



Department Epidemiology and Public Health
Unit Chronic Disease Epidemiology

Full National Burden of Disease Study in Switzerland (BoD-CH): Opportunities and Challenges

Case Study on Diabetes mellitus: Disease Burden and Patterns of Care in Switzerland

*Report of a Key Stakeholder Workshop
on 26 August 2019 at Swiss TPH in Basel
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Swiss Tropical and Public Health Institute (Swiss TPH)

Scuola Universitaria Professionale della Svizzera Italiana
(SUPSI)

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Contacts

Dr. Thomas FÜRST

Senior Scientific Collaborator
Unit Chronic Disease Epidemiology
Department Epidemiology and
Public Health
Swiss TPH (www.swisstph.ch)
Socinstrasse 57
P.O. Box
4002 Basel, Schweiz

thomas.fuerst@swisstph.ch

T: +41 61 284 87 65 (direct)

Dr. Monika Diebold

Head of Swiss Health Observatory
Swiss Health Observatory (OBSAN) (www.obsan.admin.ch)
Espace de l'Europe 10
2010 Neuchâtel, Suisse

monika.diebold@bfs.admin.ch

T: +41 58 463 65 58 (direct)

Prof. Dr. Nicole Probst-Hensch

Head of Unit & Department
Unit Chronic Disease Epidemiology
Department Epidemiology and
Public Health
Swiss TPH (www.swisstph.ch)
Socinstrasse 57
P.O. Box
4002 Basel, Schweiz

nicole.probst@swisstph.ch

M: +41 79 280 34 14

T: +41 61 284 83 78 (direct)

Administration: Nora Bauer Ott

nora.bauer@swisstph.ch

T: +41 61 284 83 88 (direct)

Prof. Dr. Carlo de Pietro

Professor of Healthservices Management and Policy
Dipartimento economia aziendale, sanità e sociale
SUPSI (www.supsi.ch)
Piazzetta 209
Via Violino
6928 Manno, Svizzera

carlo.depietro@supsi.ch

T: +41 58 666 64 62 (direct)

Dr. Carlos Quinto

Senior Scientific Collaborator
Unit Chronic Disease Epidemiology
Department Epidemiology and
Public Health
Swiss TPH (www.swisstph.ch)
Socinstrasse 57
P.O. Box
4002 Basel, Schweiz

carlos.quinto@swisstph.ch

T: +41 61 284 83 89 (direct)

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Background

Over the past two decades, the Global Burden of Disease (GBD) study has evolved into the most comprehensive worldwide descriptive epidemiological study.¹ The GBD study results are highly cited and core staff members are considered to be among “the world’s most influential scientific minds”.² Currently, the GBD consortium describes age- and sex-specific mortality and morbidity due to 359 major diseases and injuries at global, regional, national, and for selected countries also at subnational level, for the years 1990-2017.¹ Moreover, the use of a common methodology and summary measure of population health – the disability-adjusted life years (DALYs) – make all burden estimates comparable across all these dimensions. For instance, it allows for national age- and sex-specific health loss comparisons across different conditions by combining information on mortality and morbidity, which is highly relevant as “death does not tell the full story”.³ Developing and developed countries increasingly realize the value of such age- and sex-specific national and subnational burden of disease studies to inform their health policies (for instance, see ^{4,5} for England or ⁶ for Norway). Also, the standardized methodology and measure (i.e. DALYs) enables cross-country comparisons, which can provide useful hints about (in)efficiencies in a national health system.⁴⁻⁶

Discussions with national and international colleagues indicate that the more “top-down” approach from the GBD collaboration can powerfully complement more localised and cause-specific “bottom-up” approaches in assessing national population health, health policy, and data gaps. In the highly fragmented Swiss public health landscape, pragmatic national burden of disease studies constitute an interesting opportunity to combine various specialties and geographies and gain a more comprehensive and nationally and internationally comparable overview over the health of the population in Switzerland. A solid analysis of the health of the Swiss population may also help to spark broader based and better informed discussions about health system choices and priorities in times of constantly rising health insurance bills. In fact, the aforementioned English national burden of disease studies (see reference ^{4,5} above) received tremendous media attention (media coverage survey can be shared if deemed relevant) and consequently, burden of disease studies seem to provide “a new packaging for communicating old and new public health findings to the general public” (personal comment Prof. John Newton, Director of Health Improvement, Public Health England).

Of note, colleagues involved in (sub-)national burden of disease studies in other countries reported substantial inaccuracies in international burden assessments such as the GBD study when compared with national data. One of the main reasons for these inaccuracies are differences in disease progression due to differences in the (sub-)national healthcare systems (personal communication Dr. Ian Grant, Principal Researcher, Scottish Burden of Disease, Scottish Health Observatory). The provision or lack of treatment in healthcare services influence disease progression, thereby impact on population health, and should thus be reflected in burden assessments. However, international burden assessments often lack the expertise and/or resources to pay attention to the various (sub-)national patterns of care and often rely on models informed by national and international proxies and explanatory variables.

A well-structured description of patterns of healthcare services is relevant per se, of course, and beyond its importance for burden assessments. Again, in the highly fragmented Swiss healthcare system, a multitude of localised and specialised initiatives and organisations evolved over time to address various healthcare needs of the population. Often, a clear overview of such healthcare services is lacking. This lack of an overview impedes the well-informed decision making of patients, healthcare providers, politicians and other partners and stakeholders.

This report is from a workshop that focused on the disease burden of and patterns of care for diabetes mellitus in Switzerland. Diabetes mellitus was selected for the case study as it is a chronic, non-communicable disease, which constitutes a major public health problem in Switzerland and requires a complex, specialised and well-coordinated care. Furthermore, diabetes mellitus is a good example of a disease with a limited and scattered data base regarding the national descriptive epidemiology and patterns of care. The rate of under-diagnosis is likely to be substantial. As diabetes can lead to a multitude of sequelae, the disability that can be etiologically linked with diabetes is important, but difficult to evaluate. Also, most patients do not die from diabetes directly but rather its longer-term sequelae, and hence, cause of death statistics may be inaccurate. Last but not least, the subdivision of the numbers into cases of type 1 and type 2 diabetes is unknown.

