line with existing priorities (e.g. the principle of solidarity and the goal of universal health coverage) need to be carefully addressed (Rosenblatt, 1981, p. 1067). In China, introducing GP services to strengthen primary healthcare is one of those measures. Therefore, the following question has been framed:

Q 3. Will the implementation of general practitioner (GP) services strengthen China's primary healthcare delivery and how do we structure regulatory interventions to secure the successful nationwide implementation of GP services?

For the sake of driving more efficiency in delivering healthcare and preventing the inherent coercion of certain public policies, market-oriented measures are gradually introduced to healthcare systems worldwide (Enthoven, 2002). Even countries with robust public healthcare systems (e.g. the Canadian healthcare system) tend to encourage more private sector involvement in healthcare. In China, despite the fact that the public sector (i.e. public hospitals) accounts for roughly 90% of health services, the private sector (i.e. both for-profit and not-for-profit medical institutions) have increased rapidly since 2009 along with achieving the goal of universal health coverage (Yip et al., 2012, p. 379). Nevertheless, promoting private sector involvement in healthcare shall not endanger other existing values, such as solidarity and universal health coverage (Cortez, 2011, p. 360). Therefore, the following question has been framed:

Q 4. To what extent does privatisation impact healthcare in China and how does the state fulfil its role in measuring the rapid growth of private medical institutions (especially using legal/regulatory measures) from a human rights perspective?

Preconditions for an effective nationwide implementation of new health policies should at least include a sound legal/regulatory framework (Sage, 2017, p. 19). Furthermore, adhering to the 'rule of law' requires using legislation to ensure the consistency and coherence of guidance on implementing policy priorities. In China, the 13th five-year plan for healthcare sets the integration of healthcare delivery and the consolidation of three health insurance schemes as reform priorities (Li & Fu, 2017). However, health law in China has a characteristic of fragmentation, which is not likely to conform with these integrated-oriented reform priorities and may ultimately create obstacles reducing the effectiveness of reform policies. From this concern, the following question has been framed:

Q 5. To what extent is the performance of the Chinese healthcare system tied to China's health law and how do we form a coherent health law that will best meet China's new health reform initiatives?

1.5 METHODOLOGY

This methodology section briefly outlines research materials and methods used by this thesis for exploring the central question and subquestions raised above.

1.5.1 Research materials

Research materials used by this thesis can be roughly categorised into three main kinds: legal texts, statistical data, and monographs and scientific literature.

Legal texts refer not merely to laws and regulations on local, national and international levels that are relevant to health and healthcare, but also include certain case law. A vast array of laws and regulations on the domestic level was searched for via pkulaw (北大法宝)[25] which is a database of Chinese law. With regard to the international level, relevant sources are, to a large extent, directly available online to the public (e.g. International Covenant on Economic, Cultural, and Social Rights (ICESCR), International Covenant on Civil and Political Rights (ICCPR)). A systematic but brief review of these legal texts was performed to ground the basis of one essential segment of this thesis (Chapter 6). For the sake of simplifying arguments, case law is also employed in certain parts of this thesis. Relevant materials are collected from searching the HUDOC database[26] which is published by the European Court of Human Rights and the case law of the European Court of Justice.

Materials such as statistical data are mainly second-hand data collected either by government bureaus (e.g. National Bureaus of Statistics of China, National Health and Family Planning Commission of the PRC) or by relevant intergovernmental organisations (e.g. the World Health Organization, the World Bank Group); that is, data published in government documents, white papers or other authorised project reports is included.

Reviewing classic monographs and relevant literature aims at formulating a theoretical framework to ground this research, to link the five independent studies and thereby support the consistency and coherence of this thesis. Relevant literature also includes grey literature, which refers to documents and guidelines launched by governments, reports produced by non-governmental organisations, conference proceedings, theses and news released by websites sponsored by professional institutions.

25 The pkulaw website is an online database, please refer to http://pkulaw.cn/

26 HUDOC database. Please refer to https://hudoc.echr.coe.int/eng# and the case-law of the European Court of Justice. Please refer to http://curia.europa.eu/juris/.

1.5.2 Research methods

Given that the research question at the heart of this thesis is essentially a question that is at the interface of disciplinary boundaries, research methods applied therefore have an interdisciplinary character. Specifically, the methods applied in this thesis mainly include theoretical analysis, historical analysis and classic legal analysis. In certain parts of this thesis, case study is also applied for the sake of simplifying specific arguments.

