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# PRESENTATION OF THE STUDY LIVES\_SHPHEALTH ON EXPERIENCES AFTER PSYCHOLOGICAL AND PHYSICAL HEALTH PROBLEMS

## A CROSS-SECTIONAL STUDY WITHIN A LONGITUDINAL PANEL-SURVEY

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## Abstract

**Background.** In Switzerland, recovery-oriented mental health research collecting non-clinical population data remains scarce. People experiencing psychological health problems (HPs) are more likely to be stigmatised than people experiencing physical HPs. Here, we present a study in which participants of the Swiss Household Panel (SHP) were contacted for an auto-administered questionnaire survey in order to report on the impact that psychological or physical HPs had on their identity, experiences of stigmatisation, subjective state of recovery as well as positive and negative consequences for various aspects of their lives. This report describes the study aims, procedure, measures, sample selection and response analyses, sample composition and health characteristics.

**Methods.** 1426 persons were selected based on their health reports in the SHP, 713 for a psychological and 713 for a physical HP. We analysed the impact of the selection and the response process on sociodemographic characteristics and on psychosocial variables (social integration and mental health indicators). We also investigated mode (online versus paper-pencil) effects. Differences between groups were analysed using Chi-Square and t-tests.

**Results.** The response rate was 60.17%; 47.83% of the data could be used for analyses. There were slight mode effects, especially regarding sociodemographic variables. Respondents, in comparison to non-respondents, showed higher levels of education, social trust, and satisfaction in several domains. Finally, we obtained a heterogeneous convenience sample from the German and French speaking parts of the Swiss population that had experienced past or ongoing health problems. Women, individuals with high educational levels, Swiss nationals, and individuals living in the French-speaking part were overrepresented. The principal HPs reported were the most frequent and burdensome for the Swiss population, mainly depression, burnout, anxiety, orthopaedic problems, allergies and cardiac problems. Most participants had received treatment for their HP and had experienced it already for some years.

**Conclusion.** Using these data enables to analyse the impact of frequent and burdensome psychological and physical HPs on people's lives in a heterogeneous convenience sample that has already had some time to deal with their HPs. Future research should try to reach more socially isolated individuals, stigmatised illness groups and individuals without treatment.

## Keywords

**Swiss Household Panel | survey design | health | mental health | health survey**

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## 1. Introduction

Every second person in Switzerland will experience a psychological health problem (HP)<sup>1</sup> that needs treatment during his or her life (Ajdacic-Gross & Graf, 2003), for example major depression, anxiety or addiction disorders. The new century has brought the international and formal acknowledgement that “there can be no health without mental health” (Prince et al., 2007, p. 859). It has been shown that the personal, social and economic burden of mental illness is exacerbated by the impact of stigmatisation (Vigo, Thornicroft, & Atun, 2016). In line with a mental health action plan up to the year 2020 by the World Health Organisation (World Health Organisation, 2013), the Swiss government has recently defined four fields of intervention: The information and raising of awareness in the population along with destigmatisation campaigns; the fostering of prevention and early identification of mental HPs; improving existing databases and scientific communication; and ameliorating structures and networks along with financial resources (OFSP, 2016, p.4). These aims address a need for more research and a better understanding of mental HPs in Switzerland. Indeed, there is a lack of detailed information on the lived reality of psychological HPs, and a lack of Swiss-wide non-clinical research investigating how people perceive their mental HPs, their state of recovery as well as their ability to deal with the illnesses with which they are confronted.

In this research report we would like to present a survey that we conducted in order to address this research need. We selected persons that participate regularly in the Swiss Household Panel (SHP; FORS, Swiss Centre of Expertise in the Social Sciences; Tillmann et al., 2016) based on their health reports and contacted them for an additional auto-administered questionnaire survey (LIVES\_SHPHealth). The study had three aims: First, we wanted to identify psychosocial and identity-related variables that foster adversarial growth after psychological HPs, that is, factors that predict the experience of positive changes from these stressful life periods (cf., Linley & Joseph, 2004; Tedeschi & Calhoun, 1996). The second aim was to investigate the conditions under which persons living with psychological HPs can experience subjective recovery. Complementary to medical models, subjective recovery refers to a personal perception of one’s state of recovery and means that one is able to live a satisfying life and develop a positive identity in the face of the illness (Andresen, Oades, & Caputi, 2003; Anthony, 1993; Corrigan, Giffort, Rashid, Leary, & Okeke, 1999; for Swiss publications see for example Bonsack, Morandi, Favrod, & Conus, 2013; Rössler, 2013). Third, we wanted to

contrast the results that we had obtained in line with the first two aims with analyses concerning less stigmatising illness conditions, that is, experiences of persons living with *physical* HPs.

We will now outline why it is relevant to conduct this survey in Switzerland by describing the Swiss context and the available datasets. Afterwards, we will explain the selection process and analyse the selectivity of the sample that we contacted for LIVES\_SHPHealth according to sociodemographic and psychosocial characteristics (i.e., indicators for social integration and mental health, see Section 2.1). Then, we will describe the procedure of the LIVES\_SHPHealth auto-administered questionnaire study and the measures used (see Section 2.2). Last, we will analyse the selectivity of our response sample (see Section 2.3) and present the sociodemographic and psychosocial characteristics of our final study participants as well as information on the HPs they provided information on (see Section 2.4).

### *The Swiss context*

As we will outline in the following, psychological HPs are very common and represent a significant burden, but their personal, social and economic impact is exacerbated because of stigmatisation. Regarding the prevalence of mental disorders in Switzerland, almost every person will either directly experience a psychological HP or be in contact with someone who is concerned. For affective disorders (mostly major depression), lifetime prevalence is 20-25%, for anxiety disorders 14-27%, and for substance abuse disorders 24% (Ajdacic-Gross & Graf, 2003). In one year, the probability that a person living in Switzerland will experience a psychological HP is estimated to be between 17% and 24% (Jäger, Sobocki, & Rössler, 2008)<sup>2</sup>; the most frequent incidences are anxiety disorders (1,054,000 [13.4% of the Swiss population]), followed by affective disorders (506,000 [6.43% of the Swiss population]), somatoform disorders (311,000 [3.95% of the Swiss population]), addiction disorders (236,000 [3% of the Swiss population]), dementia (124,000 [1.58% of the Swiss population]), child/adolescent disorders (90,000 [1.14% of the Swiss population]), psychotic disorders (76,000 [0.97% of the Swiss population]), personality disorders (66,000 [0.84% of the Swiss population]), and eating disorders (23,000 [0.29% of the Swiss population]). If one includes neurological and brain disorders, headaches are very frequent (2,360,000 [29.99% of the Swiss population]), sleep disorders (683,000 [8.68% of the Swiss population]), stroke (71,000 [0.90% of the Swiss population]), traumatic brain injury (57,000 [0.72% of the Swiss population]), epilepsy (38,000 [0.48% of the Swiss population]), Parkinson's disease (18,000 [0.23% of the

Swiss population]), and multiple sclerosis (8,000 [0.10% of the Swiss population]; Maercker et al., 2013)<sup>3</sup>.

Mental HPs are a significant economic burden as they take 17% of the Swiss general health system costs. Affective disorders are the most costly, followed by psychotic disorders, dementia, anxiety disorders and substance abuse disorders (Maercker et al., 2013). Additional indirect costs are estimated to be 3-4% of the Swiss GDP due to lost productivity and sick leave (Jäger et al., 2008). Due to indirect costs, affective disorders end up costing 1.5 times the direct medical costs; in anxiety disorders, the total cost due to indirect costs ends up being one third times the direct medical costs more (Maercker et al., 2013). Moreover, the burden might be even underestimated because research so far has not paid enough attention to the multimorbidity of mental illness, that is, its interaction with physical health (Prince et al., 2007) and other psychological HPs (Barnett et al., 2012).

The treatment of persons with mental illness is confronted with one principal impeding factor: the likely stigmatisation of persons who have a psychological HP. First, there is not enough knowledge about psychological disorders in the Swiss population, which means that mental disorders are not recognized. For example, in one Swiss-wide study, only 40% of the population classified a vignette describing a person with prototype-illness symptoms correctly as depression, 60% thought the depicted person was only having a crisis (Lauber, Nordt, Falcato, & Rössler, 2003). Second, surveys questioning the general population of Switzerland point to discriminatory attitudes and behaviours towards persons with mental illness. When a random sample of the Swiss residential population was questioned on their potential behaviour towards an individual with depression or schizophrenia, only 65% indicated they would be willing to start to work with the depicted person (Lauber et al., 2004). When questions concerned behavioural actions going along with higher social closeness, respondents were more strongly inclined to take distance from persons with psychological HPs: Only 41.1% were willing to make friends with a person with mental illness, around 30% were willing to rent a room for or recommend the person for a job, and only 18.7% were willing to let the person take care of their child. In another Swiss-wide survey that was conducted for an anti-stigma campaign in the canton of Zug, only 43% of the 672 respondents believed in the fact that every second person in Switzerland experiences a psychological HP; 68% did not know that they were allowed to visit persons with mental illness in psychiatric hospitals, and only one third said they would visit their friends or relatives in a psychiatric hospital (Werner Alfred Selo

Stiftung, 2013). 60% stated that persons with psychological HPs were discriminated against at work.

There is some evidence that stigmatising attitudes are not equally distributed in the different language regions in Switzerland. When measuring whether the general population accepted restrictions on mentally ill people, these were more strongly enforced in the French- and Italian-speaking parts compared to the German-speaking part of Switzerland. For example, whereas in the German-speaking part, 59.5% of survey respondents agreed to take away the driver's licence and 18.7% the right to vote from a person with mental illness, in the French-speaking part, these values were 68.5% and 35.4%, respectively (Lauber, Nordt, Sartorius, Falcato, & Rössler, 2000). Also, there were indications that in the French-speaking in contrast to the German-speaking part persons with mental illness were more frequently perceived as a burden to society (53% vs. 32%) and more frequently perceived as discriminated against in the private context (40% vs. 26%; Werner Alfred Selo Stiftung, 2013).

This evidence together underlines a lack of knowledge, stigmatising attitudes and discriminative behavioural intentions towards persons with mental illness. The stigmatising attitudes of the general population are problematic as a direct link has been established between those attitudes and higher self-stigma, that is, they are related to a higher possibility that persons with mental illness accept the negative stereotypes about them (Evans-Lacko, Brohan, Mojtabai, & Thornicroft, 2012). Because of self-stigma and the fear to experience discrimination, individuals with a psychological HP are likely to avoid looking for help or treatment (Schomerus & Angermeyer, 2008; Thornicroft, 2008). Indeed, taking the example of depression, only one out of two (Baer, Schuler, Füglistner-Dousse, & Moreau-Gruet, 2013) or one out of three (Rüesch, Bänziger, & Juvalta, 2013) concerned persons living in Switzerland receive treatment. One recent representative survey with the general population aged between 16 and 40 in the canton of Bern has shown that persons who had a psychological non-psychotic HP (e.g., affective disorders, anxiety disorders) only looked for help when the illness already caused social and occupational impairment (Michel et al., 2018).

In one survey, 90% of the respondents indicated they would talk about a psychological HP to their family, whereas only 58% would address a psychiatrist, and 43% a psychologist (Werner Alfred Selo Stiftung, 2013). Only 25% would tell their employer and 11% their work colleagues. This fear to disclose the HP was again stronger in the French part of Switzerland.

Hence, because of the likely stigmatisation, persons with mental illness wait longer before they look for help and treatment. Self-stigma as well as experiences of discrimination impact the recovery process negatively. They exacerbate not only the personal burden of mental illness, but also the burden for the social environment of the concerned persons as well the burden for society including direct (e.g., health system) and indirect (e.g., work-related) economic costs. Both in order to increase research knowledge, but also in order to provide information for anti-stigma campaigns and treatment interventions, it seems important to explore under which conditions persons living with a mental HP can experience adversarial growth from their HPs and high levels of subjective recovery.

In order to know whether our analyses of processes of adversarial growth and recovery are specific to mental HPs and the stigmatisation of persons that experience these, it seems furthermore important to contrast perceptions of persons regarding a psychological HP with reports on *physical* HPs. In contrast to *psychological* HPs, persons with *physical* HPs are on average less likely to experience stigmatisation. For example, when employers of small and middle-size companies in the canton of Basel were asked to rank several job candidates, they chose as first candidate a rather lazy, unreliable employee that was in good health (Baer, 2007). They ranked second persons with a *physical* chronic health condition, and last persons with a *psychological* health condition, even if all candidates with HPs were described as well qualified, 100% able to work and in stable health through medication. Another study compared the development of the social networks of persons who had an accident or *physical* health condition and of persons that reported a *psychological* health condition (Bachmann, Burla & Kohler, 2015). Only in the psychological health condition, the social network started to decrease one year after the onset of the illness. Here, people mentioned before the onset an average of 23.3 persons in their social network. After five years, this had decreased to 15.5 persons. In the other health conditions, in the year after the onset the network size was the same as before the onset of the HP and remained stable over time.<sup>4</sup>

### *Swiss datasets*

Therefore, it seems important to investigate how persons of the general population who have experienced or are experiencing a psychological HP in contrast to persons who have experienced a physical HP perceive the impact of the illness on their lives, along with stigmatisation, identity, adversarial growth and recovery variables. Yet, there are no Swiss-

wide non-clinical datasets available that one could use to investigate these subjective perceptions. Besides medical registers, which comprise objective health statistics and clinical studies, there are three main Swiss-wide surveys:

The Swiss Health Survey (Federal Statistical Office, 2013) is conducted only every five years, and, whereas a comprehensive list of chronic physical diseases is assessed, questions on psychological HPs focus mainly on depression. There are almost no questions on perceived consequences on people's lives and their subjective recovery.

The Survey of Health, Ageing and Retirement in Europe (SHARE; <http://www.share-project.org/>) assesses a variety of health and quality of life indicators; however, it is conducted only every two years and individuals have to be at least 50 years old. Furthermore, here, too, only a few psychological disorders are assessed.

A representative survey, which assesses a broad range of sociological, psychological and health-related variables every year, is the Swiss Household Panel (SHP; FORS, Swiss Centre of Expertise in the Social Sciences; Tillmann et al., 2016). This survey provides a very good basis to investigate the interactions of health issues and subjective perceptions of one's life conditions (for recent studies that use indicators of mental health and wellbeing, see for example Schuler & Burla, 2012; Cullati, Courvoisier, & Burton-Jeangros, 2014). When the current research project was planned, the SHP held data from 1999-2016. Data are collected yearly using Computer-Assisted-Telephone-Interviewing (CATI). Initially there were 5,074 participating households with 12,931 household members (SHP I). There were 2,538 households (6,569 individuals) added in 2004 (SHP II) and another 4,093 households (9,945 individuals) in 2013 (SHP III). Participants were selected based on a stratified random sample of Swiss private households. They can be considered as a representative sample of private households in all regions of Switzerland with a likely underrepresentation of households having recently migrated to Switzerland (Tillmann et al., 2013). Yearly dropouts on an individual level are between 2% and 10% (with some exceptions for specific waves, see Voorpostel et al., 2016), but have been decreasing or stable during recent waves.