Explicit and implicit goals and objectives

In agreement with the managers of SSPH+, the initial proposal for exploring opportunities and challenges that may arise from a full (i.e. including the most important causes of mortality and morbidity) national burden of disease study by visiting and discussing the idea with a few selected key persons was revised. In order to be more concrete and profit from the synergies with a mandate from the Swiss Health Observatory (OBSAN), it was decided to focus on diabetes mellitus instead of a full national burden of disease study and to organize a diabetes stakeholder workshop with the following explicit and implicit goals:

1. Explicit goal of the workshop: Presentation of the project and its current state on the burden and patterns of care for diabetes mellitus in Switzerland.
2. Explicit goal of the workshop: Start a stakeholder dialogue and discussions with potential partners in the fields of diabetes, burden and healthcare research in Switzerland.
3. Implicit goal in the workshop: Explore opportunities and challenges that arise from burden of disease assessments in Switzerland.

These goals were broken down into the following, more specific and explicitly objectives for the workshop:

- i. Feedback on and further completion of the current database regarding (a) relevant stakeholders, (b) relevant health care providers, (c) relevant guidelines, and (d) sources of quantitative data to estimate disease burden.
- ii. Development of applicable/operational characteristics and criteria for integrated diabetes care services & utility and feasibility of identifying typical patient-centered care pathways.
- iii. Start developing a list of integrated diabetes care services and providers.
- iv. Input on potential approaches to identify additional integrated diabetes care services and providers.
- v. Input for a broader stakeholder consultation.
- vi. Discussion on next steps/way forward on the diabetes disease burden and patterns of care assessment in Switzerland, also with an eye towards the identification of potential key parameters for a potential diabetes surveillance program in Switzerland.

The main language of the workshop was English, but inputs in German, French and Italian were also welcomed and – if need be – translated in a pragmatic way by other workshop participants.

The workshop agenda is provided in Appendix 1 of this report.

Outcomes

After a first stakeholder mapping in the first half of 2019, 86 persons/organizations were invited to participate in the workshop in total. In the end, 24 persons attended the workshop and only from 9 contacts we received no reaction at all. Many of those who could not attend mentioned conflicting dates and appointments as reason. However, they usually emphasized their genuine interest in the topics, provided additional useful information and inputs via email and telephone, wanted to be kept informed and also flagged their interest in future involvement. Those 24 persons who could participate in the workshop came from all major language regions of Switzerland (Ticino, Romandie and Deutschschweiz) and had diverse but highly relevant backgrounds, expertise and affiliations/mandates (see Appendix 2 for a list and photo of all workshop participants). In order to better understand the workshop participants' motivation and also to better target potential future work, a quick written survey was conducted at the very beginning of the workshop. This survey revealed that most participants were mainly interested in the patterns of diabetes care and to a lower degree in diabetes burden assessment in Switzerland (Table 1).

Table 1: Quick written survey among workshop participants: „How important were the following topics in your decision to participate in the workshop?“

	Very important	Important	Less important	No answer	Total
"Disease Burden"	6 (25%)	12 (50%)	2 (8%)	4 (17%)	24 (100%)
"Patterns of Care"	17 (71%)	3 (13%)	0 (0%)	4 (17%)	24 (100%)

The workshop was formally opened with a short welcome note from Prof. Juerg Utzinger (Director Swiss TPH) and Prof. Nicole Probst-Hensch (Head of Department of Epidemiology and Public Health at Swiss TPH and Principal Investigator of the Case Study on the Diabetes Mellitus Disease Burden and Patterns of Care in Switzerland). After a quick round of introductions of all participants, Dr. Thomas Fürst (Coordinator of the Project) gave an input presentation on the OBSAN case study mandate on the disease burden and patterns of care of diabetes mellitus in Switzerland. Besides highlighting the current ideas and state of the work, the presentation also provided a short introduction in burden of disease assessments and the calculation of their main metric, the so-called disability-adjusted life years (DALYs) (see Appendix 3, Slides 1-39). The immediately following discussions demonstrated again that many research and applied healthcare projects have been completed over the past years or are currently ongoing. However, all these efforts focused on some specific aspects of the disease and/or covered only a rather limited/specific part of the patients and/or the Swiss population overall. Also, most input from the workshop participants referred to healthcare research and not so much to descriptive epidemiology, which may come as no surprise given the workshop participants' main interests as illustrated in Table 1. Some better or less known examples of completed or currently ongoing research and applied healthcare projects that were mentioned:

- Swiss Diabetes Registry (SwissDiab): Prospective cohort study aiming at including and collecting data of virtually all patients regularly seen and treated at the three study centres (Inselspital Bern, Kantonsspital St. Gallen, Universitätsspital Zürich; ≈ 500 patients per centre), irrespective of type, duration of diabetes or treatment – insights into disease management and course of disease – only patients seen and consenting in the three hospitals.⁷
- Family medicine International Classification of Primary Care (ICPC) Research using Electronic medical records (FIRE project): Research project lead by the Institut für Hausarztmedizin der Universität Zürich (IHAMZ) with the goal to build up a research database containing the electronic records of participating GP practices, following the ICPC classification – insights into underdiagnosis, differentiation between type 1 and 2, disease management and course of disease – only patients seen in participating GP practices.⁸

- Siscare-DT2: Research project lead by Sispha AG, which belongs to the Berufsgenossenschaft der Schweizer Apotheker (Ofac), with the aim to improve treatment adherence of people with diabetes mellitus type 2 – insights into disease management and particularly treatment adherence of people with diabetes mellitus type 2 – thus far, only a comparatively small group of people with diabetes mellitus type 2.⁹
- Health Behaviour in School-Aged Children in Switzerland (HBSC Switzerland): A World Health Organization (WHO) collaborative cross-national study, in Switzerland carried out by Sucht Schweiz, with the aim to assess health behaviour and lifestyles in 11 and 15 years old every four years, based on nationally representative samples – potentially relevant insights into risk factors and prevalence – exact data available still needs verification and only available in 11 and 15 years old, but as a nationally representative sample.¹⁰

It was also highlighted that a population-based, diabetes-specific screening or surveillance program currently is neither in place nor planned in Switzerland. However, there are some diabetes risk assessment tests, which can be used by patients as well as healthcare professionals. Furthermore, it was mentioned that in a quite successful project in the canton Vaud, pharmacies were encouraged to make also initial diabetes diagnosis as part of a more comprehensive screening of non-communicable diseases (NCDs). Nevertheless, it was emphasized that the age group of the ca. 18-45 year old people may represent a particular challenge in terms of diabetes underdiagnosis and patient loss as they are fully self-responsible and may not yet suffer from any severe and/or specific signs and symptoms. Despite this fact, the colleagues from Ticino reported that they screened approximately 1,200 people in a survey in their canton and did not detect a single new diabetes case that had not been diagnosed previously. In contrast, the optometrist/eye health specialists from Nordwestschweiz provided anecdotal evidence of patients that they see in the hospital with some ophthalmological complaints, which are then referred to a diabetes test and confirmed only then as diabetes patients. These two statements nicely highlight the substantial regional/cantonal variation that may exist in terms of healthcare and underdiagnosis within Switzerland and which one should also keep in mind when reflecting on the descriptive epidemiology and burden of diabetes. Particularly during the discussions on potentially available quantitative data on the descriptive epidemiology and from healthcare research in Switzerland, it was repeatedly confirmed that these data are usually published and should be retrievable by means of a systematic literature review, mainly focusing on PubMed.¹¹

