Summary

Introduction
Stigma plays a role in a variety of diseases and conditions. Many people with a disease or condition which is stigmatized are challenged in two ways. On the one hand, they experience the symptoms and impairments that result from the disease and possible side-effects of treatment. On the other hand, they are challenged by the stereotypes and prejudices of themselves and of others that result from conceptions of the disease or condition. These stereotypes and prejudices form the foundations for discrimination, social exclusion and self-isolation. As a result, people affected by the disease or condition have fewer opportunities in terms of education, employment, marriage, family life, religion, housing and health care than those who do not have a stigmatized condition living in similar conditions and with similar capabilities.

Leprosy is often seen as the archetype of a stigmatized health condition. Despite major achievements in the control and management of leprosy, it remains an important public health issue. In 2014, India reported the highest number of new cases (125,785) followed by Brazil (31,064) and Indonesia (17,025). Although manifestations, including social exclusion and discrimination, are nowadays more subtle and involve less ostracism, stigma is still manifest. The impact of leprosy-related stigma varies between individuals and ranges from minor implications to devastating consequences (e.g. divorce, suicide, loss of income). Manifestations of stigma differ, often depending on the severity of impairments, gender, social status and age. People associated with a person affected by leprosy, for instance family members and friends, might also be stigmatized. Given the implications for themselves and their family and friends, people affected by leprosy often try to conceal their disease which poses an additional burden.

There is a growing awareness among health professionals and researchers of the importance of stigma-reduction interventions. Research has been undertaken on stigma-reduction in the field of mental health, epilepsy and HIV/AIDS but only a few studies have focused on leprosy. From the different stigma-reduction interventions described and studied, three are considered promising: counselling, contact and socio-economic development. Empowerment plays a role in each of these interventions. The effect of these three interventions in the field of leprosy is largely unknown. The overall aim of this thesis is to enhance the understanding of leprosy-related stigma and assess the effect of stigma-reduction interventions. This understanding will inform recommendations for stigma-reduction strategies that address the needs and strengths of people, and that are effective and sustainable. It will also further the body of knowledge on stigma-reduction in general.

Theories
Conceptualizations of health-related stigma have been developed over time by scholars from different scientific disciplines (e.g. psychology, psychiatry, public health, sociology, anthropology) and for specific health conditions. Important critiques are the individual focus of many conceptualizations and the fact that they
ignore the lived experiences of stigmatized persons. Health-related stigma is defined in this thesis as:

A social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group [identified with a particular health problem]. (Weiss 2006:280)

Scholars have defined different types of stigma (e.g. internalized stigma, perceived stigma, enacted stigma), different levels at which stigma operates (e.g. structural, social and individual) and different components of stigma (e.g. labelling, stereotyping, separation, status loss and discrimination). These different types, levels and components are interrelated. Several scholars have highlighted the importance of context (the everyday lives, history and culture) for the conceptualization of stigma. Another fundamental dimension of stigma concerns the degree to which the disease or condition can be concealed and whether disclosure is voluntary or involuntary. Scholars have stated that people living with a stigmatized disease or condition are sometimes portrayed as an object, as passive or as victims, whereas, in reality, such persons do make active responses to their stigmatization. Agency is thus an important concept when studying stigmatized relationships. Not surprisingly, stigma is generally perceived as a complex and persistent problem.

The conceptualization of stigma as a complex and persistent problem has implications for the assessment of stigma. How stigma is understood influences the way stigma is assessed and the capacity to assess stigma, in turn, influences how stigma is understood. Scholars argue that it is essential to obtain perspectives from multiple participants and use multiple methods in order to understand how leprosy-related stigma affects the lives of people affected or associated with the disease. Currently, quantitative methods are more frequently used to assess stigma than qualitative methods. Options for quantitative methods include scales, several of which have been developed. Qualitative and quantitative methods need to be culturally validated before they can be applied in a certain study context.