As the SHP survey has not been constructed to focus on health issues, important information is missing: Physical and mental illnesses are assessed in one broad category each ("physical" or "psychological" HP). This does not allow the assessment of specific illness types. Furthermore, only one episodic and one chronic HP can be reported per year, which does not allow for the investigation of multimorbidity and interactions between physical and

psychological illnesses. Hence, the type and number of HPs can only roughly be assessed. Moreover, if an illness is reported, there are only some follow-up questions that concern this illness and these only refer to the illness that one is reporting at the moment, that is, the impact of previous illnesses that might be more significant to a person cannot be assessed. In sum, to analyse perceived recovery along with questions assessing the role and importance of specific and subjectively significant illnesses, more detailed questions would be needed.

Yet, compared to the previously mentioned datasets (i.e., Swiss Health Survey, SHARE), the SHP is the only Swiss-wide survey providing annual and diversified information on a representative sample of private households in Switzerland. By contacting persons who had reported either a psychological or a physical HP in the SHP, we could meet our research aims: We could contribute to a better understanding of how persons in Switzerland deal with mental illness and an identification of conditions under which they experience adversarial growth (Aim 1) as well as subjective recovery (Aim 2). As our third aim was to compare recovery processes from psychological HPs with recovery processes from physical HPs, it was important to have access to a population sample that had experienced a psychological HP, and to a sample with similar sociodemographic characteristics that had experienced a physical HP. This was possible when contacting persons on the basis of a population survey as population data provide the possibility to get access to different parts of the population all over Switzerland that can be selected according to specific characteristics.

There were several further advantages in contacting a sample that participates in the SHP: In a general population survey, respondents are not preselected because of one specific type of treatment (e.g., hospitalisation in clinical studies). Then, as recovery processes take time, by this method it was easier to contact people in order to report on a past HP or a HP that had been ongoing for some time. One last advantage is to be able to combine the information of our cross-sectional questionnaire study with the rich longitudinal data available in the SHP.

In the following part we would like to describe the survey LIVES\_SHPHealth in which persons who had reported psychological or physical HPs in the SHP were contacted in order to participate in an additional questionnaire study on the consequences, identity-related variables, adversarial growth and subjective recovery of either one principal psychological or physical HP. We will start by describing how we selected the sample that we contacted and in which way it displays specific characteristics (sociodemographic variables, indicators of social integration and mental health; see Section 2.1). Then, we will present the study procedure, the

questionnaire and the measures used (see Section 2.2). Last, we will analyse the selectivity of our response sample and of the final sample that we obtained after data cleaning (see Section 2.3). We will describe the characteristics of this sample along with information on the principal psychological or physical HPs they reported on (see Section 2.4).

## **2. Description of the LIVES\_SHPHealth survey**

### **2.1 Contact sample selection and selectivity of the contact sample**

#### *2.1.1 Contact sample selection procedure*

The identification of the sample that would be contacted for LIVES\_SHPHealth included three steps (see Figure 2.1): 1. the identification of persons who had reported either a physical or psychological HP and who were still participating in the SHP in 2013/2014; 2. the application of exclusion criteria; 3. the matching of the physical on the psychological sample according to selected sociodemographic criteria of the psychological sample (because the psychological sample was our principal sample of interest).

In the first step, respondents were identified who had reported a HP between the years 2003 and 2014 (2004 to 2013 for chronic HPs as questions were only available for the respective years). This was done by examining two questions that are asked yearly and that assess the incidence (yes/ no) of an episodic (P\$SL01/ P\$SL01R) or chronic HP (P\$SC19A/ P\$SC22B) during the last year.<sup>5</sup>

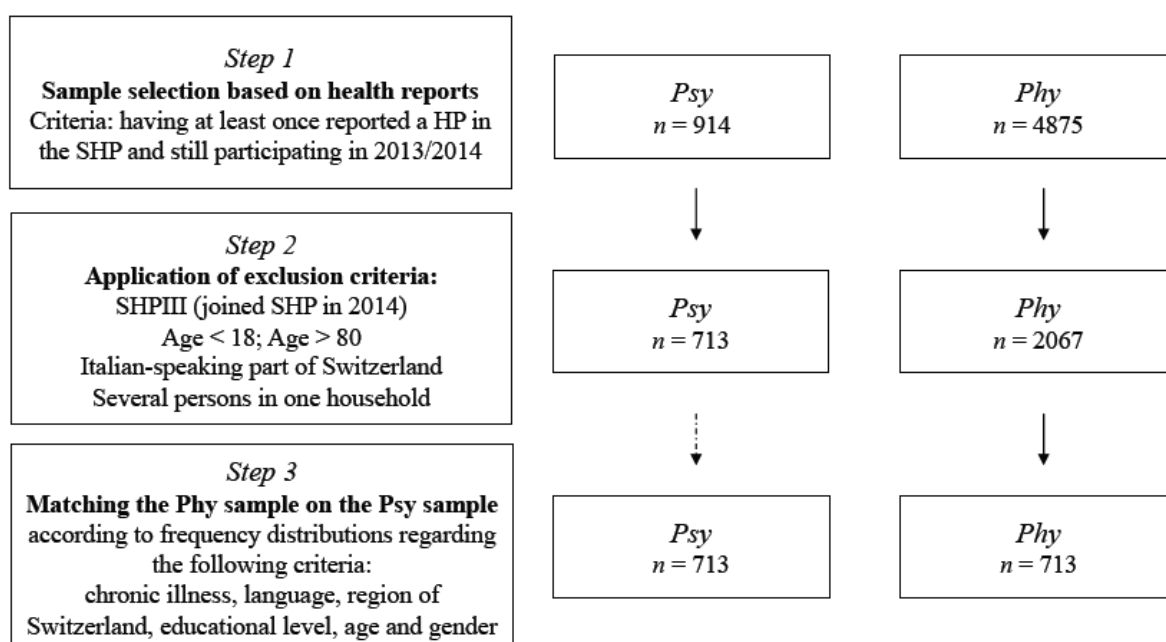
For an episodic health problem, the question is asked: *Since (insert month-year)[last time of interview], have you had an illness, an accident or another serious health problem?*, and: *What was it? (1: Physical illness, 2: Mental illness or psychological problem)*. We excluded here any answer options related to accidents. A chronic health problem is assessed by the question: *Do you suffer from (have) any chronic (longstanding) illness or condition (health problem)?*, and *Is it a physical or a psychological problem? (1: Physical, 2: Psychological, 3: Both)*. We excluded here the option “None”. We selected respondents who participated in the SHP in 2013 and/ or in 2014<sup>6</sup> in order to increase response rates for LIVES\_SHPHealth. Only for chronic HPs, there was the possibility to identify HPs due to both psychological and physical reasons; the answer option “both” was not available for episodic HPs.

In the second step, we applied several exclusion criteria: We excluded participants who had been newly included in the SHP survey (SHP III, starting from 2014), persons below the age of 18 and above the age of 80, and persons living in the Italian-speaking part of Switzerland (due to the small percentage of 4.3% of reported psychological HPs in that region). If we identified several persons with HPs within one household, only one person was chosen at

random in order to avoid dependent cases<sup>7</sup>. Finally, in the physical HP group, persons were included who had only reported a physical HP (and no HP due to both psychological and physical reasons) because this group was planned to be the comparison group for the psychological HP group.

In the third step, as we were interested in psychological HPs and in their comparison to less stigmatising physical illness conditions, we matched the physical sample based on the distributions of the following characteristics on the psychological sample: Chronic illness (chronic versus non-chronic), language (French versus German), region of Switzerland (Middleland [cantons: BE, FR, SO, NE, JU], Lake Geneva [cantons: VD, VS, GE], Zurich, East Switzerland [cantons: GL, SH, AR, AI, SG, GR, TG], Northwest Switzerland [cantons: BS, BL, AG], Central Switzerland [cantons: LU, UR, SZ, OW, NW, ZG], educational level (compulsory/lower secondary, upper secondary, tertiary), age and gender.<sup>8</sup> We did this by using the R-package “matchIt” (Ho, Imai, King, & Stuart, 2007).

Figure 2.1 shows the sample sizes after the application of each step for the sample that had reported a psychological HP (“Psy”) or a physical HP (“Phy”) in the SHP. A more detailed overview of the illness patterns that the sample had reported and that we selected in step 1 can be seen in Annex Tables 6.1-2. More information regarding selection steps 2 and 3 including the matching process can be seen in the Annex Table 6.3.



*Figure 2.1: Sample selection process*

Participants who took part in the SHP were selected in three steps. Sample sizes are indicated next to each step after the application of the respective selection step. *Psy*: sample that has reported a psychological HP in the SHP at least once; *Phy*: sample that has reported a physical HP in the SHP at least once.

Now we will analyse how the three steps of the selection process might have modified the characteristics of the participants that should be contacted for our survey. For the first step, we will now discuss this based on previous research concerning the SHP data.

### *2.1.2 Selectivity of the contact sample after application of step 1*

Among SHP survey respondents who were still participating in 2013/ 2014, 914 persons were identified who had at least once reported a psychological HP and 4875 who had at least once reported a physical HP. These displayed complex illness patterns, which can be seen in the Annex Tables 6.1-2<sup>9</sup>. By selecting persons who had reported a HP and who were still participating in 2013/ 2014, our sample composition might have been biased in several aspects.

First, the absolute frequency of illness reports that we could identify is likely to be underestimated. Out of the 17,543 persons who were interviewed at least once in the

longitudinal Swiss Household Panel survey<sup>10</sup>, we identified 8705 individuals (49.62%) who had reported at least once any serious or chronic HP between 2003 and 2014. 1214 had reported at least once a psychological HP corresponding to 13.95% of the individuals who had reported any HP and to 6.92% of all interviewed participants. Hence, over a time span of 11 years, the probability to report a psychological HP was 6.92%. This number is smaller than the prevalence calculated in other studies. For example, the Zurich-cohort-study (Angst et al., 2005) estimated a 24.2% probability to have any affective disorder (without including other frequent disorders) over a period of 20 years. For 10 years, this would mean a 12.1% probability, which is almost twice the probability of 6.92% that we calculated based on reports that include any psychological HP and do not only focus on affective disorders. Also, the yearly incidence is estimated to be 25% of the Swiss population (Ajdacic-Gross & Graf, 2003), which is 36 times the yearly incidence of 0.69% that we obtain by dividing our 6.92% probability for 10 years by 10. Hence, psychological HPs seem to be highly underreported in the SHP survey. For physical HPs the frequency seemed also underestimated, but more realistic than the reports on psychological disorders: 42.7% over a period of 10 years and hence 4.27% as yearly incidence.

Second, after having selected persons based on their health reports, we selected respondents who were still participating in the SHP in 2013/ 2014. Hence, we could not contact persons who dropped out of the longitudinal survey. Studies on attrition in the SHP have shown that dropout is related to a systematic bias. Specifically, respondents that are female, Swiss, older, higher educated, employed and married are less likely to drop out of the panel (Tillmann et al., 2013; Voorpostel et al., 2016). Furthermore, the social integration of individuals seems to play a role: Respondents who stayed in the survey were more likely to be a member of groups or clubs and showed higher values of trust in other people (Tillmann et al., 2013; Voorpostel et al., 2016). There is also some evidence that dropout is related to lower satisfaction with health (Lipps, 2007; Tillmann et al., 2013; Rothenbühler, & Voorpostel, 2016), free time or financial situation (Lipps, 2007). The variance in the probability to drop out of the survey explained by all these variables is estimated to be rather small, that is, between 3% and 7% (Voorpostel, 2009). Yet, by selecting persons who still participated in 2013 or 2014, our sample composition might have been biased. The low incidence rates that we obtained could therefore indicate that population groups that are vulnerable due to health, work or social reasons have either not participated in the survey or have dropped out.

### *2.1.3 Selectivity of the contact sample after application of steps 2 and 3 - method*

After having identified the initial sample that had reported a health problem and was still participating in the survey, our sample composition might have been modified by the application of exclusion criteria in step 2 and the matching process in step 3. In order to investigate the selectivity of our sample through the application of these two next steps, we will compare respondents who we selected with those who we did not select using the following indicators in the SHP survey: sociodemographic characteristics, questions measuring social integration and mental health (all as reported in the year 2015 before respondents were contacted for LIVES\_SHPHealth).

#### ***Measures***

##### *Sociodemographic characteristics:*

Language (French/ German; PLINGU\$\$), age (AGE\$\$), gender (SEX\$\$), level of education (aggregated to lower secondary/ upper secondary / tertiary; from EDUCAT\$\$), occupation (aggregated to working/ having an occupation/ not working/ having no occupation; from OCCUPA\$\$), being in a partnership (yes/no; recoded from P\$\$D29), nationality (Swiss/ other; recoded from NAT\_1\_\$\$).

*Social integration:* As indicators for social integration we chose the following questions: *Taking part in groups* (P15N34): Do you take part in clubs' or other groups' activities, religious groups included? (yes, no); *General trust* (P15P45): “Would you say that most people can be trusted or that you can't be too careful in dealing with people, if 0 means "Can't be too careful" and 10 means "Most people can be trusted"?”; for those working we looked at the *perceived risk to become unemployed* in the following year (P15W228): “How do you evaluate the risk of becoming personally unemployed in the next 12 months, if 0 means "no risk at all" and 10 "a real risk"?”

##### *Indicators of mental health:*

*Optimism* (P15C18): This was assessed by the question: “Are you often full of strength, energy and optimism, if 0 means "never" and 10 "always"?”

*Depression* (P15C17): This was assessed by the question: “Do you often have negative feelings such as having the blues, being desperate, suffering from anxiety or depression, if 0 means "never" and 10 "always"?”

*Mean satisfaction*: We calculated the mean of satisfaction with different domains, all of which were assessed on an 11-point Likert scale (“Overall how satisfied are you with...”): *Satisfaction with life* (P15C44), *health* (P15C02), *job* (P15W228), *financial situation* (P15I01), *relationships* (P15QL04), *leisure activities* (P15A06) and *free time* (P15A05).

## Analyses

We compared sociodemographic characteristics, social integration and mental health indicators for participants who we selected in order to be contacted for the LIVES\_SHPHealth survey with those who we did not select after the previously described selection steps. We conducted two-sample independent t-tests for the continuous variables (e.g., social integration and mental health indicators), and Pearson’s  $\chi^2$  -tests to test equal frequency distributions for sociodemographic variables. R statistical programming software was used (<https://www.r-project.org>) and packages “gmodels” (Warnes et al., 2018), “psych” (Revelle, 2018) and “effsize” (Torchiano, 2017).

### 2.1.4 Selectivity of the sample after application of step 2 - results

In step 2, we applied several exclusion criteria (see also Figure 2.1). This reduced our sample size. Specifically, the sample size of the sample that had reported a psychological HP was reduced from 914 to 713, whereas the size of the sample that had reported a physical HP was reduced from 4875 to 2067. We will report here for both samples separately whether the participants who we did not select (“out”) were significantly different regarding sociodemographic and psychosocial variables compared to the sample that we selected (“selected”). A detailed overview of the results regarding a variety of sociodemographic characteristics, indicators of social integration and mental health can be seen in Table 2.1.

***Analysis of selectivity regarding the sample selected for psychological health problems***

Several significant differences regarding sociodemographic variables could be observed: Compared to those who were not selected for our study, our selected sample was more likely to have participated in the SHP in 2015, to have Swiss nationality, to be working, to be in a partnership, and to have upper secondary and tertiary education, while the probability to have lower secondary education was lower. The selected sample was slightly younger and there were more persons who reported on a chronic HP.