Regarding the diabetes guidelines in Switzerland, it was literally mentioned that „it is a jungle“ by the workshop participants. There seem to be various players, which adopt or adapt existing and sometimes also develop their own guidelines. However, when reviewing the websites of the Swiss Medical Association (FMH),¹² the Schweizerische Gesellschaft für Endokrinologie und Diabetologie (SGED),¹³ the Programme Cantonal Diabète Vaud¹⁴ and QualiCCare,¹⁵ probably most relevant Swiss guidelines would be covered. From the GPs, it was also criticized that the guidelines are not always very useful as they could frequently not adhere to them because of the often very individual and complex patient situation. As one response to this situation, a „Recommendation pour la Pratique Clinique“ (RPC) for multimorbid patients has been developed by the Programme Cantonal Diabète Vaud¹⁶ and is currently being adapted and tested in two pilot studies in different language regions also in collaboration with QualiCCare.¹⁷ In general, for diabetes patients as well as multimorbid patients suffering from various NCDs, the coordination of care, the compliance, clear patient pathways and the patients' (health) literacy is difficult but critical. Improvements in IT tools that facilitate information sharing and the development of appropriate financing and accounting structures were identified as additional essential factors to better coordinated and potentially even integrated care.

In conclusion, and instead of further working through the advanced versions of a quantitative data database, a guidelines database and a stakeholder database in detail (see Appendix 3, Slides 40-50), it was agreed that these databases will be shared with the workshop participants and they can then further comment and provide input via email.

After a tea break, the focus was more specifically on integrated diabetes care. This second part of the workshop started again with an input presentation by Dr. Thomas Fürst (see Appendix 3, Slides 51-58) and was then co-moderated by Prof. Carlo de Pietro and Dr. Thomas Fürst. It was pointed out that integrated

diabetes care is desirable, but that currently and generally no consensus and/or definition of integrated care exists. Hence, the questions arise what integrated diabetes care means, what would be relevant and operationalizable definitions and criteria for integrated diabetes care, and how thus defined and existing integrated diabetes care initiatives could be captured/identified. The criteria of the first Swiss Survey on Integrated Care (SSIC) were confirmed as a promising potential starting point.^{18,19} The SSIC was not condition-specific and used the following inclusion criteria to define integrated care initiatives:

- Formalization: formal written agreement between organizations/institutions.
- Integration at healthcare services level: at least two healthcare services from different levels (e.g. physician-led primary care, non-physician-led primary care, specialised medial outpatient service, home care, community services, etc.).
- Integration at healthcare professionals level: at least two healthcare professionals from different levels (e.g. specialist physician, GP, general nurse, specialist nurse, FaGE (=assistant(e) en soins et santé)/MPA (=assistant(e) médicales), nutritionist, pharmacist, optometrist, physiotherapist, etc.).
- Currently ongoing.

These criteria could be further tailored to the specificities of diabetes care and thereby the precision of the definition and criteria for integrated diabetes care further increased. As an additional critical aspect of integrated diabetes care, the exchange of information and medical data between the different providers was emphasised. However, it was pointed out that a lot of smaller diabetes care networks may exist and hence, there may be some hundred different integrated diabetes care initiatives in Switzerland.

In a short reaction and summary, Dr. Carlos Quinto stated that the work on the descriptive epidemiology and patterns of care for diabetes in Switzerland is of great interest also for the FMH, of course. He also expressed the FMH's willingness to participate and support future efforts. Furthermore, he stressed the substantial heterogeneity that characterises the course and care of diabetes and deduced two key aspects from that: First, the will to work together across professional and institutional boundaries will be essential to further carve out the descriptive epidemiology and patterns of care for diabetes in Switzerland. Second, one has to be careful about the complexities of diabetes and break it down into meaningful (research) questions and projects. Dr. Monika Diebold agreed with these statements, also confirmed the importance of the discussed topics for OBSAN, thanked everybody for all their efforts and expressed her hope to jointly move on. Finally, Prof. Nicole Probst-Hensch concurred with the two previous speakers and officially closed the workshop.

Potential next steps

- The whole materials and information has been digested and summarized in this short meeting report. A near-final version of the meeting report will be shared with all workshop participants for further input/revisions. The final version of the meeting report will be shared again with all workshop participants.
- Together with the near-final version of the meeting report, the advanced versions of the quantitative data database, the guidelines database and the stakeholder database will be shared with the workshop participants so that they can further comment and provide input.
- Since the workshop, various participants already shared further material, information and insights with the organizers (e.g. additional advice, contacts and references, reports and publications, insights about criteria and labels of good diabetes care, etc.)
- A systematic review will be conducted to summarize the available quantitative data on prevalence, incidence, under-diagnosis, mortality, and differentiation between type 1 and type 2 diabetes (whenever available age- and sex-specific). Together with the records in the already established quantitative data database, this will enable us to provide clear, evidence-based answers on the following diabetes-specific questions:
 - What do we know and what not about the epidemiologic key parameters in Switzerland?
 - What are all the relevant quantitative data sources?
 - What are limitations of the existing data/data sources?
- All diabetes-specific guidelines for Switzerland in the guidelines database will be reviewed and this will enable us to provide clear, evidence-based answers on the following questions:
 - For which aspects do guidelines exist?
 - Based on this guidelines review, which core set of ca. 10-20 aspects/indicators could potentially serve as a core set in a population-based diabetes surveillance in Switzerland?
 - What diabetes surveillance exists in other countries (particularly Germany, France, United Kingdom) and what core indicators do they use?
- All above-mentioned steps will serve as a basis for discussion regarding an improved diabetes surveillance in Switzerland.