Evidence suggests that stigma-reduction interventions can reduce stigma but stigma-reduction theory is not yet well developed. Based on several theories, I hypothesize first that understanding leprosy-related stigma in the local context is important. In efforts to reduce stigma, the perceptions, ideas and opinions of a diversity of local stakeholders should be the starting point. Different worldviews and mind-sets need to be made explicit in order to appreciate and address the complexities of stigma. Second, I hypothesize that a stigma-reduction approach must address the fundamental causes of stigma. These include a fear of transmission and religious or cultural beliefs about causations. Finally, I hypothesize that multi-level (e.g. intrapersonal, interpersonal, community) and multi-faceted approaches are essential for stigma-reduction interventions. If these are not in place, positive outcomes might erode over time.
Summary

Research design
The main research question that guides this thesis is:

How can leprosy-related stigma be understood and addressed in an appropriate, effective and sustainable manner and the body of knowledge on stigma reduction be advanced?

The main research question is further specified in five sub-questions:
1. How is leprosy understood and what are the experiences with leprosy of persons affected and not affected by the disease in Cirebon District, Indonesia?
2. How are different mindsets influencing the execution of a transdisciplinary stigma-reduction project?
3. What insights can be gained from the implementation of the leprosy-related stigma-reduction interventions in Cirebon District, Indonesia?
4. What is the cultural validity of the Social Distance Scale (SDS) and Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) in Cirebon District, Indonesia?
5. What is the effect of a contact intervention on leprosy-related stigma in Cirebon District, Indonesia?

The research described in this thesis is part of the Stigma Assessment and Reduction of Impact (SARI) project that ran from 2010 to 2015. An intervention study using a transdisciplinary approach was applied. With this Interactive Learning and Action (ILA) approach, a broad diversity of views in the context are taken into account and the knowledge of diverse actors is integrated.

Cirebon District in West Java was selected as the area of research and project implementation. It has a relatively high number of new leprosy cases annually and – according to local experts – more leprosy-related stigma than in other districts. Administratively, the district consists of 40 kecamatan (sub-districts) which were allocated to be either an exploratory study area (10 kecamatan) or intervention/ control area (30 kecamatan). The 30 sub-districts of the intervention/ control area were randomly allocated a paired intervention or became control (‘care as usual’) areas. The main study population are people affected by leprosy and community members in Cirebon District. Community members include key persons such as health professionals, teachers, religious leaders and community leaders.

The SARI project follows the five phases of the ILA approach: exploratory phase, in-depth phase, integration phase, prioritization and action planning phase, implementation phase. Since the SARI project aimed to measure the effect of the interventions, a baseline and final survey were organized. The instruments for the baseline and final survey were tested during the pilot and validation study before the start of the baseline. Research assistants from the local area were hired and trained, and became part of the
SARI team. Six of SARI’s researchers and research assistants are persons with disabilities or affected by leprosy.

A range of both qualitative and quantitative research methods have been applied in this study. Methods include in-depth interviews, focus group discussions, personal reflections, notes of meetings, semi-structured interviews, stigma scales, such as the EMIC-CSS and SDS, notes of counselling sessions and so on. The number of respondents varies per phase. For example, during the in-depth phase, 53 in-depth interviews and 17 focus group discussions were organised with a diversity of stakeholders. To assess the impact of the contact intervention on community members, the baseline was conducted with 49 semi-structured interviews and 259 scale interviews. The final survey comprised 3 focus group discussions and 375 scale interviews. Multiple strategies such as triangulation and member checking were used to enhance the validity of the data. Ethical issues, such as confidentiality and dealing with emotions that might arise during interviews, were considered.

Part 1 Understanding for the design of stigma-reduction interventions

The study in Chapter 4 provides insights into the experiences of persons affected by leprosy and the meaning they and key persons in Cirebon District ascribe to leprosy, highlighting aspects of aetiology, treatment, side-effects and spirituality. Leprosy is understood in different and sometimes contradictory ways by the research participants and these understandings influence personal attitudes and behaviours towards leprosy. Experiences like discrimination, exclusion and devaluation may be relevant for some persons affected but not for others. The negative impact of the disease tends to decline over time, but some persons affected – also those without impairments or visible signs – continue to suffer long after having been cured. In addition, the impact of the disease on the person affected and the attitudes of those not affected intersect with other aspects of a person’s identity (e.g. gender, age or socio-economic status). Understanding the whole spectrum of perceptions and associations with the disease is important for understanding attitudes and behaviour towards leprosy.