Employing theoretical analysis aims to address two fundamental issues that are not only relevant to the whole research but also essential to each individual study included: (1) to clarify terminologies and thereby define the scope of this research; (2) to explain the reasoning behind the research question and subquestions.

Historical analysis is conducted for this research. It is a method of discovering and examining past evidence and thereby helps to understand why things happened (Thorpe & Holt, 2008). Institutions like healthcare systems have their unique developing history, which could profoundly influence the subsequent performance of these institutions. Thus, examining historical evidence is of great importance, especially in terms of helping to develop a better understanding of the system design. Taking China's healthcare system for example, employing historical analysis will help to explain why its delivery system now has a three-tier structure. Furthermore, historical analysis can provide evidence and justification for explaining why certain old institutions prove to be incompatible with reality and need to be revised or even abolished, such as China's three basic healthcare insurance schemes. In addition, historical analysis is a meaningful method to evaluate past experience and thereby provide lessons for new developments.

In order to answer the final subquestion regarding the interactions between the performance of the Chinese healthcare system and China's health-related legislation, classic legal analysis is used to evaluate laws and regulations on both national and international levels that are effective in governing health and healthcare in China. The analysing process follows the IRAC framework, which consists of four sections: issue, rule, application and conclusion; that is, identifying the *issue* in concern, exploring the applicable legal *rules*, *applying* relevant legal rules to the facts of the issue, and drawing a *conclusion* (Miller & Charles, 2009, p. 193). The section of *application* also requires an explanation of the reason why certain legal rules are applicable or not applicable to the issue concerned. Furthermore, case study is also employed in answering this subquestion, because typical cases are useful to identify the *issue* concerned.

1.6 STRUCTURE OF THE THESIS

This thesis consists of seven chapters. Besides the introduction (Chapter 1) and the conclusion (Chapter 7), Chapters 2 to 6 are independent but interrelated papers, which are designed around the central research question (Figure 1.4). These five papers can be arranged into two

major perspectives (personal responsibility and structural injustice) and three specific themes (patient empowerment, healthcare delivery model and a supportive legal environment).

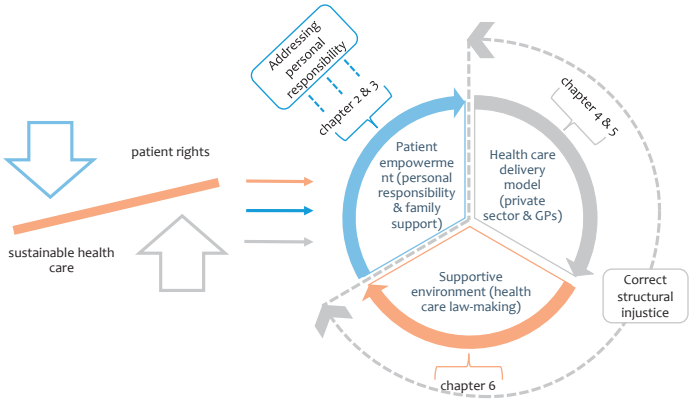

Figure 1.4 Structure of thesis

In the part of patient empowerment, I claim that personal responsibility is a plausible criterion in achieving distributive justice in healthcare (Chapter 2). Meanwhile, I argue that it is of great importance to involve family as a supplementary consideration to assist the implementation of the principle of personal responsibility in healthcare when taking the Chinese context (e.g. the Confucian tradition and the Chinese bioethics) into account (Chapter 3). Nevertheless, designing a healthcare delivery model is de facto setting the scope of 'choice architects'[27] for patients. Therefore, in the part considering the healthcare delivery model, I argue that the hospital-based healthcare delivery system needs to be reoriented. In this regard, I focus my attention on two evolving parties: the general practitioner (Chapter 4), and the private medical institutions (Chapter 5). The conditions under which patients are empowered to claim their denied but reasonable medical needs and the healthcare delivery system is structured and operated are of great importance. Therefore, a supportive environment, especially a sound legal framework, is in great need. To respond to this concern, I briefly review all health-related laws and regulations on both national and international levels, draw lessons from representative theoretical debate on the coherence of health law, and thereby make corresponding recommendations (Chapter 6).

27 'Choice architects' is a concept formulated by Richard Thaler and Cass Sunstein. It refers to an organised context in which people are able to make better choices. For detailed explanations, please refer to Thaler & Sunstein, (2003, 2008); Sunstein & Thaler, (2003).

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