The sample that we selected and the sample that we did not select were also different regarding variables indicating social integration and satisfaction: Persons in the selected sample were more likely to be a member of groups or clubs, they showed higher values of trust and there was a marginally significant tendency that they perceived the risk to lose their job as lower.

Also, they showed higher values in indicators of mental health: They reported more optimistic feelings, and less depressive feelings. Their mean satisfaction was marginally significantly higher; when looking at separate domains of satisfaction, they had higher levels of financial satisfaction ( $M_{\text{selected}} = 6.82$ ,  $SD_{\text{selected}} = 2.35$ ;  $M_{\text{out}} = 6.26$ ,  $SD_{\text{out}} = 2.71$ ,  $t(233.73) = 2.42$ ,  $p < .05$ ,  $d = 0.23$ ), whereas no other satisfaction domain reached significance ( $.90 > \text{all } ps > .153$ ).

***Analysis of selectivity regarding the sample selected for physical health problems***

After step 2, when exclusion criteria were applied on the sample that had reported a physical HP, there was a marginally significant tendency that there were fewer women in the selected sample. There were significantly more persons of the active population, persons who were in a partnership, who were younger and who had tertiary or upper secondary educational level. In the selected sample, the percentage of persons with a chronic HP was higher.

Differences could also be observed in social integration indicators: The selected sample had a higher percentage of persons who were members of groups or clubs and showed higher levels of trust. Also, reported levels of optimism were higher and depressive feelings lower. Mean satisfaction was higher, which could be especially explained by higher satisfaction with

health ( $M_{\text{out}} = 7.17$ ,  $SD_{\text{out}} = 1.9$ ;  $M_{\text{selected}} = 7.6$ ,  $SD_{\text{selected}} = 1.59$ ,  $t(4016.3) = 7.86$ ,  $p < .001$ ,  $d = 0.24$ ) and activities ( $M_{\text{out}} = 7.71$ ,  $SD_{\text{out}} = 1.88$ ;  $M_{\text{selected}} = 7.85$ ,  $SD_{\text{selected}} = 1.63$ ,  $t(3964.2) = 2.63$ ,  $p < .01$ ,  $d = 0.08$ ) and a slight tendency for higher financial satisfaction ( $M_{\text{out}} = 7.31$ ,  $SD_{\text{out}} = 2.08$ ;  $M_{\text{selected}} = 7.43$ ,  $SD_{\text{selected}} = 1.81$ ,  $t(3965.3) = 1.86$ ,  $p = .063$ ,  $d = 0.06$ ).

### *2.1.5 Selectivity of the sample after application of step 3 - results*

In the matching process, the sample that had reported a physical HP was again reduced as participants were selected based on the distributions of sociodemographic criteria of the 713 persons of the sample who had reported a psychological HP.

Because of the matching process, the sociodemographic variables of the phy-HP-sample were now more similar to those of the psy-HP-sample. Now the phy-HP-sample had a higher percentage of female participants than those who were not selected, a higher amount of persons living in the French-speaking part of Switzerland, who had reported a chronic HP and were younger.

Moreover, in the selected sample there was a greater percentage of persons who were working, and a marginally significant higher tendency of persons with Swiss nationality.

With regard to the psychosocial variables, only one significant difference could be observed: Compared to those who were not selected, the selected sample showed higher values of mean satisfaction, which could be especially explained by higher financial satisfaction ( $M_{\text{out}} = 7.53$ ,  $SD_{\text{out}} = 1.76$ ;  $M_{\text{selected}} = 7.23$ ,  $SD_{\text{selected}} = 1.88$ ,  $t(1150.2) = 3.29$ ,  $p < .01$ ,  $d = 0.17$ ) and freetime ( $M_{\text{out}} = 7.64$ ,  $SD_{\text{out}} = 2.09$ ;  $M_{\text{selected}} = 7.27$ ,  $SD_{\text{selected}} = 2.16$ ,  $t(1179.4) = 3.49$ ,  $p < .001$ ,  $d = 0.18$ ) and slightly by satisfaction with activities ( $M_{\text{out}} = 7.91$ ,  $SD_{\text{out}} = 1.58$ ;  $M_{\text{selected}} = 7.75$ ,  $SD_{\text{selected}} = 1.71$ ,  $t(1134.2) = 1.93$ ,  $p = .054$ ,  $d = 0.1$ ) and satisfaction with life ( $M_{\text{out}} = 8.08$ ,  $SD_{\text{out}} = 1.25$ ;  $M_{\text{selected}} = 7.95$ ,  $SD_{\text{selected}} = 1.24$ ,  $t(1229.4) = 2.06$ ,  $p < .05$ ,  $d = 0.1$ ).

Table 2.1: Characteristics of SHP participants after steps 2 and 3 of the selection process

	Step 2 – After application of exclusion criteria						Step 3 – After matching		
	Psy HP n = 914			Phy HP n = 4875			Phy HP n = 2067		
	Out n = 201	Selected n = 713		Out n = 2808	Selected n = 2067		Out n = 1354	Selected n = 713	
	%, M (SD)	%, M (SD)	t/ $\chi^2$	%, M (SD)	%, M (SD)	t/ $\chi^2$	%, M (SD)	%, M (SD)	t/ $\chi^2$
<i>Sociodem.</i>									
SHPpart. %	82.1	89.3	7.66**	82.2	83.8	2.15	83.6	84.3	0.16
Edu, %									
Tertiary	27.4	38.2		32.7	36.4		36.7	35.9	
Upper second.	44.3	47.4		47.2	52.2		52.8	51.1	
Lower second.	28.4	14.5	22.76***	20.4	11.4	70.36***	10.5	13.0	3.04
Active, %	52.5	65.9	6.06***	57.2	64.1	23.61***	60.6	70.6	20.31***
Female, %	66.2	64.2	0.26	56.8	53.7	3.32†	48.3	63.8	45.20***
Swiss, %	85.6	91.4	6.06*	91.9	91.9	0.001	92.8	90.3	3.74†
Partner, %	58.7	73.4	16.05***	78.9	75.2	9.53**	78.7	79.4	0.13
French, %	22.4	32.4	149.44***	21.2	24.6	7.59**	20.3	32.8	39.37***
Chronic, %	57.2	80.8	47.23***	67.8	76.0	39.19***	73.7	80.0	9.94**
Age	53.61 (21.13)	50.62 (14.55)	1.89†	54.61 (20.29)	53.21 (15.86)	2.71**	54.72 (15.67)	50.35 (15.83)	5.99***
<i>Social integration</i>									
Groups, %	31.9	46.3	11.09***	49.9	46.1	5.86*	49.2	51.1	0.52
Trust	5.67 (2.48)	6.12 (2.3)	2.07*	6.33 (2.12)	6.51 (1.9)	2.79**	6.46 (1.91)	6.54 (1.90)	0.83
Fear job	2.98 (3.04)	2.39 (2.68)	1.69†	1.85 (2.36)	2.04 (2.44)	1.94	2.11 (2.49)	1.99 (2.42)	.78
<i>Mental health</i>									
Optimism	6.09 (2.22)	6.57 (1.91)	2.54*	6.91 (1.83)	7.18 (1.56)	5.08***	7.19 (1.56)	7.15 (1.56)	0.46
Depression	4.36 (2.85)	3.28 (2.43)	4.48***	2.42 (2.16)	2.03 (1.87)	6.12***	1.99 (1.84)	2.12 (1.9)	1.45
Mean sat.	7.16 (1.35)	7.36 (1.22)	1.77	7.71 (1.9)	7.8 (1.02)	2.77**	7.87 (0.99)	7.69 (1.06)	3.42***

*Note.* Steps 2-3 of the selection process of SHP respondents who would then be contacted for the LIVES\_SHPHealth questionnaire survey.

*Psy HP:* Respondents who reported a psychological health problem in the SHP. *Phy HP:* Respondents who reported a physical health problem in the SHP; *Out:* Respondents who were not selected compared to *selected* respondents.

Next to differences in %, the  $\chi^2$ -statistic is displayed; next to differences in means, *t*-statistic is displayed.

*Sociodem.:* Sociodemographic characteristics; *SHPpart.:* Participation in the SHP in 2015 (before being contacted for LIVES\_SHPHealth); *Partner:* In partnership; *Chronic:* Having reported a chronic HP in the SHP; *Groups:* Being a member of groups or clubs; *Fear job:* Fear to lose one's job; *Mean sat.:* Mean satisfaction.

Social integration and mental health indicators were assessed on an 11-point-Likert scale ranging from 0 to 11.

†  $p < .1$ , \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

## **2.2 Study procedure and questionnaire**

After the selection of the contact sample, the respective respondents were invited to participate in the LIVES\_SHPhealth survey. In this section we will present the study procedure, how participants were contacted, the questionnaire, the measures and additional variables that we coded to have information on health and sociodemographic characteristics.

### *2.2.1 Study procedure*

#### ***Ethical approval and contact letter***

The study was approved by the Swiss cantonal Ethics Committee on research involving humans responsible for single-centre studies directed from the canton of Vaud (CER-VD). It was submitted to the Ethics Committee because it involved the collection of sensitive information on health problems. Hence, the possibility of the respondents to refuse to participate, to be provided numbers of help hotlines in case that questions should evoke psychological stress, as well as high anonymity of the data had to be assured. The selected sample was contacted in June 2016 by the independent research institute M.I.S. Trend, which is responsible for data collection of the annual SHP survey.

Participants received a letter with a link for participation in a web survey on the topic of health and the role that HPs play for people's lives (see Annex B). A 10 CHF note (approximately 10 USD) was added to the letter as a reward for participation. After one month, respondents who had not yet replied received a reminding letter to which a paper-pencil questionnaire was added. Data collection was finished in August 2016. The research institute then provided an anonymised dataset to the researchers; via identification codes, questionnaires could be related to information obtained by the annual SHP survey.

#### ***Questionnaire translation and testing***

The languages of the questionnaire were French and German. The questionnaire was developed in French; when there were only English scales available, they were translated and back-translated. The questionnaire was translated into German and revised by two experienced bilingual survey researchers. Five cognitive interviews were conducted after which the

formulation of some questions was slightly changed to make them more easily understandable. Health- and treatment-related sections were revised by two medical doctors (one internal specialist and one psychiatrist).

### ***General description of the questionnaire***

The questionnaire consisted of a general part regarding the assessment of satisfaction with life and health (each one item), perceptions of physical and psychological wellbeing, control over these as well as responsibility for recovery. Also it was asked how participants perceived most people's opinion on these issues. Then, a list of physical illnesses and a list of psychological illnesses were provided and respondents were asked whether they had ever been diagnosed by a medical doctor with one of the listed HPs. There was also an open category where further HPs could be noted.

Afterwards, one principal health problem<sup>11</sup> was selected for the specific questions of the remaining parts of the questionnaire. Our study aim was to identify the impact of *psychological* HPs on psychosocial variables and to contrast experiences from these stigmatising health conditions with less stigmatising *physical* HPs. Therefore, if respondents had reported *any psychological* HP, this HP was automatically selected as the principal HP. If several psychological HPs were reported, respondents were asked to choose the HP that was most important to them. Only if respondents *had not reported any psychological* HP, one *physical* HP was selected as the principal HP (respondents could here also choose the most important one if they had reported several physical HPs). Then, two lists of questions followed in which the principal HP was addressed in more detail. The first part dealt with symptoms and treatment history, the second part encompassed positive and negative consequences for one's life, stigmatisation, identity related questions and perceived recovery. In the online version, the principal HP was displayed on the screen for each section of questions (i.e., "your HP: depression"); in the paper-pencil version, participants had to note the HP they were going to report on in a separate line. Respondents were reminded several times that the following sections concerned only the selected principal HP. There were two slightly differing questionnaire versions depending on whether participants reported on an ongoing or past HP. The completion of the questionnaire was planned to take between 30 and 45 minutes. The actual time for completion for the online questionnaires could be measured and was on average 30.33 minutes. The whole questionnaire can be found in the Annex B.

### *2.2.2 Description of measures and additional information*

The selection of measures was guided by the following criteria:

- Short measures (or possibility to shorten with permission of the authors) due to time constraints for the questionnaire completion
- Translations in French (or German) language available
- Relevance to life course approach as study was conducted in the framework of a research program on vulnerability over the life course (LIVES)
- Common quality criteria (reliability, validity, ecological validity)

All quantitative items were answered on a 5-point-Likert scale with the following values and labels: “1”, “not at all”; “2”, “a little”; “3”, “moderately”; “4”, “a lot”; “5”, “a great deal”. In the following, we will describe the measures. Cronbach’s alpha will be reported for the psychological- and physical-HP groups each if a scale with several items was used to assess a specific construct.

#### ***General part (questions not addressing the selected principal HP)***

*Satisfaction with life:* This was assessed with one item at the beginning and the end of the questionnaire: “How satisfied are you with your life at the moment?”

*Satisfaction with health:* This was assessed with one item at the beginning and the end of the questionnaire: “How satisfied are you with your health at the moment?”

*Importance of psychological (physical) wellbeing:* This was assessed by 2 questions, one concerning psychological and one concerning physical wellbeing: “In your opinion - To what extent is psychological[physical] wellbeing important to you?”

*Importance of psychological (physical) wellbeing (perception of most people’s opinion):* This was assessed by 2 questions, one concerning psychological and one concerning physical wellbeing: “How you see most people’s opinion - To what extent is psychological[physical] wellbeing important to most people?”

*Control over psychological (physical) wellbeing:* This was assessed by 2 questions, one concerning psychological and one concerning physical wellbeing: “In your opinion - To what

extent are you able to take (any kind of) actions in order to maintain or increase your psychological [physical] wellbeing?”

*Control over psychological (physical) wellbeing (perception of most people's opinion):* This was assessed by 2 questions, one concerning psychological and one concerning physical wellbeing: “How you see most people's opinion - According to most people, to what extent is it possible to take (any kind of) actions in order to maintain or increase one's psychological [physical] wellbeing?”

*Responsibility for psychological (physical) wellbeing:* This was assessed by 2 questions, one concerning psychological and one concerning physical wellbeing: “In your opinion - To what extent are persons who have a psychological health problem (for example burnout, depression, schizophrenia) [physical health problem (for example hypertension, diabetes, cancer)] responsible for their recovery?”

*Responsibility for psychological (physical) wellbeing (perception of most people's opinion):* This was assessed by 2 questions, one concerning psychological and one concerning physical wellbeing: “How you see most people's opinion - According to most people, to what extent are persons who have a psychological health problem (for example burnout, depression, schizophrenia) [physical health problem (for example hypertension, diabetes, cancer)] responsible for their recovery?”

*Link between psychological and physical wellbeing:* The following question was asked: “In your opinion, what is the relationship between physical and psychological wellbeing? Only one answer is possible”. The answer options were: “There is no relationship between physical and psychological wellbeing”, “Physical wellbeing influences psychological wellbeing to a greater extent than vice versa”, “Psychological wellbeing influences physical wellbeing to a greater extent than vice versa”, and “Physical and psychological wellbeing influence each other to the same extent”.

*Qualitative questions assessing perceptions of wellbeing and control strategies:* Several open questions were asked. These were (one each for psychological or physical wellbeing): “What does psychological[physical] wellbeing mean for you if you had to describe it in a few words?”; “What do you do in order to maintain or increase your psychological[physical] wellbeing? If you would like to give some examples, you can write them down here:”. And, regarding the questions addressing the representation of most people's

opinion, it was asked: “When you think of “most people”, who do you think of, in a few words?”