The study in Chapter 5 focuses on the experiences of women affected by leprosy, considering whether they concealed or disclosed their status, and looking specifically at their agency. Concealment is a direct effect of the anticipation of stigma. The extent to which leprosy is concealed or disclosed – voluntary or involuntary – varied. Most often ‘significant others’, such as spouses, knew but some women did not inform anyone. Disclosure creates the opportunity for care but may also result in negative experiences. Concealment prevents both, but concealment needs to be managed and the burden is then carried alone. Furthermore, how people respond to leprosy and stigma was an important variable in the analysis of women. Openly acting against existing power structures and focusing on achievements helped the women in this study. Three sources of agency were identified: spirituality or religion, relationships and goal or hope of being cured. This study highlights that current stigma theories can provide a valid and helpful
Summary

perspective but that there is also the risk of missing out on a wealth of other more positive social and psychological experiences of leprosy that could provide a basis for reducing stigma.

The SARI project is an example of transdisciplinary research. From the start, scientific and social stakeholders, such as staff from a national disabled people organisation, health professionals from the community health clinics and persons affected by leprosy, met and co-operated to address the complex and persistent problem of stigma. The study in Chapter 6 analyses the mindsets of stakeholders who were involved during the implementation of the interventions. The study was able to identify differences in attitudes to scientific validity and ethics of research, different expectations in terms of interventions and timing, conflicting intrinsic models of disability, and diverse attitudes to people affected by leprosy. Diversity is desired and intentionally sought in transdisciplinary research but can also lead to serious challenges, for example, decisions regarding the study design, timing and approaches. By making mindsets explicit, this study tried to increase insights into how to deal with the differences that could potentially lead to problems. Acknowledgement of power dynamics was found to be important and relationships needed to be established, taking time, flexibility and commitment of those involved.

Part 2 Understanding and assessing the effects of stigma reduction interventions

Chapter 7 portrays the initial experiences with counselling as a stigma-reduction approach based on the perspectives of lay and peer counsellors. The involvement of people affected by leprosy was one of the strengths of this intervention. People affected by leprosy as peer counsellors felt a high level of responsibility towards their peers, were keen to share their newly acquired knowledge and were trusted by their clients. Although participation was overall a strength, it also generated some challenges. Sharing knowledge about leprosy with clients was an important task of the lay and peer counsellors in this study but some peer counsellors were overly keen to share their knowledge and experience and failed to listen to the clients. Another challenge related to the wish to conceal the illness. Fear of disclosure was an important reason for people affected by leprosy to reject counselling. Observing and analysing the different steps of the lay and peer counselling process showed the potential of and barriers to this approach. The study concludes that lay and peer counselling holds much promise and highlights barriers that need be addressed for it to become an effective and appropriate leprosy-related stigma reduction strategy.

Chapter 8 provides insights into another stigma-reduction strategy: participatory video. It centres on the impact of participatory video on the video makers who are affected by leprosy and increases understanding of how to deal with foreseeable difficulties. The analyses show that participatory video provided a variety of opportunities for the participants who benefitted in different ways. The diversity of impacts made it difficult to pinpoint what exactly contributed to reduced stigma and for whom. In total, 11 factors
were identified through which participatory video contributed to a reduction of stigma, including sense of togetherness, knowledge and increased self-esteem. The study increased an understanding of the challenges. Some participants’ hand impairments posed challenges to operating the devices. A more important challenge was addressing participants’ wishes for concealment: screening the video in their own village was a step too far for some participants. This had implications for the distribution of the video. Provided that these and other challenges are taken into account, participatory video has the potential to address stigma at three levels – intrapersonal, interpersonal and community.

The effect of the stigma-reduction interventions on the community also needed to be evaluated. Chapter 9 describes the cross-cultural validation of two instruments to assess aspects of social stigma: the EMIC-CSS and SDS. The findings demonstrated that, according to current international standards, the EMIC-CSS and SDS have adequate validity to assess social stigma of leprosy in the Bahasa Indonesia-speaking population in Cirebon District. This is promising but there were also two important reservations. First, despite the validity of the current instruments, several suggestions for improvement were made. Second, data collection can create discomfort or concerns among the interviewees. This needs to be prevented or addressed, for example, by a comprehensive training of the interviewers. Hence, continued effort needs to be put into the development of scales and guidelines for their proper use.