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Appendix 1: Workshop agenda

Time	Topic	Structure
14:00-14:10	Welcome	Juerg Utzinger & Nicole Probst-Hensch
14:10-14:30	Introduction of participants	Plenum
14:30-15:00	Presentation of the project	Input presentation 1, Thomas Fürst
15:00-15:15	Immediate Q/A, reactions, discussion	Plenum, Moderation Thomas Fürst
15:15-15:30	Feedback/further completion stakeholder database	Plenum, Moderation Thomas Fürst
15:30-15:45	Feedback/further completion guidelines database	Plenum, Moderation Thomas Fürst
15:45-16:00	Feedback/further completion quantitative data database	Plenum, Moderation Thomas Fürst
16:00-16:30	Break	Break with refreshments
16:30-16:45	Integrated and patient-centered diabetes care	Input presentation 2, Thomas Fürst
16:45-17:00	Integrated and patient-centered diabetes care: criteria and characteristics?	Plenum, Co-Moderation Carlo de Pietro & Thomas Fürst
17:00-17:15	Integrated and patient-centered diabetes care: first list of providers and services known to participants	Plenum, Co-Moderation Carlo de Pietro & Thomas Fürst
17:15-17:30	Integrated and patient-centered diabetes care: approach to identifying additional providers and services after the workshop	Plenum, Co-Moderation Carlo de Pietro & Thomas Fürst
17:30-17:45	Input for a broader stakeholder consultation	Plenum, Moderation Thomas Fürst
17:45-17:50	Relevance of work on diabetes disease burden and patterns of care for him as GP, public health expert and representative of FMH	Plenum, Moderation Carlos Quinto
17:50-17:55	Relevance of work on diabetes disease burden and patterns of care for OBSAN	Plenum, Moderation Monika Diebold
17:55-18:00	Conclusion, thanks and farewell/closure	Plenum, Moderation Monika Diebold & Nicole Probst-Hensch

Appendix 2: Workshop participants

(in alphabetic order)

Name	Relevant affiliation(s) and mandate(s)	Stakeholder classification
Czock Astrid	<ul style="list-style-type: none"> • QualiCCare • Schweizerische Gesellschaft für Endokrinologie und Diabetologie (SGED/SSED) 	<ul style="list-style-type: none"> • Academia/Expert • Healthcare: Specialist doctors
De Pietro Carlo	<ul style="list-style-type: none"> • Dipartimento economia aziendale, sanità e sociale, Scuola Universitaria Professionale della Svizzera Italiana (SUPSI) 	<ul style="list-style-type: none"> • Academia/Expert
Diebold Monika	<ul style="list-style-type: none"> • Swiss Health Observatory (OBSAN) 	<ul style="list-style-type: none"> • Administration
Fankhauser Pia	<ul style="list-style-type: none"> • Independent Physiotherapist • Physioswiss • Plattform Interprofessionalität 	<ul style="list-style-type: none"> • Healthcare: Physiotherapists • Academia/Expert
Fischer-Taeschler Doris	<ul style="list-style-type: none"> • Schweizerische Diabetes Stiftung (SDS) • Schweizerische Gesundheitsligenkonferenz (GELIKO) • Schweizerische Gesellschaft für Endokrinologie und Diabetologie (SGED/SSED) • Schweizerischen Gesellschaft für Pädiatrische Endokrinologie und Diabetologie (SGPED/SSEDP) • DIAfit 	<ul style="list-style-type: none"> • Patients • Healthcare: Counselling & Representation • Healthcare: Specialist doctors
Fürst Thomas	<ul style="list-style-type: none"> • Department Epidemiology and Public Health, Swiss TPH 	<ul style="list-style-type: none"> • Academia/Expert
Gabutti Luca	<ul style="list-style-type: none"> • Internal Medicine, Ente Ospedaliero Cantonale (EOC) • Facoltà di Scienze Biomediche, Università della Svizzera Italiana (USI) 	<ul style="list-style-type: none"> • Healthcare: Hospitals • Healthcare: Specialist doctors • Academia/Expert
Güntert Bernhard	<ul style="list-style-type: none"> • Curafutura 	<ul style="list-style-type: none"> • Health Insurance
Hagon-Traub Isabelle	<ul style="list-style-type: none"> • Médecin Responsable Pôle Diabétologie, Ensemble Hospitalier de la Côte • Directrice Programme Diabète Canton Vaud • Vorstand diabetesschweiz 	<ul style="list-style-type: none"> • Healthcare: Specialist doctors • Healthcare: Counselling & Representation • Patients

Name	Relevant affiliation(s) and mandate(s)	Stakeholder classification
Huber Claudia	<ul style="list-style-type: none"> Unité de Recherche en Interventions Infirmières complexes, Haute Ecole de Sante Fribourg Co-Präsidentin Schweizerische Interessengruppe für Diabetesfachberatung (SIDB) des Schweizer Berufsverband der Pflegefachfrauen und Pflegefachmänner (SBK/ASI) 	<ul style="list-style-type: none"> Academia/Expert Healthcare: Nursing Healthcare: Counselling & Representation
Kaiser-Pfarrmann Eva	<ul style="list-style-type: none"> Independent GP Haus- und Kinderärzte Schweiz (mfe) 	<ul style="list-style-type: none"> Healthcare: GP
Krummenacher Isabelle	<ul style="list-style-type: none"> Schweizerischer Apotheker Verband (pharmaSuisse) 	<ul style="list-style-type: none"> Healthcare: Pharmacies
Kündig Martin	<ul style="list-style-type: none"> Optometrist and manager Iseli Optik Basel Schweizerische Berufsverband für Augenoptik und Optometrie (SBAO) 	<ul style="list-style-type: none"> Healthcare: optometrists/optician
Leimgruber Christine	<ul style="list-style-type: none"> Diabetes Schweiz 	<ul style="list-style-type: none"> Healthcare: Counselling & Representation Patients
Lucchini Barbara	<ul style="list-style-type: none"> Capo Servizio di Endocrinologia e Diabetologia, Ente Ospedaliero Cantonale (EOC) 	<ul style="list-style-type: none"> Healthcare: Hospitals Healthcare: Specialist doctors
Müller Beatrice	<ul style="list-style-type: none"> Klinik und Poliklinik für Innere Medizin, Universitätsspital Zürich Schweizerische Gesellschaft für Allgemeine Innere Medizin (SGAIM) 	<ul style="list-style-type: none"> Healthcare: Hospitals Healthcare: Specialist doctors
Müller Nina C.	<ul style="list-style-type: none"> Augenklinik, Universitätsspital Basel Schweizerische Berufsverband für Augenoptik und Optometrie (SBAO) 	<ul style="list-style-type: none"> Healthcare: optometrists/optician Healthcare: Hospitals