### ***Specific part – questions concerning one selected principal HP***

#### *Illness and treatment characteristics*

*Health problems:* These were assessed by two questions: “Have you ever been diagnosed with one of the following psychological or neurological [physical] health problems by a medical doctor?” Then, a list of health problems was provided (see Annex B) as well as a category “other” where further health problems could be noted.

*Principal health problem (HP):* The principal HP that was selected automatically or by the participants.

*Ongoing HP:* This variable was based on the question: “Is it an ongoing health problem or a health problem that still affects you?” (yes/ no)

*Age at onset:* The age of onset for the HP was assessed here.

*Treatment:* It was assessed whether, in the past or present, persons had received any *medical, psychological or complementary* treatment for the HP; afterwards, lists of frequent treatment types were provided (see Annex B). Furthermore, it was asked whether persons had been *hospitalised* (no, yes, duration) because of the HP and *how long* they had taken after the onset of the first symptoms until they *looked for professional help*.

*Symptoms:* A list was provided where respondents could select the symptoms that they experienced related to their HP (see Annex B).

*Subjective recovery:* This was measured by the Recovery Assessment Scale (RAS; Corrigan, Salzer, Ralph, Sangster, & Keck, 2004). The scale assesses five subdimensions of subjective recovery: Personal confidence and hope (example: “I’m hopeful about my future”, “I like myself”); willingness to ask for help (example: “I ask for help, when I need it”); goal and success orientation (example: “I have my own plan for how to stay or become well”, “I believe I can meet my current personal goals”); reliance on others (example: “I have people I can count on”); no domination by symptoms (example: “Coping with my illness is no longer the main focus of my life”). With the permission of the scale developers, 11 items were chosen

(at least one item for each subdimension) that provided the highest factor loadings and that during the cognitive interviews seemed to be most comprehensive and not too repetitive to respondents. One should note that persons who indicated that their principal HP was no longer ongoing were not given the items assessing whether one's life is dominated by symptoms.

Cronbach's alpha for the total scale was: Phy HP: .79; psy HP: .85.

### ***Adversarial growth***

In order to assess a broad range of different positive changes, three measures were used to assess whether persons had experienced adversarial growth from the HP: One first measure of adversarial growth that assesses positive consequences of the HP for different domains of one's life (1); next, a scale assessing three positive aspects regarding one's personal development (2; King et al., 2007; Morandi et al., 2013); last, the SLQ-questionnaire (3; Bride, Dunwoody, Lowe-Strong, & Kennedy, 2008; Sodergren & Hyland, 2000), a more general measure that assesses various aspects of adversarial growth including positive changes for one's personal development and interpersonal relationships, and that has been developed specifically for illness experiences.

*1) Adversarial growth (positive consequences):* Here, perceived positive consequences for life in general, and then positive consequences regarding five specific subdomains (relations with close ones, relations with colleagues (work or volunteering activities), professional (or volunteering activity) development, personal development, living comfort including financial situation) were assessed. The question was: "To what extent does this health problem have positive consequences on...?". A study on the consequences of cancer was taken as orientation here (Pinquart, Fröhlich, & Silbereisen, 2007). To compute adversarial growth, mean values were computed for all six items. Cronbach's alpha was: Phy HP: .9; psy HP: .88.

*2) Personal growth:* The three items of the positive subscale of the Stigma Scale (see also below, *stigmatisation*; King et al., 2007; Morandi et al., 2013) were used here. We decided to use this scale rather than the often used Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996) because it was specifically developed using reports from persons who suffer from mental illness and who reported positive aspects from it. The items were: "Having (had) this health problem has made me a more understanding person", "This health problem has

made me more accepting of other people”, and “Having (had) this health problem has made me a stronger person”. Cronbach’s alpha was: Phy HP: .85; psy HP: .73.

3) *General adversarial growth-SLQ*: The Silver Lining Questionnaire (Bride, Dunwoody, Lowe-Strong, & Kennedy, 2008; Sodergren & Hyland, 2000) was developed based on qualitative research in order to assess a variety of positive consequences specifically after physical illness experiences (with one person suffering from depression) with the subdimensions: Improved personal relationships, greater appreciation for life, positive influence on others, personal inner strength and changes in life philosophy. With permissions of the authors, we selected eight of the original items with high factors loadings and according to our main research interests: The development of personal strength and control perceptions as well as the impact on social relationships. The eight items were: “Because of my health problem I find it easier to accept what life has in store”, “This health problem made me more aware of my strengths”, “This health problem helped me find myself”, “This health problem made me face up to problem areas of my life”, “Because of this health problem I can offer more to other people”, “I have been an inspiration to others because of this health problem”, “This health problem made me put an end to troublesome relationships” and “Because of this health problem I am more open to spirituality” (slightly reformulated after cognitive interviews). The items were analysed and aggregated by mean values. Cronbach’s alpha was: Phy HP: .91; psy HP: .87.

Further items were added by the authors in line with research interests and in order to complement the SLQ questions: “Because of this health problem it is easier for me to accept that there are situations that I cannot control”, “Because of this health problem I can better act in order to maintain or increase my physical wellbeing”, “Because of this health problem I can better act in order to maintain or increase my psychological wellbeing”, “This health problem has completely changed me as a person”, “This health problem has made me more creative”.

*Identity centrality*: Four items of the Centrality of Event Scale (CES; Berntsen & Rubin, 2006) assessing the centrality of an event for one’s identity and one’s life history were assessed with the permission of the authors to shorten the scale. The items were: “I feel that this health problem has become part of my identity”, “This health problem has changed the way I understand myself and the world”<sup>12</sup>, “I feel that this health problem has become a central part of my life story” and “This health problem was a turning point in my life”. As the CES does not assess the perception of others, that is, whether one’s social categorisation was also affected

by the health problem, an additional item assessing the perception of others (“This health problem has changed the image that others have of me”) was added by the authors. Cronbach’s alpha was: phy HP: .87; psy HP: .85.

*Stigmatisation:* The degree of perceived stigma due to the health problem (either past health problem or actual health problem) was assessed by the Stigma Scale (King et al., 2007; Morandi et al., 2013), which assesses in nine items the subdimensions discrimination, disclosure and positive aspects (*see measure for personal growth*) of the illness. The items for discrimination were: “I am angry with the way people have reacted to my health problem”, “People have avoided me because of my health problem” and “People have insulted me because of my health problem”. The alpha for the group phy HP was: .78, the alpha for the group psy HP was: .81. The items for disclosure were: “I worry about telling people that I receive (have received) treatment”, “I find it hard telling people I have (had) this health problem”, and “I am scared of how other people will react if they find out about this health problem”. The alpha for the group phy HP was: .81, the alpha for the group psy HP was: .91. The Cronbach’s alpha after aggregation of all itmes was for phy HP: .86; psy HP: .85.

*Perceived negative consequences:*

In order to assess the currently experienced negative consequences of the HP, perceived negative consequences for life in general, and negative consequences regarding five specific subdomains (relations with close ones, relations with colleagues (work or volunteering activities), professional (or volunteering activity) development, personal development, living comfort including financial situation) were assessed. The question was: “To what extent does this health problem have negative consequences on...?”. Cronbach’s alpha was: Phy HP: .9; psy HP: .91.

*Perceived current impact of the health problem:* The current impact of the HP on the respondents was assessed by the question: “To what extent does the health problem affect you today?”.

### ***Social variables***

#### *More participation in groups:*

Based on findings of the positive effects of group-memberships for health (Jetten et al., 2017) and that joining new groups reduces relapse in depression (Cruwys et al., 2013), we included the following two items: “Because of this health problem I started one or more new group activities“ and “Because of this health problem, I am part of one or more new groups”.

*Support due to the health problem:* Support for the health problem was measured using one item that was added by the authors to the questionnaire. The item was: “People have supported me because of the HP”.

#### *Qualitative material regarding suggestions in dealing with HP:*

As open question at the end of the questionnaire was asked: “If you had to give some advice to others with the same health problem as yours, what would be the three main points you would offer them in order support them in coping with their situation?”

### ***Variables that we computed additionally in order to assess the severity of the health problem and of additional health problems reported***

*Duration of the health problem:* For an ongoing HP, the duration was assessed by subtracting the reported age of onset from the age of the respondents in 2016. For a past HP, the duration was computed by subtracting the reported age at the end of the HP from the reported age at onset.

*Time since onset:* The year of diagnoses was subtracted from the year 2016.

*Multimorbidity:* As indicators for multimorbidity, the number of HPs that were reported in addition to the principal HP were reported (*add. ongoing HPs*) as well as the number of additional HPs that were still ongoing (*add. ongoing HPs*) at the time point of the survey. Also, as an indicator of comorbidity the number of HPs were identified that had the same year of onset as the principal HP (*comorbid HPs*).

*Disability weights in order to estimate the objective severity of a HP*

We derived several indicators in order to be able to describe and compare the objective severity of the HPs that were reported in the questionnaire: *disability weight (DW)*, and *years of life lost due to death (YLL)* or *disability (YLD)* on a population level.

*Disability weight (DW)*: This indicates the degree of disability caused by a HP ranging from 0 (“no disability”) to 1 (“complete disability”). Originally, health care professionals rated a variety of different illnesses in terms of the disability they cause for the person experiencing them, such as in the Global Burden of Disease study (Murray et al., 2012, Murray & Lopez, 1996). The European disability weights, however, were calculated based on judgements of the general population (Salomon et al., 2015). Participants were asked to choose the healthier one between two health conditions (lay descriptions of illnesses were provided) for the illnesses included in the Global Burden of Disease study, but also for a number of additional health states (Haagsma et al., 2015). Disability estimations were for most HPs insensitive to whether a HP was framed as temporary or chronic (Salomon et al., 2015).

Hence, the studies above gave an overview of European DWs for a range of different illnesses. We derived DWs from these studies and attributed the respective DW to each of the illnesses that participants reported in our questionnaire. If there were several DWs for different stages of specific illnesses, we chose DWs for moderate or primary stages. If there were no European estimations, we took estimations from the global study. If there were separate DWs for women and men, we attributed the gender-specific one. For some HPs (e.g. “adjustment” disorders) there were no DWs; if there was a category “other” (e.g., “other psychological HPs”), we took this category as approximation.

*Threat of death or disability due to the HP (YLL, YLD)*: Estimations of *YLD* (years of life lost due to disability) and *YLL* (years of life lost) were derived from the WHO Global Burden of disease study 2015 estimations for Switzerland. Both indicators measure the burden of a HP on a population level. As for the HP “allergy”, there existed only Australian and no European or global estimations, the Australian estimations were taken as approximation of the disability caused by allergic rhinitis (Access Economics Pty Limited, 2007).

### ***Sociodemographic characteristics of the participants derived from the SHP data***

This information was not asked in the questionnaire, but derived from the annual SHP data (survey year 2014 according to the year of selection of the participants). The following sociodemographic variables were assessed: Language (French/ German; PLINGU14), age (AGE14), gender (SEX14), level of education (aggregated to lower secondary/ upper secondary/ tertiary; from EDUCAT14), occupation (aggregated to working/ having an occupation/ not working/ having no occupation; from OCCUPA14), being in a partnership (yes/ no; recoded from P14D29), nationality (Swiss/ other; recoded from NAT\_1\_\$), being a member of groups or clubs (yes/ no; from P14N34)

*Additional variables that we coded:* Type of Panel (SHP I or SHP II; from FILTER14), mode of the LIVES\_SHPHealth questionnaire (online vs paper-pencil).

## **2.3 Analyses of response bias and selectivity of the final sample**

### ***2.3.1 Response rate and data cleaning***

We contacted 1426 persons. 60.17% (858 persons) responded to the LIVES\_SHPHealth questionnaire<sup>13</sup>. The data were coded (e.g., HPs reported in the category “other”) by two researchers and cleaned (e.g., it was checked whether especially in the paper-pencil version the filter questions had been understood by the respondents, and the amount of missing values were calculated). A detailed overview of excluded cases and reasons can be seen in the Annex Table 6.4. Cases had to be excluded because persons indicated that they had never had a HP (76 respondents), HPs could not be identified (e.g., a person reported several HPs in the category “other” and it could not be identified what the principal HP was; the HP listed in the category “other” was not a diagnosable HP; a person reported a psychological HP in the paper version, but reported then on a physical HP as principal HP; 82 respondents) or because there were too many missing values (18 respondents). After the process of data cleaning, 682 respondents remained of which the questionnaires could be used for data analyses (47.83% of the contacted sample).

### 2.3.2 Analysis of the selectivity of respondents and the final sample

#### ***Measures used to analyze response bias and selectivity***

We used the same indicators of sociodemographic variables, social integration and mental health as in the analysis of the contact sample selectivity (see Section 2.1.3). For participants who had partaken in LIVES\_SHPHealth, but who were not included in the final sample (e.g. because of interruption of their participation or missing values), we looked at their ratings of satisfaction with life and health at the beginning of the questionnaire (see Section 2.2.2).

#### ***Comparison of respondents and non-respondents***

We compared the group that responded to LIVES\_SHPHealth (resp) with the group that did not reply (non-resp). A detailed overview of the results regarding sociodemographic variables, and indicators of social integration and mental health can be seen in Table 2.2.

Respondents were more likely to have participated in the SHP in 2015 than non-respondents. There were marginally significant tendencies that respondents were more likely female and had Swiss nationality. Respondents had reported fewer chronic HPs, they were more likely to be not working (especially due to retirement), and they were older than non-respondents. They were more likely to have tertiary education than non-respondents, and less likely to have lower secondary education.

Regarding variables of social integration, respondents showed higher levels of trust and perceived the likelihood to lose their job as lower. Respondents showed higher levels of mean satisfaction. This difference could be explained by higher values in satisfaction with life ( $M_{\text{nonresp}} = 7.64$ ,  $SD_{\text{nonresp}} = 1.56$ ;  $M_{\text{resp}} = 7.82$ ,  $SD_{\text{resp}} = 1.35$ ,  $t(742.94) = 1.98$ ,  $p < .05$ ,  $d = 0.12$ ), financial situation ( $M_{\text{nonresp}} = 6.74$ ,  $SD_{\text{nonresp}} = 2.26$ ;  $M_{\text{resp}} = 7.15$ ,  $SD_{\text{resp}} = 2.07$ ,  $t(775.45) = 3.11$ ,  $p < .01$ ,  $d = 0.19$ ), job satisfaction marginally ( $M_{\text{nonresp}} = 7.67$ ,  $SD_{\text{nonresp}} = 1.59$ ;  $M_{\text{resp}} = 7.86$ ,  $SD_{\text{resp}} = 1.36$ ,  $t(520.83) = 1.71$ ,  $p = .09$ ,  $d = 0.13$ ) and satisfaction with free time ( $M_{\text{nonresp}} = 6.88$ ,  $SD_{\text{nonresp}} = 2.41$ ;  $M_{\text{resp}} = 7.35$ ,  $SD_{\text{resp}} = 2.14$ ,  $t(773.98) = 3.36$ ,  $p < .001$ ,  $d = 0.21$ ), whereas there was no difference for satisfaction with activities, relationships or health (all  $ps > .25$ ).