After designing the three stigma-reduction interventions and implementing them for two years in Cirebon District, the impact of all interventions was assessed. The effect of the contact intervention is described in Chapter 10. The primary aim of this intervention was to reduce stigma at the community level. The contact intervention of the SARI project consisted of contact events in which an interactive presentation on leprosy was provided, a testimony was given, videos were broadcasted and discussed, and take-home comics were distributed and discussed. A secondary aim was to empower people affected by leprosy through activities related to the intervention. These activities included making videos and comics. In total, 91 contact events were organized in 62 villages, directly reaching about 4,400 community members (mean 49 per event). The intervention was shown to be effective in increasing knowledge about leprosy and in changing attitudes towards leprosy to become more positive. A large impact was seen in community members who attended the contact events. They were encouraged to share the messages of the event with others and about 80% indicated in the final survey that they had done this. Some of the surveyed participants had disseminated the newly acquired knowledge to 50 –100 community members. Some data on knowledge and attitudes was collected immediately after the contact events and some up to 20 months after the event, indicating there is a longer term impact of the intervention. Some findings suggested that the level of knowledge remained stable, while the improvement in attitudes reduced moderately over time. A few changes in behaviour due to the contact events were also reported. Overall, the contact intervention had a positive
effect on several proxies of stigma, making it an effective and thus promising stigma-reduction intervention.

Discussion and conclusion
Toward the end of this thesis, I conclude that understanding leprosy-related stigma in the local context, addressing the causes of stigma and implementing multi-level and multi-faceted approaches are essential for stigma-reduction interventions. Analysis of the context and the understanding of the complexity and persistency of stigma elucidate and specify the pathways that can be followed to reduce stigma.

In other words, the complexity and persistence that are at the core of the stigma problem also provide the seeds and resources for dealing with it. In the discussion, I provide four insights on how to take into account the complexities and persistence of stigma. The first approach is that designing, implementing and assessing stigma-reduction interventions starts with working with people who know the local context and have a thorough understanding of stigma, including its causes and consequences. In the SARI's case, research assistants including people affected by leprosy and disabled people were hired. Involving the right people and creating an environment in which they can learn and reflect is key to reducing stigma. The second approach is the exploration of the local context by focusing on perceptions, needs and strengths of people affected by leprosy and other stakeholders. In the SARI project, we incorporated the findings of the exploratory study in the design of the stigma-reduction interventions. Third, counselling, contact and socio-economic development interventions as paired interventions were unmistakably multi-level and multi-faceted approaches. Interestingly, single elements of the SARI interventions, such as the participatory video activity, have also shown the potential to address multiple levels and multiple facets of stigma. This is valuable for two reasons. If stigma-reduction interventions address only one mechanism, it is likely that the effect erodes with time because other mechanisms remain in force. But equally important, the participants can benefit according to their own personal needs which differ substantially between participants. Fourth, the space that is created because of the reduction of stigma should be replaced with something new. Stigma-reduction interventions that aim to reduce exclusion should, at the same time, cultivate inclusion.

These attitudes and behaviours can be described as affirming attitudes and affirmative actions. This thesis contributes to stigma theory in several ways. First, experiences of stigma and its consequences might indeed be remarkably similar for different health conditions and across cultures and countries, this study confirms that individual understandings and experiences differ considerably. Second, this study identifies three themes in stigma theory that lack sufficient attention and contributed to each of these: concealment, capacity to act and contradictory experiences. Third, a transdisciplinary approach is expected to be beneficial also in other settings and for other objectives in the future. Through analysis of mindsets, projects that adopt a transdisciplinary
“I am not shy... so I don’t have leprosy, right?”

approach can develop a greater understanding of the anticipated nature and diversity of mindsets. The experience of the SARI project shows that a new transdisciplinary stigma-reduction project needs to incorporate: awareness of power dynamics; the development of relationships within a team and with the stakeholders; and appropriate structures for learning and reflection.

I conclude that the complexity and persistence of stigma that make stigma-reduction efforts difficult also create opportunities. Due to the complexity, there is a wealth of issues that can be addressed and due to the persistence, there are several feedback loops that can reinforce positive changes. In every context that is properly understood, the issues and feedback loops that need to be addressed can be illuminated. Thus, the complexity and persistence of stigma should be understood and can, through the opportunities this creates, be used for the better.