Name	Relevant affiliation(s) and mandate(s)	Stakeholder classification
Peytremann-Bridevaux Isabelle	<ul style="list-style-type: none"> • Institut Universitaire de Médecine Sociale et Préventive (IUMSP), Université de Lausanne • Centre Hospitalier Universitaire Vaudois (CHUV) 	<ul style="list-style-type: none"> • Academia/Expert • Healthcare: Specialist doctors
Prandi Cesarina	<ul style="list-style-type: none"> • Dipartimento economia aziendale, sanità e sociale (Focus Nursing), Scuola Universitaria Professionale della Svizzera Italiana (SUPSI) 	<ul style="list-style-type: none"> • Academia/Expert • Healthcare: Nursing
Probst-Hensch Nicole	<ul style="list-style-type: none"> • Department Epidemiology and Public Health, Swiss TPH 	<ul style="list-style-type: none"> • Academia/Expert
Quinto Carlos	<ul style="list-style-type: none"> • Department Epidemiology and Public Health, Swiss TPH • Zentralvorstand FMH • Independent GP 	<ul style="list-style-type: none"> • Academia/Expert • Healthcare: GP
Rodella Sapia Mirjam	<ul style="list-style-type: none"> • Servizio di Medicina Interna, Ente Ospedaliero Cantonale (EOC) • Independent GP • Fachrat Public Health Schweiz • Lecturer Scuola Universitaria Professionale della Svizzera Italiana (SUPSI) 	<ul style="list-style-type: none"> • Healthcare: Hospitals • Healthcare: GP • Academia/Expert
Schenk Marianne	<ul style="list-style-type: none"> • Schweizerischer Verband Medizinischer Praxis-Fachpersonen (SVA) • OdA Berufsbildung Medizinische Praxisassistentin (Odamed) 	<ul style="list-style-type: none"> • Healthcare: medical practice assistants and medical practice coordinators
Wieser Simon	<ul style="list-style-type: none"> • Winterthurer Institut für Gesundheitsökonomie (WIG), Zürcher Hochschule für Angewandte Wissenschaften (ZHAW) 	<ul style="list-style-type: none"> • Academia/Expert



Appendix 3: Slides presented during workshop

Swiss TPH
Swiss Tropical and Public Health Institute
Schweizerisches Tropen- und Public Health Institut
Institut Tropical et de Santé Publique Suisse
Associated Institute of the University of Basel

Thomas Fürst
Department Epidemiology and Public Health

Stakeholder Workshop
Diabetes Mellitus: Disease Burden and Patterns of Care in Switzerland
26 August 2019
Swiss TPH

SSPH+ SWISS SCHOOL OF PUBLIC HEALTH
SUPSI
Schweizerisches Gesundheitsobservatorium
Observatoire suisse de la santé
Osservatorio svizzero della salute
Swiss Health Observatory

Welcome & Introduction myself

Swiss TPH

WELCOME

> MA Geography, Economics, Sociology (University of Basel)
 > PhD Epidemiology (Swiss TPH)
 > Honorary Research Associate, Imperial College London
 > Senior Scientific Collaborator, Swiss TPH

> Scientific Council Member, Global Burden of Disease (GBD) Collaboration
 > Steering Group Member, WHO European Health Information Initiative (WHO EURO EHII)
 > Founding Member, Joint IHME/WHO European Burden of Disease Network (EBoDN)
 > Management Committee, COST Action <burden-eu>

26 August 2019 Workshop Diabetes 2

Welcome & Introduction myself

Swiss TPH

Burden of disease (BoD) background...

> Workshop participation of a large, diverse, highly qualified group...
 > Presentation of work in progress and some ideas...
 > Wonderful opportunity – slightly nervous...
 > BEAR WITH ME!

26 August 2019 Workshop Diabetes 3

This Workshop

Swiss TPH

> Excellent moment for a workshop!
 > Receive input on first outputs
 > Receive input on potential way(s) forward/ideas/"visions"
 > Very positive feedback on workshop invitations – despite relatively short notice and during holiday season
 > In the end 86 contacts and only from 9 no reaction at all
 > Many who could not attend provided already additional input and emphasized their interest also in future involvement (outputs, other meetings, etc.)
 > Slightly overwhelmed by reaction and also workshop attendance
 > → active, spontaneous input from participants also on workshop structure most welcome – we have to be and are flexible!
 > Topics of the project broad – backgrounds of workshop participants also diverse and interdisciplinary → bodes well!

26 August 2019 Workshop Diabetes 4

This Workshop

Swiss TPH

Time	Topic	Structure
14:00-14:10	Welcome	Jürg Utzinger & Nicole Probst-Hensch
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17:55-18:00	Conclusion, thanks and farewell/closure	Plenum, Mod. Monika Diebold & Nicole Probst-Hensch

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The project

Swiss TPH

Schweizerisches Gesundheitsobservatorium
 Observatoire suisse de la santé
 Osservatorio svizzero della salute
 Swiss Health Observatory

SSPH+ SWISS SCHOOL OF PUBLIC HEALTH

SUPSI

zhaw

OBSAN mandate: "Diabetes mellitus: Disease Burden and Patterns of Care in Switzerland"

Financing workshop to explore "Burden of Disease Studies in Switzerland: Opportunities and Challenges" within its seed money programme "Foster Interuniversity Initiatives and Collaborations"

Partners in the SSPH+ workshop (and hopefully beyond...) (Carlo de Pietro, Luca Crivelli)

Partners in the OBSAN mandate and the SSPH+ workshop (and hopefully beyond...) (Simon Wieser, Julia Dratva)

26 August 2019 Workshop Diabetes 6

The project

Swiss TPH

"Be clear about 'stated' and 'latent' objective"

Jan P. Vandenbroucke



Stated/explicit objective of the research:	Latent/implicit objective in the research:	
1) Diabetes mellitus (DM): disease burden in Switzerland	3) Start stakeholder dialogue with (potential) partners in the fields of diabetes, burden and healthcare research in Switzerland	4) Explore opportunities and challenges that arise from burden of disease assessments in Switzerland – content-wise and personally
2) Diabetes mellitus (DM): patterns of care in Switzerland		
Main theme	Workshop contributing	Workshop contributing

26 August 2019

Workshop Diabetes

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The project

Introduction burden of disease

Swiss TPH

- Who has heard of/knows what a (global) burden of disease study is?
- Who has heard of/knows what disability-adjusted life years (DALYs) are?

«Burden» and «Summary measures of population health (SMPH)» of a disease, injury, or risk factor often used in a wider, intuitive, but also unprecise way – for instance, often just as a synonym for prevalence, incidence, clinical manifestations, mortality, socioeconomic consequences, etc.

In a narrower, stricter and preciser sense, the (health) «burden» of a disease, injury, or risk factor is assessed by using «summary measures of population health (SMPH)» as measurement methods.