Table 2.2: Characteristics of respondents and final sample of LIVES\_SHPHealth

	1) Contacted sample n = 1426			2) Data cleaning n = 858		
	Non-resp. n = 568	Resp. n = 858	<i>t</i> / $\chi^2$	Out n = 176	Final n = 682	<i>t</i> / $\chi^2$
	%, M (SD)	%, M (SD)		%, M (SD)	%, M (SD)	
<i>Sociodem.</i>						
SHPpart, %	73.6	95.6	144.25***	93.2	96.0	2.64
Edu, %						
Tertiary	31.0	41.0		36.4	42.2	
Upper second.	48.8	49.5		51.7	49.0	
Lower second.	20.3	9.4	38.37***	11.9	8.8	2.84
Active, %	71.7	66.0	4.97*	62.1	67.2	1.60
Female, %	61.1	66.0	3.53†	68.2	65.2	0.54
Swiss, %	89.1	92.1	3.66†	88.0	93.1	4.94*
Partner, %	77.4	74.8	1.25	74.4	78.3	1.20
French, %	31.5	33.3	0.52	33.5	33.4	0.001
Chronic, %	83.3	78.6	4.84*	76.7	79.2	0.51
Age	47.81 (15.96)	52.26 (14.41)	5.36***	52.19 (16.52)	52.21 (13.95)	0.01
Online <sup>a</sup> , %	-	-	-	55.1	76.2	30.93***
<i>Social integration</i>						
Groups, %	47.7	49.1	0.21	47.3	49.5	0.25
Trust	6.01 (2.19)	6.42 (2.08)	3.16**	6.02 (2.22)	6.52 (2.03)	2.64**
Fear job	2.52 (2.83)	2.11 (2.45)	2.15*	1.83 (2.13)	2.17 (2.52)	1.48
<i>Mental health</i>						
Optimism	6.83 (1.89)	6.86 (1.71)	0.24	7.00 (1.69)	6.83 (1.72)	1.56
Depression	2.74 (2.4)	2.7 (2.19)	0.31	2.38 (2.05)	2.78 (2.22)	2.19*
Mean sat.	7.37 (1.23)	7.6 (1.12)	3.12**	7.67 (1.17)	7.58 (1.1)	0.95
Sat. life <sup>a</sup>	-	-	-	3.78 (0.75)	3.67 (0.73)	1.66
Sat. health <sup>a</sup>	-	-	-	3.50 (0.89)	3.43 (0.81)	2.19

Note. Comparison of 1) Respondents and non-respondents of the contacted sample, 2) Respondents who were excluded after data cleaning with respondents who were in the final sample.

Next to differences in %, the  $\chi^2$ -statistic is displayed; next to differences in means the  $t$ -statistic is displayed.

*Sociodem.*: Sociodemographic characteristics; *SHPpart.*: Participation in the SHP in 2015 (before being contacted for LIVES\_SHPHealth); *Partner*: In partnership; *Chronic*: Having reported a chronic HP in the SHP; *Groups*: Being member of groups or clubs; *Fear job*: Fear to lose one's job; *Mean sat.*: Mean satisfaction; *Online*: Questionnaire mode (vs. paper-pencil); *Sat. life*: Satisfaction with life; *Sat. health*: Satisfaction with health. Social integration and mental health indicators were assessed on an 11-point-Likert scale ranging from 0 to 11.

a. These variables were derived from the LIVES\_SHPHealth-survey and assessed on a 5-point-Likert scale, while the others were derived from the annual SHP survey.

†  $p < .1$ , \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

### ***Characteristics of the final sample after data cleaning***

We compared our final sample (“final”) to the respondents whom we had excluded after data cleaning (“out”). Only a few variables showed significant differences. The final sample had a higher percentage of persons with Swiss nationality. They were more likely to have replied online than those who we had excluded from analyses. The reason for this is probably that the filter questions were more difficult in the paper-pencil version, whereas in the online version they were automatic. Our final sample compared to those that we excluded reported higher values in trust, but also in depressive feelings. Also, they were less satisfied with free time ( $M_{\text{out}} = 7.66$ ,  $SD_{\text{out}} = 2$ ;  $M_{\text{final}} = 7.28$ ,  $SD_{\text{final}} = 2.17$ ,  $t(270.87) = 2.17$ ,  $p < .05$ ,  $d = .18$ ), whereas all other satisfaction values were the same in the final sample and in the respondents who we had excluded (all  $ps > .214$ ).

### ***Characteristics of respondents who denied having had health problems***

76 participants who had reported a HP in the SHP participated in the first part of our questionnaire, but indicated then that they never had been diagnosed with any HP. Analyses revealed that 37 of these respondents had reported a chronic physical HP in the SHP, 17 an episodic physical HP, 5 an episodic psychological HP, and 17 a chronic psychological HP. We compared this subsample to our final sample in order to analyse in which characteristics they differed.

There were significant differences in age and education: The group indicating that they had never had a HP (“denial”) was younger than our final sample ( $M_{\text{denial}} = 46.61$ ,  $SD_{\text{denial}} = 15.88$ ;  $M_{\text{final}} = 52.75$ ,  $SD_{\text{final}} = 14.26$ ,  $t(87.16) = 3.25$ ,  $p < .01$ ,  $d = 0.43$ ). Also, in the denial-group the percentage of lower secondary educated persons was higher (17.11% vs 8.70%), whereas the percentage of the tertiary educated was lower (34.21% vs 41.69%),  $\chi^2(2) = 6.15$ ,  $p < .05$ . There were no significant differences in participation in the SHP in the year before the survey ( $\chi^2(1) = 0.10$ ,  $p = .753$ ), gender ( $\chi^2(1) = 1.64$ ,  $p = .201$ ), language-region ( $\chi^2(1) = 0.649$ ,  $p = .420$ ), nationality ( $\chi^2(1) = 1.73$ ,  $p = .188$ ), being selected for a chronic HP ( $\chi^2(1) = 2.88$ ,  $p = .09$ ), working ( $\chi^2(1) = 3.81$ ,  $p = .051$ ) or being in a partnership ( $\chi^2(1) = 2.85$ ,  $p = .091$ ).

Regarding social integration indicators, persons who denied that they had had a HP did not differ from our final sample in group memberships ( $\chi^2(1) = 0.01$ ,  $p = .941$ ), nor in the

perceived risk to lose their job ( $M_{\text{denial}} = 2.12$ ,  $SD_{\text{denial}} = 2.16$ ;  $M_{\text{final}} = 2.1$ ,  $SD_{\text{final}} = 2.48$ ,  $t(73.524) = 0.06$ ,  $p = .952$ ). Although there were no significant differences in trust, they showed a tendency of less trust ( $M_{\text{denial}} = 6.06$ ,  $SD_{\text{denial}} = 2.49$ ;  $M_{\text{final}} = 6.45$ ,  $SD_{\text{final}} = 2.03$ ,  $t(80.345) = 1.32$ ,  $p = .192$ ,  $d = 0.19$ ).

Differences could be observed in mental health: Respondents who denied their HP reported lower levels of depressive feelings, ( $M_{\text{denial}} = 1.88$ ,  $SD_{\text{denial}} = 1.67$ ;  $M_{\text{final}} = 2.78$ ,  $SD_{\text{final}} = 2.22$ ,  $t(97.09) = 4.26$ ,  $p < .001$ ,  $d = 0.41$ ) and higher levels of optimism ( $M_{\text{denial}} = 7.26$ ,  $SD_{\text{denial}} = 1.52$ ;  $M_{\text{final}} = 6.82$ ,  $SD_{\text{final}} = 1.73$ ,  $t(89.62) = 2.31$ ,  $p < .05$ ,  $d = 0.26$ ). Values of mean satisfaction were higher in this group ( $M_{\text{denial}} = 7.98$ ,  $SD_{\text{denial}} = 0.95$ ;  $M_{\text{final}} = 7.56$ ,  $SD_{\text{final}} = 1.13$ ,  $t(91.20) = 3.49$ ,  $p < .001$ ,  $d = 0.38$ ), which meant life satisfaction ( $M_{\text{denial}} = 8.17$ ,  $SD_{\text{denial}} = 1.05$ ;  $M_{\text{final}} = 7.78$ ,  $SD_{\text{final}} = 1.37$ ,  $t(96.13) = 2.88$ ,  $p < .01$ ,  $d = 0.29$ ), satisfaction with health ( $M_{\text{denial}} = 8.22$ ,  $SD_{\text{denial}} = 1.33$ ;  $M_{\text{final}} = 7.17$ ,  $SD_{\text{final}} = 1.93$ ,  $t(102.04) = 6.08$ ,  $p < .001$ ,  $d = 0.56$ ) and satisfaction with relationships ( $M_{\text{denial}} = 8.46$ ,  $SD_{\text{denial}} = 1.28$ ;  $M_{\text{final}} = 8.04$ ,  $SD_{\text{final}} = 1.33$ ,  $t(86.521) = 2.63$ ,  $p < .01$ ,  $d = 0.31$ ). There were no differences for satisfaction with free time, activities or financial situation (all  $ps > .176$ ).

Respondents who denied having had a HP showed also higher ratings of satisfaction with life in the LIVES\_SHPHealth ( $M_{\text{denial}} = 3.89$ ,  $SD_{\text{denial}} = 0.56$ ;  $M_{\text{final}} = 3.67$ ,  $SD_{\text{final}} = 0.74$ ,  $t(103.52) = 3.21$ ,  $p < .01$ ,  $d = 0.30$ ) and higher values of satisfaction with health ( $M_{\text{denial}} = 3.84$ ,  $SD_{\text{denial}} = 0.61$ ;  $M_{\text{final}} = 3.41$ ,  $SD_{\text{final}} = 0.83$ ,  $t(104.5) = 5.69$ ,  $p < .001$ ,  $d = 0.53$ ).

When we controlled whether the HP might have been forgotten because a long time might have passed since the HP had been reported in the SHP, the HP of those who denied having one was reported even one year later in the SHP than the one reported by our final sample ( $M_{\text{denial}} = 2008.55$ ,  $SD_{\text{denial}} = 3.01$ ;  $M_{\text{final}} = 2007.72$ ,  $SD_{\text{final}} = 3.2$ ,  $t(91.20) = 3.01$ ,  $p < .001$ ,  $d = 0.38$ ).

The two samples did not differ in the questionnaire mode that they used,  $\chi^2(1) = 0.80$ ,  $p = .371$ .

### 2.3.3 Analysis of mode effects

We tested whether there were any mode effects regarding sociodemographic variables and regarding our variables of interest. Persons who chose the paper-pencil version were older

( $M_{\text{online}} = 50.99$ ,  $SD_{\text{online}} = 13.6$ ;  $M_{\text{paper}} = 56.03$ ,  $SD_{\text{paper}} = 14.37$ ,  $t(255.15) = 3.93$ ,  $p < .001$ ,  $d = 0.37$ ). They were more likely to have a lower secondary level of education (paper: 16.2% vs online: 6.8%), whereas the online version was more likely to be used by persons with tertiary level of education (online: 45.4% vs paper: 29.9%),  $\chi^2(2) = 32.92$ ,  $p < .001$ ). Respondents who were not in a partnership (28.57% vs 19.65%;  $\chi^2(1) = 5.73$ ,  $p < .05$ ) and who did not work used more often the paper-pencil version (42.86% vs 29.67%;  $\chi^2(1) = 9.69$ ,  $p < .01$ ). Regarding psychosocial indicators from the SHP study, there was only one significant effect: Persons who used the paper-pencil version reported in the year of the study higher levels of depressive feelings ( $M_{\text{online}} = 2.68$ ,  $SD_{\text{online}} = 2.15$ ;  $M_{\text{paper}} = 3.14$ ,  $SD_{\text{paper}} = 2.42$ ,  $t(256.68) = 4.04$ ,  $p < .001$ ,  $d = 0.21$ ).

There were slight effects of questionnaire mode on the following variables that we assessed directly in the LIVES\_SHPHealth questionnaire: Respondents who used the paper-pencil version reported higher levels of current negative consequences of their HP ( $M_{\text{online}} = 1.9$ ,  $SD_{\text{online}} = 0.84$ ;  $M_{\text{paper}} = 2.08$ ,  $SD_{\text{paper}} = 0.92$ ,  $t(249.25) = 2.15$ ,  $p < .05$ ,  $d = 0.20$ ) and considered marginally significantly their HP as more central to their identity ( $M_{\text{online}} = 2.43$ ,  $SD_{\text{online}} = 1.03$ ;  $M_{\text{paper}} = 2.6$ ,  $SD_{\text{paper}} = 1.07$ ,  $t(258.14) = 1.79$ ,  $p = .074$ ,  $d = 0.17$ ). There were no other effects on the variables that we assessed in our questionnaire (all  $ps > .115$ )<sup>14</sup>.

## **2.4 Final sample composition and illness reports**

### ***Final sample composition and comparison of psychological and physical health problem groups***

Our final sample consisted of 328 persons reporting on a psychological HP as their principal illness (“psy”) and 354 persons reporting on a physical HP (“phy”) as their principal illness. Here, the characteristics of these two groups of respondents will be described (see Table 2.3, columns 1-3) and compared to the general sample of the SHP and the Swiss population (see Table 2.3, columns 5-6).

In both groups, there were about twice as many female than male respondents as well as twice as many respondents living in the German-speaking than in the French-speaking part of Switzerland. Compared to the Swiss population and participants of the SHP, the percentage living in the French-speaking part and women were overrepresented in our survey.

The mean age was about 50 years, participants were about 10 years older than the Swiss population. About half of the persons in both groups had upper secondary level of education, and about 40% had tertiary education. Compared to the Swiss population and SHP participants, the distribution of educational levels was similar with an underestimation of the percentage of persons with lower secondary educational level and an overestimation of persons with tertiary educational level. There was a marginally significant tendency that in the psychological-HP-group, the number of persons with low educational level was more strongly underrepresented than in the physical-HP-group. In both groups, two thirds worked or had an occupation.

Most of the participants had Swiss nationality. Compared to the Swiss population, this is a strong underestimation of persons with foreign nationality. About three quarters of the sample were in a partnership; in the physical-HP-group, significantly more persons were in a partnership.

*Table 2.3: Characteristics of psychological and physical health problem groups, and comparative values of the final sample, participants of the SHP and the Swiss population*

	<i>Differences between psy-HP and phy-HP-groups</i>			<i>Comparative values</i>		
	Psy HP <i>n</i> = 328	Phy HP <i>n</i> = 354	<i>t/χ</i> <sup>2</sup>	Final sample (psy & phy) <i>n</i> = 682	Participants of SHP <sup>a</sup> <i>n</i> = 7068	Swiss population <i>n</i> = 8419550
	%, M (SD)	%, M (SD)		%, M (SD)	%, M (SD)	%, M (SD)
<i>Sociodem.</i>						
Edu, %						
Tertiary	43.0	41.5		42.2	34.5	37 <sup>c</sup>
Upper second.	50.9	47.2		49.0	46.8	50 <sup>c</sup>
Lower second.	6.1	11.3	5.81†	8.8	18.7	14 <sup>c</sup>
Active, %	69.5	65.0	1.67	67.2	68.4	68.6 <sup>d</sup>
Female, %	67.7	63.0	1.65	65.2	54.2	50.4 <sup>d</sup>
Swiss, %	93.2	93.0	0.02	93.1	91.1	75.0 <sup>d</sup>
Partner, %	73.8	82.5	7.59**	78.3	75.0	42.8 <sup>de</sup>
French, %	33.5	32.8	0.003	33.4	26.3	22.7 <sup>d</sup>
Age	50.72 (13.01) 17-77	53.58 (14.65) 18-78	2.70*	52.21 (13.95)	48.88 (19.55)	42.1 <sup>d</sup>
<i>Social integration</i>						
Groups, %	47.2	51.6	1.31	49.5	47.1	-
Trust	6.46 (2.02)	6.58 (2.04)	0.79	6.52 (2.03)	6.40 (2.05)	-
Fear job	2.31 (2.57)	2.04 (2.46)	1.12	2.17 (2.52)	1.98 (2.41)	-
<i>Mental health</i>						
Optimism	6.36 (1.87)	7.27 (1.44)	6.96***	6.83 (1.72)	7.07 (1.71)	-
Depression	3.45 (2.34)	2.16 (1.91)	7.71***	2.78 (2.22)	2.24 (2.07)	-
Mean sat.	7.38 (1.22)	7.76 (0.95)	4.47***	7.58 (1.1)	7.75 (1.08)	-
Sat. health	7.04 (1.99)	7.42 (1.73)	2.57**	7.24 (1.86)	7.67 (1.74)	-
Sat. life	7.53 (1.48)	8.04 (1.14)	4.84***	7.80 (1.34)	8.05 (1.3)	-
Sat. life2 <sup>b</sup>	3.52 (0.77)	3.81 (0.66)	5.35***	3.76 (0.73)	-	-
Sat. health2 <sup>b</sup>	3.31 (0.88)	3.55 (0.72)	3.77***	3.43 (0.81)	-	-

*Note.* Comparison of respondents who reported on a psychological HP (*Psy HP*) and a physical HP (*Phy HP*). Next to differences in %, the  $\chi^2$ -statistic is displayed; next to differences in means, the *t*-statistic is displayed.

*Comparative values* refer to the *final sample* (all respondents of LIVES\_SHPHealth, that is, psy-HP- and phy-HP-groups), the *general participants of SHP* (regular and irregular participants), and the *Swiss population*.

*Sociodem.*: Sociodemographic characteristics; *Partner*: In partnership; *Groups*: Being member of groups or clubs; *Fear job*: Fear to lose one's job; *Mean sat.*: Mean satisfaction; *Sat. life*: Satisfaction with life; *Sat. health*: Satisfaction with health. Social integration and mental health indicators were assessed on an 11-point-Likert scale ranging from 0 to 11, *Sat. life2* and *Sat. health2* were assessed on a 5-point-Likert scale in the beginning of the LIVES\_SHPHealth questionnaire.

a: These values were computed using data from SHP wave 17 (end of 2015), the survey year before participants were contacted for LIVES\_SHPHealth. They concern regular and irregular participants of the SHP who had not dropped out of the panel in 2015. For a description of who is classified into regular ("always in") or irregular participant ("ever out"), see Voorpostel, 2009.

b: These variables were assessed in the beginning of the LIVES\_SHPHealth questionnaire.

c: Numbers for 25-64 olds, OECD, 2014.

d: Statistics derived from OFS, 2016.

e: This number includes only married or registered partnerships, whereas the numbers in our final LIVES\_SHPHealth sample also include unregistered partnerships.

†  $p < .1$ , \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

We analysed further psychosocial variables that might help distinguish the two groups reporting on either a psychological or a physical HP (see Section 2.1.3). Regarding questions asked in the SHP, there were no differences for indicators of social integration, that is, being a member of groups or clubs, social trust or perceived risk to becoming unemployed. These values were furthermore similar to reports of SHP participants.

Yet, both in comparison to the physical-HP-sample and to general SHP participants, the psy-HP-group reported higher levels of depressive feelings and lower levels of optimism and energy. They furthermore reported lower mean satisfaction values than the physical-HP-group, that is, lower satisfaction with life ( $M_{\text{psy}} = 7.53$ ,  $SD_{\text{psy}} = 1.48$ ;  $M_{\text{phy}} = 8.04$ ,  $SD_{\text{phy}} = 1.14$ ,  $t(590.62) = 4.84$ ,  $p < .001$ ,  $d = 0.38$ ), health ( $M_{\text{psy}} = 7.04$ ,  $SD_{\text{psy}} = 1.99$ ;  $M_{\text{phy}} = 7.42$ ,  $SD_{\text{phy}} = 1.73$ ,  $t(625.52) = 2.57$ ,  $p < .05$ ,  $d = 0.20$ ), financial situation ( $M_{\text{psy}} = 6.88$ ,  $SD_{\text{psy}} = 2.26$ ;  $M_{\text{phy}} = 7.41$ ,  $SD_{\text{phy}} = 1.89$ ,  $t(614.05) = 3.29$ ,  $p < .01$ ,  $d = 0.26$ ), relationships ( $M_{\text{psy}} = 7.87$ ,  $SD_{\text{psy}} = 1.38$ ;  $M_{\text{phy}} = 8.21$ ,  $SD_{\text{phy}} = 1.2$ ,  $t(623.29) = 3.37$ ,  $p < .001$ ,  $d = 0.27$ ) and job ( $M_{\text{psy}} = 7.73$ ,  $SD_{\text{psy}} = 1.52$ ;  $M_{\text{phy}} = 7.99$ ,  $SD_{\text{phy}} = 1.22$ ,  $t(430.62) = 2.02$ ,  $p < .05$ ,  $d = 0.19$ ). These indicators were lower in the psychological-HP-sample compared to SHP participants. Yet, the physical-HP-sample showed similar values to the SHP participants, except for lower levels in satisfaction with health.

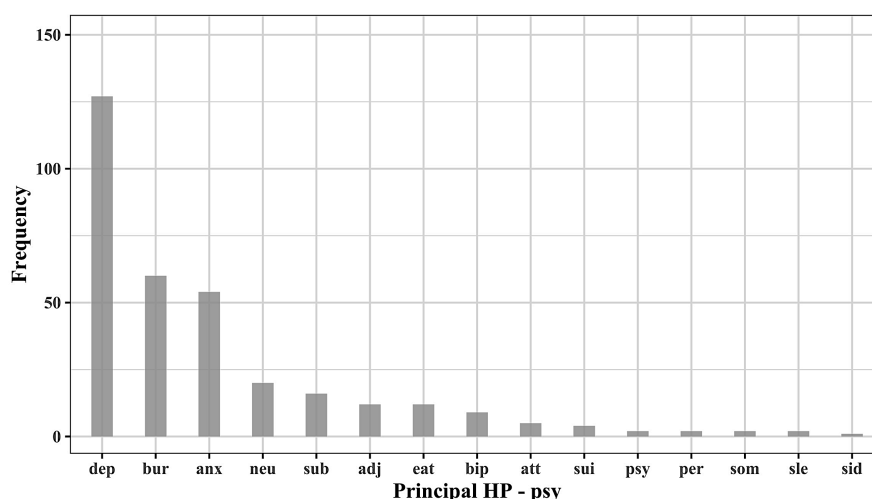
Last, in the beginning of LIVES\_SHPHealth, the psychological-HP-sample reported lower levels of satisfaction with life and health compared to the phy-HP-group.

### ***Illness reports and characteristics of principal HPs reported***

Figures 2.2 and 2.3 show the frequencies of principal HPs reported in the psychological-HP- and the physical-HP-group. It is important to note that these are the HPs that the respondents chose to focus on in LIVES\_SHPHealth; on average, respondents reported 2.09 ( $SD = 2.0$ ) additional HPs (see also Table 2.3) in the lists that were provided in the questionnaire.

A detailed overview of the principal psychological HPs and their characteristics is displayed in Table 2.3. More than half of the reported HPs were depressive disorders, followed by burnout, anxiety disorders, neurological disorders and substance disorders. In terms of prevalence in the population, the most frequent disorders were reported, that is mood disorders, anxiety disorders and substance abuse disorders (Wittchen et al., 2011); yet, anxiety and

substance abuse disorders seemed to be underrepresented, whereas depression seemed to be overrepresented. Dementia, somatoform and sleeping disorders, which are also high in prevalence (Wittchen et al., 2011), were almost not reported. The gender distribution seemed realistic with 2-3 times more women being concerned regarding depressive disorders, 2 times regarding anxiety disorders, whereas for other disorders gender is more equally distributed (Ajdacic-Gross & Graf, 2003).



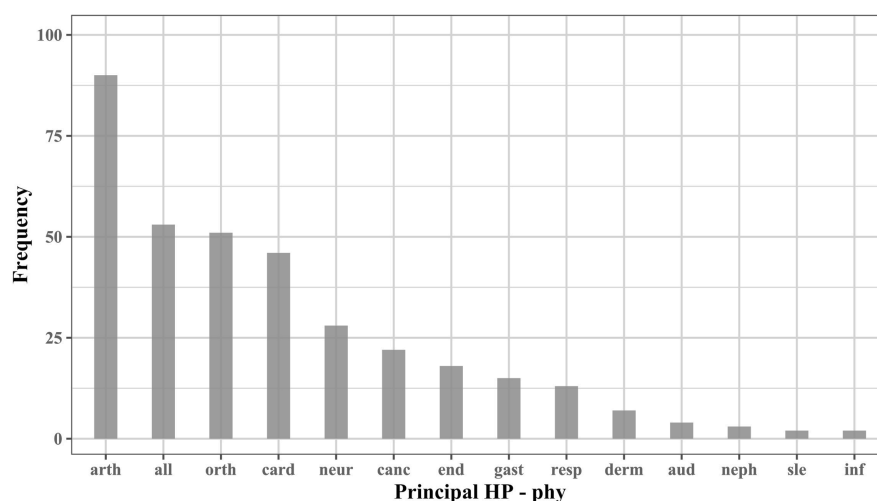
*Figure 2.2: Frequencies of principal psychological HPs reported*

*Note.* Groups of disorders from left to right: depression, burnout, anxiety, neurological, substance abuse, adjustment, eating, bipolar, attention, suicide, psychotic, personality, somatoform, sleeping and sexual identity disorders.

One can also note that in general our sample reported on less stigmatising mental HPs as the most stigmatised are often found to be schizophrenia or substance abuse (Lauber et al., 2004).

Figure 2.3 shows the principal physical HPs reported and details can be seen in Table 2.3. Here, too, respondents chose to report on the most prevalent HPs in the Swiss population: With rheumatoid arthritis, hay fever or allergies and cardiac problems, especially hypertension, the most prevalent chronic physical HPs have been focused on (OFS, 2012). Yet, cardiac (hypertension) and endocrinological HPs (especially diabetes) seemed to be underrepresented. Respondents reported numerous orthopaedic problems in the category “other”, which were mainly back problems. This points to the great prevalence of orthopaedic problems, especially

back pain (Obsan, 2015, p. 85). The gender distribution seemed to be realistic with more women than men being concerned by orthopaedic problems.



*Figure 2.3: Frequencies of principal physical HPs reported*

*Note.* Groups of diseases from left to right: arthrosis/ rheumatism, allergies, other orthopaedic problems, cardiovascular, neurological, cancer, endocrinological, gastrointestinal, respiratory, dermatological, auditory, nephrological, sleeping, infectious.

In general, the principal HPs that the final sample reported on belong to the 10 diseases that represent the biggest burden in disability adjusted live years in Switzerland: Back pain (rank 1), depression (rank 5), anxiety (rank 8); even if less frequently reported, there were also cases of diabetes (rank 9), migraine (rank 7), chronic obstructive pulmonary disease (rank 4) and hearing problems (rank 6; Vos et al., 2015).

Table 2.3 shows aggregated characteristics for principal physical and psychological HPs that were reported. More detailed information regarding the types of HPs and their characteristics can be seen in the Annex Tables 6.5-6. On average, both reported physical and psychological HPs were related to about 20 years of life lost due to disability on a population level. This shows that the HPs reported are of significant burden. The mean disability weight, that is, the estimated degree of disability for the individual due to the HP was significantly higher for psychological HPs. The years of life lost due to death on a population level were expectedly higher for physical HPs.

The physical HPs that were reported on were more likely to be ongoing at the time point of the survey, whereas only half of the psychological HPs were ongoing. In both samples, most of the HPs reported had a duration of at least one or two years.<sup>15</sup> In the physical sample, the HPs were also related to significantly more frequent reports of several episodes. Nevertheless, the mean duration of illness was in both groups relatively high, and most of the sample reported on a HP whose onset was at least two years ago.

Moreover, most respondents reported on a HP for which they had received treatment. For physical HPs, this was mostly medication, for psychological HPs either psychotherapy or a combination of psychotherapy and medication. About one third in each group reported to have been hospitalised for the HP; in the psychological group, the duration was about five times longer than in the physical group. On average, persons with a psychological HP reported to have taken six months longer before they looked for the first professional help than persons with a physical HP. This difference was not significant. The median in both groups was six months; in the psychological group, the distribution for people who waited longer than six months was larger and there were more extreme cases.

One should also note the multimorbidity reported, especially in the psychological sample. Persons reporting on a psychological HP reported about twice as many additional HPs than persons reporting on a physical HP. In the psychological sample, persons reported an average of 0.36 ( $SD = 0.8$ ) additional ongoing psychological HPs and 1.43 ( $SD = 1.3$ ) additional physical ongoing HPs. On average, 0.41 ( $SD = 0.76$ ) comorbid psychological HPs were reported and 0.25 ( $SD = 0.64$ ) comorbid physical HPs were reported.

*Table 2.3: Health problem characteristics for the group reporting on a psychological HP and the group reporting on a physical HP*

	<i>Group</i>		<i>t/χ<sup>2</sup></i>
	Psychological (n = 328)	Physical (n = 354)	
	%, M (SD) Range	%, M (SD) Range	
Ongoing HP, %	48.17	79.94	76.38***
Several episodes of HP, %	41.46	80.51	38.27***
Age at diagnosis	38.47 (14.49) 3-76	40.01 (19.92) 0-78	1.15
Time since diagnosis (years)	15.25 (12.57) 1-64	16.61 (13.13) 0-68	1.43
Duration of illness (years)	10.22 (11.50) 1-51 <sup>b</sup>	15.63 (13.32) 0-68 <sup>a</sup>	5.76***
Time taken after first symptoms to look for help (months)	26.68 (56.99) 0.03-420.00	20.41 (42.38) 0.03-364.00	1.54
DW	0.26 (0.10) 0.02-0.78	0.24 (0.14) 0.01-0.44	2.35*
YLD	20.17 (14.38) 0.20-39.70	20.72 (26.95) 0.10-82.06	0.33
YLL	0.70 (3.29) 0-46.50	6.05 (12.20) 0-88.5	7.93***
Additional reported HPs	3.09 (2.2) 0-14	1.17 (1.2) 0-6	10.93***
Additional ongoing HPs	1.83 (1.58) (0-11)	0.73 (0.93) 0-5	14.07***
Comorbid HPs	0.66 (1.02) 0-7	0.18 (0.49) 0-2	7.60***
<b>Treatment</b>			
Any past or present treatment, %	95.99	91.81	2.45
Hospitalisation, %	28.05	25.71	0.42
Time of hospitalisation (months)	0.75 (2.92) 0-36	0.14 (0.64) 0-8.5	3.67***
Medication, %	68.90	71.47	0.54
Psychotherapy, %	65.85	1.98	312.77***
Medication & Psychotherapy, %	46.65	1.98	153.36***
Complementary, %	29.88	23.73	3.29

*Note.*

*DW*: Disability weight going along with the HP reported ranging from 0 to 1. *YLD*: Years of life lost due to disability. *YLL*: Years of life lost due to death.

a. Duration < 2 years: *n* = 23; Duration ≤ 2 years & ongoing: *n* = 9

b. Duration < 2 years: *n* = 37; Duration ≤ 2 years & ongoing: *n* = 6

### 3. Discussion

This research report presented the LIVES\_SHPHealth study that was conducted in order to address limited Swiss-wide research on the impact of mental health problems on people's lives. The aims were to analyse the conditions under which persons with a psychological HP experience adversarial growth (Aim 1) and subjective recovery (Aim 2) from their illness, and to contrast the obtained results with the experiences of persons with less stigmatising physical HPs (Aim 3). To these ends, participants of the SHP were selected based on their health reports and contacted in order to participate in an additional auto-administered questionnaire survey. The analyses conducted in this research report reveal several main results. These regard the selectivity of our final sample, health reports and differences between the group reporting on a psychological HP and the group reporting on a physical HP. Each of the aspects will be discussed in the following.