Summary measures of population health are measures that combine information on mortality and non-fatal health outcomes to represent the health of a particular population as a single number.
(Field & Gold 1998)

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Workshop Diabetes

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The project

Introduction burden of disease

Swiss TPH

- What should be considered in a «summary measure of population health»?

1. Progression of a health condition/causally attributable sequelae
2. Incidence of sequelae
3. Prevalence of sequelae
4. «Morbidity» / «Severity» of sequelae
5. Duration of sequelae
6. Remission/Cure rate from sequelae
7. Case fatality/Mortality of sequelae
8. Health-service attendance due to sequelae
9. Socioeconomic status of person with sequelae
10. Equity / «Fairness» considerations
11. Other (also non-health) factors

Briefly (2-3 min. max) discuss pros and cons with your neighbour(s) of each indicator on its own and/or in combination(s)

Basic descriptive epidemiology key indicators!!!

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Workshop Diabetes

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The project

Introduction burden of disease

Swiss TPH

- Traditionally, often mortality indicators in the form of cause-specific case fatality rates, life tables and life expectancies used
- Still today, a good «natural» starting point as basis to understand the construction of most further refined «summary measure of population health»
- (Cause-specific) mortality tells you a lot about the health of a population... but it does not tell you the full story!
- Some of the most prevalent and expensive conditions for a health system – particularly in high-income countries – are chronic and do not (anymore) lead to much premature death
- Probably the two most often used «summary measure of population health» at the moment
 - Quality-adjusted life years (QALYs)
 - Disability-adjusted life years (DALYs)



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The project

Introduction burden of disease

Swiss TPH

- DALYs time-based measure of health loss and calculated – for a certain population, year, and sequela – as follows:

- DALYs = YLL + YLD
- YLL = Years of life lost (due to premature death)
= N * L
- YLD = Years lived with disability
= P * DW (= I * D * DW)
- N = Number of deaths
- L = (Standard) Life expectancy at age of death
- P = Prevalence
- DW = Disability weight (scale from 0=full health to 1=death; analogy disability insurance IV/AI)
- (• I = Incidence)
- (• D = Duration)
- (• R = Remission/Cure rate)

Qualitative model for progression of condition / causally attributable sequelae

Quantitative data

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The project

Introduction burden of disease

Swiss TPH

	OBSAN / BFS	IDF	GBD
Reference year	2017	2017	2017
Reference population	Residents, ≥15 y. o.	Residents, 20-79 y. o.	All residents
DM prevalence "confirmed", in % of total pop.	4.6	4.8	10.5
DM prevalence "undiagnosed", in % of total pop.	?	2.6	?
DM prevalence "total", in % of total pop.	4.6	7.4	10.5
Total number of deaths due to DM	1,274	1,800	1,123
Total DALYs lost due to DM	?	?	74,780
Cause-specific ranking DM* (*if all overall health losses measured in DALYs)	?	?	4
Additional annual health expenditure per diabetic** (**people with diabetes have average two times higher healthcare expenditure than people without diabetes)	?	CHF 5,000-6,000	?

- Short extrapolation:

National difference in prevalence of 1% ≈ 85,000 people;
→ national difference in annual health expenditure: CHF 425-510 Mio.

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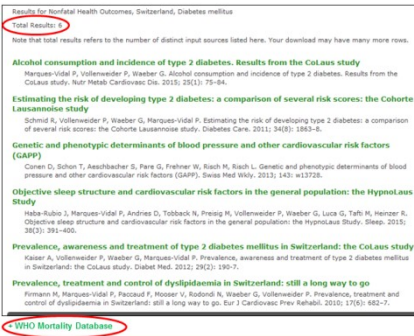
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The project Introduction burden of disease

Swiss TPH

- Swiss data the "gold standard"
- E.g. GBD results:



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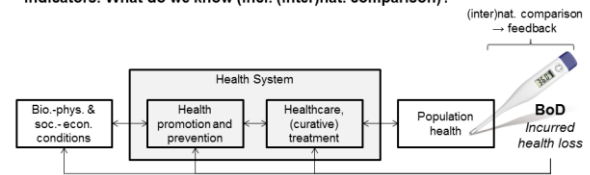
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- Pro 1: Systematic approach to look at basic descriptive epidemiology key indicators: What do we know (incl. (inter)nat. comparison)?



- Easily comparable quantitative estimates of health loss – considering mortality and morbidity – across causes, populations and population groups (e.g. by age and/or sex), locations and time
- "Top-down"/"remote sensing"; assembling bits and pieces to provide an as high-resolution picture of the overall population health/health loss as possible – no need to necessarily have data linked at individual level, therefore also less data protection issues → highly relevant in "fragmented" Swiss public health landscape
- Current state of knowledge and knowledge gaps (inexistence or inaccessibility of data)

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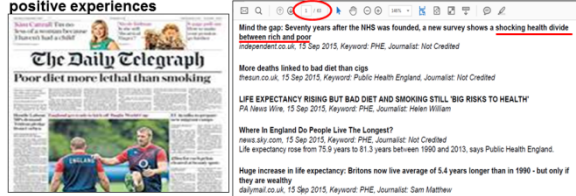
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- Pro 2: Some countries also in Western Europe (e.g. England, Scotland, Norway, Germany) working and using BoD approach and generally report positive experiences



"Burden of disease studies seem to provide a new packaging for communicating old and new public health findings to the general public"

John Newton

(Director of Health Improvement, Public Health England)

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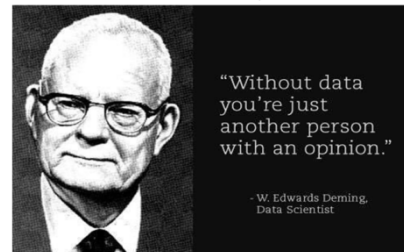
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- Pro 3 / Con 1: Start the discussion, based on a clear methodology, but...



- Con 2: (Over-)Simplification

- Con 3: DALYs only on one condition not useful... (However, start somewhere and continuous further refinements...?)

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The project Introduction burden of disease

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Workshop Diabetes

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The project DM patterns of care in Switzerland

Swiss TPH

- Patterns of care ↔ disease progression ↔ population health ↔ BoD assessments
- Substantial inaccuracies in international efforts (e.g. GBD study) recognized in some countries (e.g. Scotland)
- Patterns of care relevant per se, of course!

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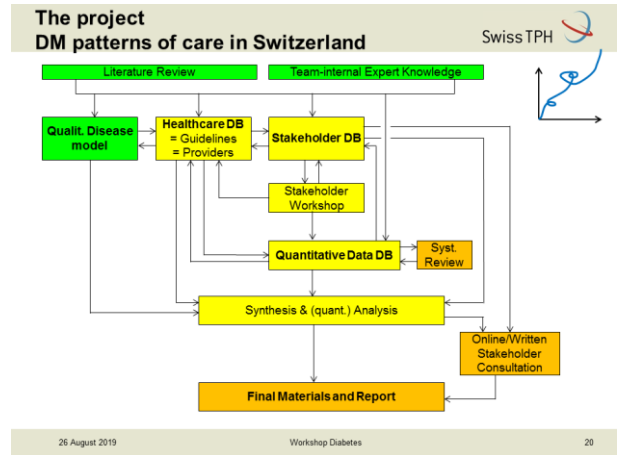
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The project DM patterns of care in Switzerland			Swiss TPH
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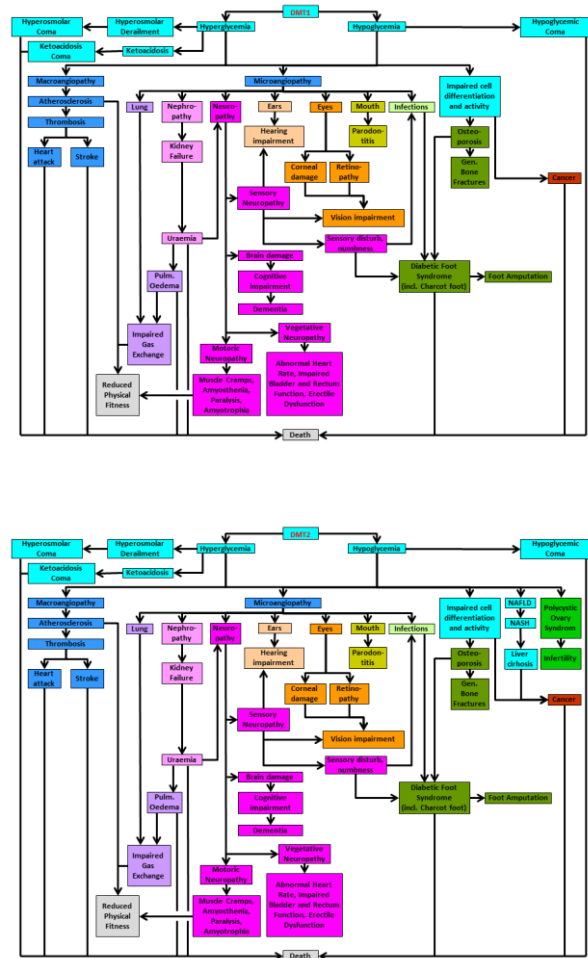
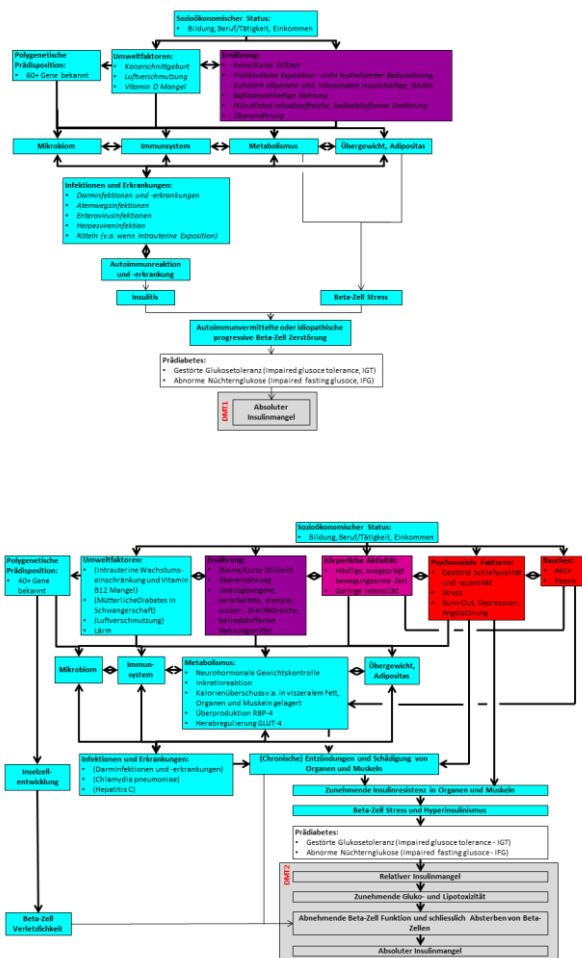
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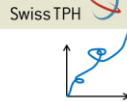
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The project DM patterns of care in Switzerland



Healthcare database

> Guidelines:

- > FMH online platform (www.guidelines.fmh.ch)

> Healthcare providers:

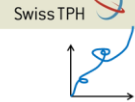
- > Combination of health professions from
 - Schweizerisches Dienstleistungszentrum Berufsbildung/Centre Suisse de Services Formation Professionnelle (EDK; www.berufsberatung.ch)
 - FMH Facharzt/-ärztin und Schwerpunkte/FMH Titres de Spécialiste et Formations approfondies (FMH; www.fmh.ch/siwf/siwf/weiterbildung/facharzt/-ärztin-und-schwerpunkte.cfm)
 - Oggier (2015) Gesundheitswesen Schweiz 2015-2017. Hogrefe Verlag, Bern.
 - BFS (2017) Schweizerische Berufsdaten 2000 / Nomenclature Suisse des Professions 2000
- > Relevance of health professions in diabetes care based on disease model
- > Based on relevant health professions identified relevant institutions and organizations

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The project DM patterns of care in Switzerland



Healthcare database

> Healthcare providers

→ Briefly switch to XLS

Stakeholder Database

- > Healthcare providers: professions, institutions, organizations
- > Patients
- > Health Insurance
- > Administration
- > Academia / Experts

(Limited) snowball sampling



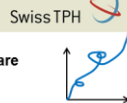
Workshop participants, i.e. YOU

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The project DM patterns of care in Switzerland



- > Despite good match between disease models and healthcare providers, not happy – do not capture “patterns of care” very well...

- > No clear “...overview of diabetes healthcare providers and services to inform health professionals, politicians, patients and other partners...”