First, by contacting participants of a panel survey, we obtained data from a heterogeneous convenience sample of the Swiss population that had reported health problems. Yet, compared to the Swiss population and to participants of the SHP, in our final sample women, Swiss nationals, individuals living in the French part of Switzerland and persons with a tertiary level of education were overrepresented, whereas persons with compulsory/ lower secondary education were underrepresented. Furthermore, respondents compared to non-respondents were more satisfied with several domains of their lives (life satisfaction, financial satisfaction and satisfaction with free time), showed higher levels of trust in other persons and estimated the risk to lose their job as lower. Last, there were indications that there is a general bias regarding health reports in the SHP. Especially psychological HPs seem to be underreported compared to official illness incidence estimations.

The bias of our sample towards higher education, Swiss nationals, and persons with higher trust occurred in three steps. First, we selected only participants that had participated recently in the SHP and hence had not dropped out of the survey. Persons who are still participants of the SHP have been found to more likely have Swiss nationality, higher education and show higher levels of trust (Tillmann et al., 2013; Voorpostel et al., 2016).

Second, higher education, Swiss nationality, having work, living in the French part of Switzerland, higher levels of trust and higher indicators of mental health were more pronounced in our sample after we had selected participants of the SHP according to specific exclusion criteria (e.g., age, living in the German or French part of Switzerland).

Third, after we had contacted the selected participants for our survey, higher educated persons, Swiss nationals and more trusting persons were more likely to respond to our questionnaire. There were also slight effects that after we had cleaned the data (missing values, having correctly followed the filter questions of the questionnaire), these groups of respondents were more likely to be represented in our final sample.

The higher percentage of women can be explained by the fact that we selected persons who reported on a psychological HP first; there is a higher percentage of women for most psychological HPs (Ajdacic-Gross & Graf, 2003). There were contrasting effects regarding age and having work: While one of our exclusion criteria was being aged above 80, participants who we selected were younger and more likely to be working compared to participants who we did not select to be contacted for our survey. Yet, after being contacted for our survey, respondents were more likely to be older and to have no work (due to retirement). In the end, however, the percentage of active individuals in our sample was similar to participants of the SHP and the Swiss population.

The outlined selection effects should be taken into account when interpreting research that is conducted using these data. Characteristics that were distributed differently in our final sample than in SHP participants who we did not select or non-respondents have been found to be related to a gradient in physical and mental health (Bachmann, Burla & Kohler, 2015, for an overview, see Spini, Pin, & Klaas, 2016): A lower level of education and foreign nationality are especially likely to be related to lower mental health. Also, we might not have reached socially isolated persons; feelings of connectedness and being integrated in groups are central factors for the development of psychological HPs and the recovery from them (for a review regarding depression, see Cruwys, Haslam, Dingle, Haslam, & Jetten, 2014). Hence, when doing analyses with our data, one has to consider the overrepresentation of factors that are related to higher mental health, especially Swiss nationality, higher levels of education, higher levels of trust and satisfaction, and importantly: having made the step to disclose one's HP and looking for help in dealing with it (here as expressed in treatment).

Turning to the illness information provided by our final survey sample, participants reported on a variety of psychological and physical HPs. The most frequent psychological HPs persons reported on were depressive disorders, followed by burnout, anxiety disorders, neurological disorders and substance abuse disorders. The most frequent physical HPs were rheumatoid arthritis, hay fever or allergies and cardiac problems. These are among the most

frequent and burdensome in Switzerland and globally (Vos et al., 2015). In the psychological-HP-group, there was a strong focus on depression and burnout, anxiety disorders were underreported as well as strongly stigmatising disorders such as substance abuse disorders or psychotic disorders. Regarding the physical HPs reported, it is possible that pain and orthopaedic problems were increased due to higher age and higher percentages of female gender due to the matching process on the psychological sample.

The fact that burnout was the most frequent principal HP after depression points to the importance of this illness. Burnout is not a diagnosis on its own in ICD10 (World Health Organisation, 1978), but it can be diagnosed in the category “Problems related to life management difficulty” (diagnosis code Z73.0) indicating a state of physical and emotional exhaustion. In line with this, we had to exclude some persons from our analyses who reported very diffuse HPs and who they described using words in the field of stress (e.g. “stress”, “excessive demand”). This points additionally to the necessity to consider exhaustion-related HPs.

Respondents varied on whether they reported on a past or an ongoing HP and according to the type of treatment they had received; yet, most of the respondents had received treatment for their HP and reported on a HP that had been diagnosed at least two years ago. This underlines that our sample is very specific in the sense that it is not reporting on acute HPs and respondents have had treatment for their HPs.

By selecting our participants based on health reports in the SHP, we might only have reached a specific group that discloses HPs in a general population survey. Our calculations of incidence rates in the SHP underline this by showing that especially psychological HPs in the SHP were underreported compared to official illness incidence estimations. It is likely that those individuals who are especially affected by their health conditions, who are not part of a registered household (e.g., homeless people), and who are affected by stigma and social isolation have not participated, have dropped out, or have not reported their HP in the SHP. In this line, more stigmatised illnesses (psychotic disorders, substance abuse disorders) might also be underreported.

In this line, there were also participants who had reported a HP in the SHP, however, denied that they had had any HP when they filled out the LIVES\_SHPHealth questionnaire. Our analyses revealed that in the year of the survey as well as in our questionnaire, these respondents had higher values of satisfaction regarding a number of different domains. This

could be in line with a recent study that found that the denial of a mental HP in a general population survey was related to higher wellbeing (Thoits, 2016). We do not know which types of HPs these respondents had reported in the SHP and whether these were associated with stigma. There was a slight tendency that “deniers” had lower values of trust. This effect was not significant, but it was surprising; Unlike all other variables of mental health where “deniers” showed higher values, regarding trust the pattern was reversed and they reported lower values.

One last interesting finding is that although for half of the sample reporting on a psychological HP the HP was not ongoing anymore (compared to around 80% reporting on a physical HP), in the year before they were contacted for LIVES\_SHPHealth as well as in the beginning of our questionnaire, respondents reporting on a psychological HP, compared to respondents reporting on a physical HP and to general participants of the SHP, reported lower satisfaction values regarding a number of different domains including job, financial situation, relationships, life and health. They also displayed lower optimism and higher levels of depressive feelings. This is in line with findings that persons with psychological HPs rate their quality of life lower than persons with physical medical conditions (Cook & Harman, 2008).

In the end, it is likely that our questionnaire primed a separation in “physical” and “psychological HPs”, a separation that is also given by the questions in the SHP (“Was the HP you experienced physical or psychological or both?”). Our analyses indicate that this separation is problematic, especially when one cannot control what type of HP a person has experienced. For example, in our questionnaire, respondents reported Alzheimer’s disease, multiple sclerosis or epilepsy both in the “psychological” and “physical” list of HPs. This suggests that neurological disorders are a category “in between” and our respondents underlined this by explicitly reporting their neurological HP in the list with physical illnesses, although they had already reported it in the list with psychological illnesses. Furthermore, detailed analyses revealed that respondents that we selected based on their health reports in the SHP for either a psychological or a physical HP reported different types of HPs in our questionnaire. This might be in part because in our questionnaire we asked also for HPs before the time period of the SHP survey (i.e., before 2003). Yet, nevertheless, this suggests that the categorisation of “psychological” and “physical” might sometimes not be clear for respondents or that, if only these two categories are provided, they choose the less stigmatising category or the label with which they are more comfortable.

We recommend that HPs should be measured in a more exact and simpler way in the SHP. We propose to have one single question: “Have you had a health problem during the last year?” followed by: “Is it chronic, that is, a long-standing medical condition lasting for at least six months?”; followed by, if possible, a selection of central physical and psychological HP categories, as well as the possibility to report several HPs. There should be the option to indicate whether the HP is psychological, physical or both psychological and physical. This would very much simplify the number of existing questions. This would also allow reports of several health problems that are chronic or non-chronic, psychological, physical or both. Hence, the high degree of multimorbidity revealed by our sample could be addressed. Indeed, multimorbidity is estimated at about 40% in all patients with disorders and seems especially related to socioeconomic deprivation in combination with mental health disorders (Barnett et al., 2012). It is also related to reduced quality of life (Hodek, Ruhe, & Greiner, 2010).

In summary, the study provides the possibility to conduct research on respondents who report their subjective perceptions regarding frequent and burdensome psychological or physical HPs that lie in the past or that they have had for at least two years, and for which they have received treatment. The heterogeneous convenience sample consists of respondents both from the German- and the French-speaking parts of the Swiss population with an overrepresentation of women, Swiss nationals, individuals with high educational levels, and an underrepresentation of persons with low educational levels.

#### 4. Notes

<sup>1</sup> “Mental health problem”, “psychological health problem” or “mental illness” refer to the definition of mental disorders in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013): “A mental disorder is a syndrome characterized by a clinically significant disturbance in an individual’s cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behavior (e.g., political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual (...).”

<sup>2</sup> These numbers are based on estimations of different epidemiological studies.

<sup>3</sup> Numbers are based on the year 2010. Percentages are calculated relative to the size of the Swiss population ( $N = 7,870,134$ ) in 2010.

<sup>4</sup> One has to be careful, however, to interpret this finding as something forcibly negative. Focusing on those social relationships that provide a person with feelings of belonging, meaning and social support and leaving those relationships behind that are related to lower wellbeing (and that might have revealed intolerant behaviour in dealing with the fact that one has mental illness) can also be an experienced positive outcome of an episode of mental illness. Besides, however, there is convincing evidence that experiences of stigmatisation and social distance from other persons are more likely when one experiences mostly psychological compared to mostly physical HPs.

<sup>5</sup> Answers to these questions do not seem to be reactive to attrition in the SHP, that is, they have not been found to be biased due to loss of individuals over time (Weaver, 2010).

<sup>6</sup> The selection process was in 2015 and SHP survey data were only available up to year 2014.

<sup>7</sup> The number of dependent cases would not be high enough for substantial investigation; also, we did not want to overcharge households with several questionnaires.

<sup>8</sup> Nationality is another important factor that can relate to the development of health problems (*cf.*, Spini, Pin, & Klaas, 2016). We did not include this additional variable in the matching process because of the small percentage of cases with foreign nationality (8.6%) and the heterogeneity among non-Swiss nationalities.

<sup>9</sup> Both Annex Tables 6.1 and 6.2 have to be considered to calculate the initial number of 914 persons that have reported a psychological HP. Table 6.2 includes only individuals who have reported, in addition to their various health problems, a HP due to both psychological and physical reasons. Table 6.1 includes individuals who have *not* reported a HP due to both psychological and physical reasons.

<sup>10</sup> SHP-I starting from 1999:  $n = 7799$ ; SHP-II starting from 2004:  $n = 3654$ ; SHP-III starting from 2013:  $n = 6090$ ; *cf.* Voorpostel et al., 2016.

<sup>11</sup> Because of time constraints, *only one* health problem was selected for specific questions.

<sup>12</sup> The original wording was “HP as a reference point”; however, in cognitive interviews persons did not understand this item, so it was therefore slightly reformulated.

<sup>13</sup> The response rate was 58.49% for persons that had been contacted for a physical HP and 61.85% for a psychological HP. Yet, the type of HP the persons were contacted for differed from what they reported as a principal HP (see also Annex Table 6.4 for details); likely reasons for this are that respondents could choose their principal HP for a time span that started before the SHP survey (1999), under- or misreporting for example due to stigmatisation, or the way in which HPs are assessed in the SHP.

<sup>14</sup> There was no correlation between age and level of education on the one hand with negative consequences and identity centrality on the other hand (all  $ps > .204$ ).

<sup>15</sup> The estimation for duration is quite rough as respondents reported only age of onset and age at end of HP (for ongoing HPs current age was taken). This means that the duration calculated here can vary +/- 1 year.

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## 6. Annex

### A

*Table 26.1: Selection step 1(a). Frequency of different illness patterns in the active sample of the SHP 2003-2014 (2004 – 2013 for chronic health problems) for individuals who did not report a chronic health problem due to both psychological and physical reasons*

		Reported psychological HP				
		<i>Nopsy</i>	<i>Psy</i>	<i>Chrpsy</i>	<i>Psy &amp; chrpsy</i>	
Reported physical health problem	<i>Nophy</i>	-	90	65	34	189
	<i>Phy</i>	1337	20	29	22	1408
	<i>Chrphy</i>	1193	35	61	27	1316
	<i>Phy &amp; chrphy</i>	1845	78	124	32	2079
		4375	223	279	115	4992
<p>Number of persons in the active sample of the Swiss Household Panel (SHP) displaying different illness patterns. Combinations that we included in our study are framed.</p> <p><i>Nopsy</i>: No reported psychological health problem at all; <i>Nophy</i>: No reported physical health problem at all; <i>Psy</i>: Psychological health problem, reported at least once;</p> <p><i>Phy</i>: Physical health problem, reported at least once; <i>Chrpsy</i>: Chronic psychological health problem, reported at least once; <i>Chrphy</i>: Chronic physical health problem, reported at least once.</p> <p>Both Tables 6.1 and 6.2 have to be considered to calculate the initial number of selected cases that is displayed in Figure 2.1 (Selection step 1).</p>						

**Table 2.** *Error! Main Document Only.: Selection step 1(b). Frequency of different illness patterns in the active sample of the SHP 2003-2013 for individuals who reported a chronic health problem due to both psychological and physical reasons*

Chrboth in connection with		Reported psychological HP				
		<i>Nopsy</i>	<i>Psy</i>	<i>Chrpsy</i>	<i>Psy &amp; chrpsy</i>	
<b>Reported physical health problem</b>	<i>Nophy</i>	48	4	13	12	77
	<i>Phy</i>	30	8	12	13	63
	<i>Chrphy</i>	112	5	36	12	165
	<i>Phy &amp; chrphy</i>	358	46	88	48	540
		548	63	149	85	845
<p>Number of persons in the active sample of the Swiss Household Panel (SHP) who have reported between 2004 and 2013 at least once a chronic illness due to both psychological and physical reasons. Frequencies for all possible illness patterns over the years are listed. Combinations that we included in our study are framed.</p> <p><i>Chrboth</i>: Chronic health problem which has both psychological and physical reasons, reported at least once; <i>Nopsy</i>: No reported psychological health problem at all; <i>Nophy</i>: No reported physical health problem at all; <i>Psy</i>: Psychological health problem, reported at least once; <i>Phy</i>: Physical health problem, reported at least once; <i>Chrpsy</i>: Chronic psychological health problem, reported at least once; <i>Chrphy</i>: Chronic physical health problem, reported at least once.</p> <p>Both Tables 6.1 and 6.2 have to be considered to calculate the initial number of selected cases that is displayed in Figure 2.1 (Selection step 1).</p>						

*Table 6.3: Detailed overview of step 2 & 3 – Application of exclusion criteria and matching of the phy-HP sample on the psy-HP sample*

Health problem		Sample 1		Sample 2	
		Phy (n = 4875)	Psy (n = 914)	Phy (n = 2067)	Psy (n = 713)
Sex	male	2191 (44.94%)	323 (35.34%)	958 (46.35%)	255 (35.76%)
	female	2684 (55.06%)	591 (64.66%)	1109 (53.65%)	458 (64.24%)
Age	M	54.13	51.28	53.21	50.62
	SD	18.55	16.26	15.86	14.55
	Span	14-99	15-98	17-78	17 - 78
Education	Lower sec.	808 (16.57%)	160 (17.51%)	235 (11.37%)	103 (14.45%)
	Upper sec.	2403 (49.29%)	427 (46.72%)	1079 (52.20%)	338 (47.41%)
	Tertiary	1664 (34.13%)	327 (35.78%)	753 (36.43%)	272 (38.15%)
Region	Lemanic	736 (15.10%)	188 (20.57%)	341 (16.50%)	154 (21.60%)
	Mittelland	1273 (26.11%)	221 (24.18%)	570 (27.58%)	183 (25.67%)
	North-West	733 (15.04%)	120 (13.13%)	313 (15.14%)	97 (13.61%)
	Zurich	859 (17.62%)	170 (18.60%)	363 (17.56%)	134 (18.79%)
	Oriental	616 (12.64%)	97 (10.61%)	264 (12.77%)	74 (10.38%)
	Central	488 (10.01%)	83 (9.08%)	216 (10.45%)	71 (9.96%)
Language	Tessin	170 (3.49%)	35 (3.83%)		
	French	1063 (21.81%)	276 (30.20%)	509 (24.63%)	231 (32.40%)
	German	3609 (74.03%)	598 (65.43%)	1558 (75.37%)	482 (67.60%)
Nationality	Italian	203 (4.16%)	40 (4.38%)		
	Swiss	4482 (91.94%)	823 (90.14%)	1900 (91.92%)	651 (91.43%)
	Non-Swiss	393 (8.06%)	90 (9.86%)	167 (8.08%)	61 (8.57%)
Chronic	No	1367 (28.04%)	223 (31.29%)	496 (24.00%)	137 (19.22%)
	Yes	3508 (71.96%)	691 (68.65%)	1571 (76.00%)	576 (80.79%)

*Table 6.4: Detailed overview of selection process and data cleaning*

	<i>Phy</i>	<i>Psy</i>
Selection step 1 (SHP)		
Having reported at least once a HP	7491	1214
Having participated in 2013 as well as in 2014 in the SHP	4923	914
Deletion of cases with only HP both to phy and psy reasons	4875	
Selection step 2 (SHP)		
Delete combinations physical HP - HP both to phy and psy reasons	4646	
Selection of only SHP I and II	4033	864
Not living in common households	2518	796
No Italian language/ not living in Tessin	2378	754
Age ≤ 18 in 2016	2361	753
Age ≥ 80 in 2016	2067	713
Selection step 3 – Matching (SHP)		
Matched cases contacted for survey	713	713
Selection step 4 – survey (LIVES_SHPHealth)		
Obtained responses	417	441
Selection step 5 – Data cleaning (LIVES_SHPHealth)		
Indicated that they had never had a HP	54	22
Multiple HPs reported and principal HPs not indicated	10	8
Indicated a psychological HP in the psychological list; however, they reported on a physical as principal HP in parts 3 and 4 of the questionnaire (only the case for paper-pencil questionnaires)	9	14
HP reported in category “other”: No diagnosable HP could be identified	4	7
HP reported in category “other”: Multiple HPs or no HP indicated (e.g. “no answer”)	9	14
HP reported in category “other”: HP is clearly (sport-related) accident	2	1
All or all-1 answers missing in at least one of our principal scales of interest	9	9
Commentary indicates that person had difficulties with the questionnaire	2	0
Clearly not psychological or physical HP	1	1
Obtained analysable questionnaires	317	365
Of these, in LIVES_SHPHealth, reported on a psy HP	82	246
Of these, in LIVES_SHPHealth, reported on a phy HP	235	119
Summary – Analysable questionnaires by category of the principal HP that was reported in LIVES_SHPHealth	354 (235 + 119)	328 (82 + 246)

*Table 6.5: Details of the principal psychological HPs reported.*

HP	N (n female) (n ongoing) (n freq. epis.)	DW	YLL	YLD	Age at diagnosis	Duration	Help (months)
Depressive disorders	127 (f = 89) (ong = 60) (freq = 45)	0.29	0	39.7 (f) 26.8(m)	40.57 (13.62) 7 - 76	11.37 (11.20) 1 - 45	23.14 (48.03) 0 - 288
Burnout	60 (f = 34) (ong = 17) (freq = 45)	0.29	0	4.6 (f) 8.1 (m)	43.45 (11.08) 17 - 63	4.20 (6.62) 1 - 45	13.87 (21.12) 0.03 - 120
Anxiety <sup>a</sup> disorders	54 (f = 42) (ong = 27) (freq = 20)	0.12	0	23.3 (f) 11.80 (m)	34.48 (13.27) 3 - 60	10.47 (12.46) 1 - 49	24.93 (69.61) 0 - 420
Neurological disorders <sup>b</sup>	20 (f = 14) (ong = 15) (freq = 6)	0.36	5.76	3.46	38.05 (18.31) 16 - 74	9.22 (11.0) 1 - 45	23.73 (43.68) 0.03 - 180
Substance abuse disorders	16 (f = 8) (ong = 11) (freq = 2)	0.36	4.2 (f) 12.5 (m)	7.5 (f) 17.3 (m)	37.38 (13.77) 19- 58	14.06 (13.69) 1 - 43	65.71 (63.51) 0 - 180
Adjustment disorders	12 (f = 9) (ong = 6) (freq = 8)	0.12	0	4.6 (f) 8.1 (m)	42.50 (17.24) 17 - 63	3.75 (2.80) 1 - 9	4.64 (3.64) 0 - 12
Eating disorders	12 (f = 10) (ong = 8) (freq = 3)	0.22	0.9 (f) 0.0 (m)	5.4 (f) 0.7 (m)	27.75 (18.74) 9 - 73	14.17 (15.58) 2 - 44	57.03 (119.97) 0 - 420
Bipolar	9 (f = 5) (ong = 7) (freq = 9)	0.49	0	8.5 (f) 5.4 (m)	35.67 (11.03) 20 - 52	21.44 (17.79) 4 - 51	78.16 (92.36) 0.03 - 240
Hyperactivit y/ attention dis.	5 (f = 2) (ong = 2) (freq = 2)	0.05	0	0.2 (f) 0.4 (m)	15.00 (17.07) 3 - 45	11.20 (11.61) 1 - 29	34.33 (53.46) 1 - 96
Suicide attempts	4 (f = 2) (ong = 0) (freq = 4)	0.29	0	4.6 (f) 8.1 (m)	21.5 (10.72) 13 - 37	-	-
Schizophreni a/ Psychotic disorders	2 (f = 2) (ong = 1) (freq = 1)	0.78	1.0 (f) 0.8 (m)	7.9 (f) 8.3 (m)	43.0 39, 47	16.5 2, 31	-
Personality disorders <sup>c</sup>	2 (f = 2) (ong = 2) (freq = 0)	0.12	0	4.6 (f) 8.1 (m)	31 22, 40	8,8	84 84,120
Sleeping disorders	2 (f = 2) (ong = 1) (freq = 0)	0.12	0	4.6 (f) 8.1 (m)	40.00 30, 50	2.00 1,3	2.02 0.03,4

	2	0.12	0	4.6 (f) 8.1 (m)	35.5 25, 46	7 4, 10	6.5 1, 12
Psychosomatic disorders	(f = 1) (ong = 1) (freq = 0)						
Sexual identity disorder	1 (ong = 1) (freq = 1)	0.29	0	4.6 (f) 8.1 (m)	13	36	240

*Note.*

*f* = *n* female; *ong* = *n* ongoing; *freq* = *n* who had more than one episode of the HP.

a Anxiety disorders: Posttraumatic stress disorder: *n* = 18; Generalised anxiety disorder: *n* = 18; Specific phobia: *n* = 3; Social phobia: *n* = 5; Panic disorder: *n* = 15; Obsessive compulsive disorders: *n* = 1, YLD: 11.8 (m), 23.3 (f); double indications possible;

b Epilepsy: *n* = 7, DW = .26, YLL = 2.2(m), 1.4(f), YLD = 1.6; Parkinson: *n* = 2, DW = .24, YLL = 5.2(m), 4.2(f), YLD = 0.9; Multiple sclerosis: *n* = 8 DW = .47, YLL = 1.4(m), 2.4(f), YLD = 1.5 (m), 3.6 (f), 1 neurovegetative dystonia, 1 facial paraplegia YLD = 0.9 (m), 1.3 (f), YLL = 9.9 (m), 6.9 (f), 1 alzheimer's disease: DW: 0.43, YLD = 8.1 (m), 18.3 (f), YLL = 24.6 (m), 46.5 (f)

c 1 paranoid & anxious personality disorder, one anxious-avoidant personality disorder

*Table 6.6: Details of the principal physical HPs reported.*

HP	Freq (female) (ongoing) (sev. epis)	DW	YLL	YLD	Age at diagnosis	Duration	Help (months)
Arthrosis/ rheumatism	90 (f = 59) (ong = 80) (freq = 9)	0.34	0.7 (f) 0.2 (m)	6.8 (f) 2.9 (m)	48.26 (13.49) 16 - 78	11.99 (10.99) 1 - 58	24.21 (39.15) 0.03 - 240
Other orthopedic		0.34					
Mostly back and other body parts	26 (f = 19) (ong = 21) (freq = 5)		3.2 (f) 1.8 (m)	15.6 (f) 10.3 (m)	33.54 (18.44) 10 - 70	17.96 (14.24) 1 - 48	12.11 (26.75) 0.03 - 120
Pain without known cause	17 (f = 13) (ong = 12) (freq = 2)		3.2 (f) 1.8 (m)	15.6 (f) 10.3 (m)	40.12 (16.26) 14 - 70	10.53 (6.76) 1 - 25	14.18 (21.21) 0.03 - 60
Osteoporosis	8 (f = 7) (ong = 7) (freq = 4)		3.2 (f) 1.8 (m)	15.6 (f) 10.3 (m)	55.62 (8.60) 40 - 69	10.12 (6.92) 1 - 22	43.00 (70.83) 0 - 180
Hay fever, allergies	53 (f = 29) (ong = 46) (freq = 1)	0.006	2.76 (f) 3.07 (m)	82.06 (f) 68.26 (m)	20.45 (16.06) 0 - 73	24.15 (14.72) 3 - 58	38.27 (71.63) 0 - 364
Cardiovascular	46 (f = 19) (ong = 39) (freq = 12)	0.27	21.20	2.70	48.67 (17.68) 4 - 76	15.54 (11.16) 1 - 43	6.34 (9.64) 0 - 36
Neurological	28 (f = 23) (ong = 18) (freq = 6)	0.39	3.55	18.11	28.32 (16.93) 7 - 64	16.68 (13.35) 1 - 43	25.80 (33.73) 0 - 120
Cancer, tumour	22 (f = 15) (ong = 10) (freq = 18)	0.26	19.52	2.85	53.57 (14.54) 7 - 71	4.43 (4.61) 1 - 18	7.02 (13.04) 0 - 48
Endocrinologi cal	18 (f = 12) (ong = 17) (freq = 6)	0.15	8.18	11.69	48.56 (16.94) 10 - 70	15.83 (9.92) 1 - 40	14.33 (39.01) 0 - 131.47
Gastrointestina l	15 (f = 12) (ong = 9) (freq = 4)	0.12	5.01	2.21	43.67 (19.74) 17 - 65	9.00 (9.41) 1 - 35	9.36 (15.66) 0.03 - 60
Respiratory	13 (f = 6) (ong = 9) (freq = 0)	0.08	3.83	9.82	26.54 (23.95) 3 - 70	25.92 (13.41) 3 - 43	9.52 (12.89) 0 - 36
Dermatologica l	7 (f = 3) (ong = 6) (freq = 0)	0.19	0.67	7.89	30.29 (21.78) 1 - 55	25.43 (17.41) 6 - 55	45.50 (95.40) 1 - 240

Auditory	4 (f = 3) (ong = 4) (freq = 1)	0.09	0	7.47	35.25 (29.68) 6 - 76	24.50 (29.85) 5 - 68	8.01 (6.91) 0.03 - 12
Nephrological	3 (f = 1) (ong = 2) (freq = 1)	0.11	3.20	3.17	49.67 (24.58) 22 - 69	20.00 (23.07) 2 - 46	0.17 (0.15) 0.03 - 0.33
Sleeping disorders	2 (f = 1) (ong = 2) (freq = 0)	0.03	0	6.35	38.00 20,56	23.00 0,46	-
Infectious	2 (f = 1) (ong = 1) (freq = 1)	0.20	1.45	0.55	43.50 25,62	9.50 8,11	7.50 3,12

*Note:* f = n female; ong = n ongoing; freq = n who had more than one episode of the HP.

Other orthopaedic: Mostly back and other body parts: n = 26, YLD: 46.5(m), 64.1(f), YLL: 1.8 (m), 3.2 (f); Pain without known cause: n = 17; osteoporosis: n = 8. Cardiovascular: Hypertension: n = 31, YLD: 0.2 (m), 0.2 (f), YLL: 7.7 (m), 10.8 (f); Acute Coronary Syndrome: 7, YLD: 4.6 (m), 4.4 (f), YLL: 88.5(m), 60.9 (f); Unspecified: 8, e.g. arrhythmia, YLD: 11.1 (m), 9.8 (f), YLL: 20.9 (m), 18.4 (f); Neurological: Migraine n = 23, DW: 0.441, YLD: 13.4 (m), 22.7 (f), YLL: 0; Stroke/ cerebrovascular accident = 4, DW: 0.075, YLD: 2.9 (m,f), YLL: 20.9 (m), 25.4 (f); Spinal chord infarction = 1, YLD: 0.9 (m), 1.3 (f), YLL: 9.9 (m), 6.9 (f); Cancer: 16 possibly more strongly linked to identity: Cervical (n = 1), Ovarian (n = 1), skin (n = 3), prostate (n = 3), breast (n = 9), brain (n = 1), 6 other (e.g. thyroid, bone, blood, knee (n = 6)). DWs/ YLL/ YLD introduced for specific cancers and gender. Endocrinological: Diabetes n = 14, thyroid disease n = 4, Respiratory: Asthma n = 11, Chronic bronchitis n = 2; Gastrointestinal: Gastric ulcer n = 4, Other: E.g. Irritable Bowel Syndrome, Diverticulitis, Gall stones; Dermatological: e.g. Psoriasis, Rash, eczema, Lichen Planus, Lip Herpes; Auditory, e.g. Hardness of hearing, Tinnitus, hearing loss; Nephrological, e.g. kidney stones, renal failure, bladder prolapse; Infectious: 1 HIV.