- > Not very systematic; separate listings/databases, but no clear interlinkage

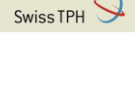


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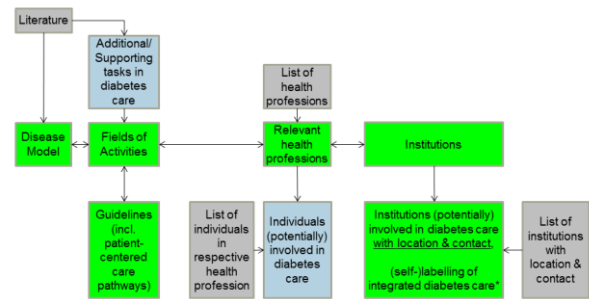
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The project DM patterns of care in Switzerland



> Structure/Conceptualization

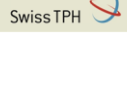


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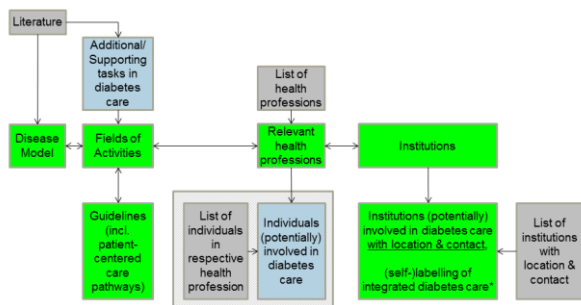
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The project DM patterns of care in Switzerland



> Structure/Conceptualization

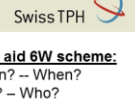


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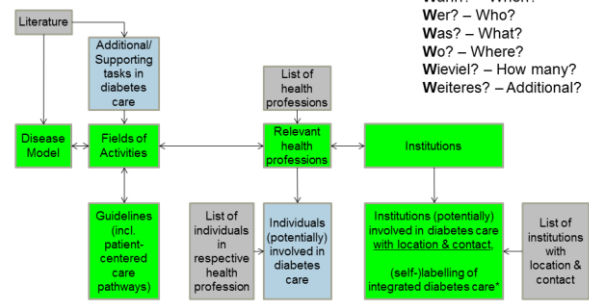
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The project DM patterns of care in Switzerland



> Structure/Conceptualization

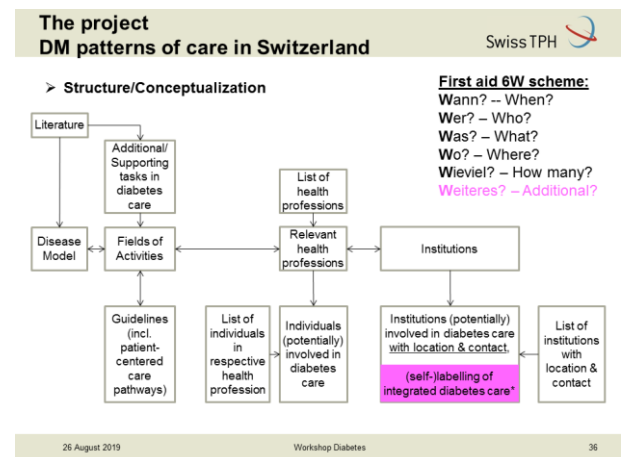
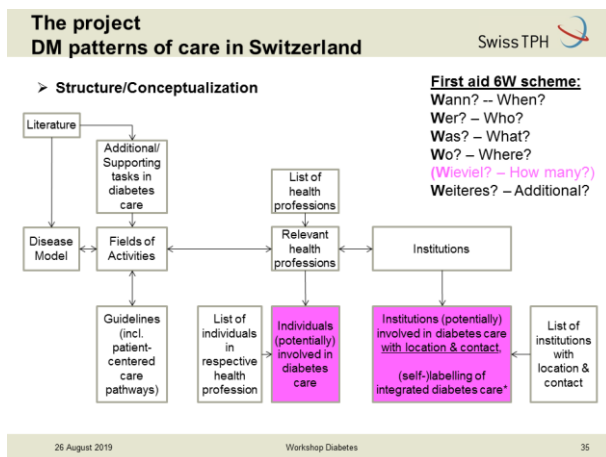
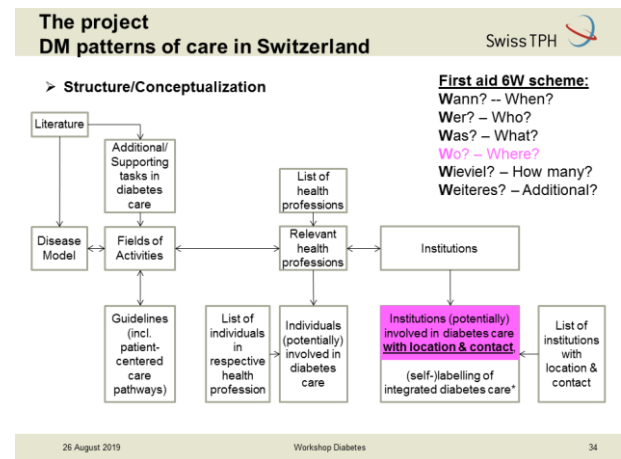
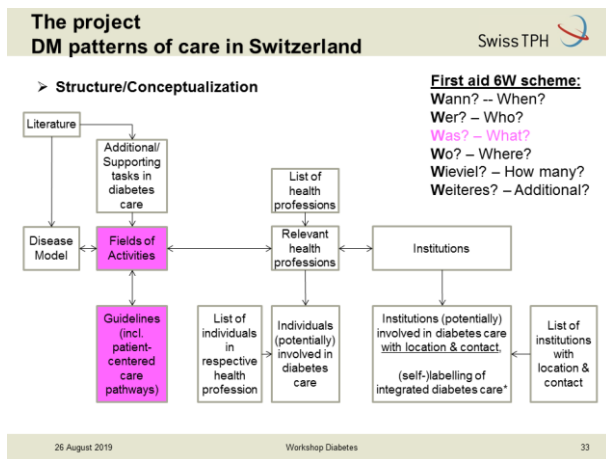
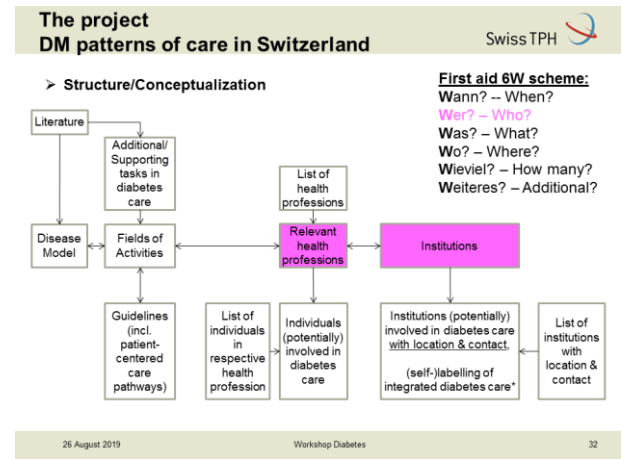
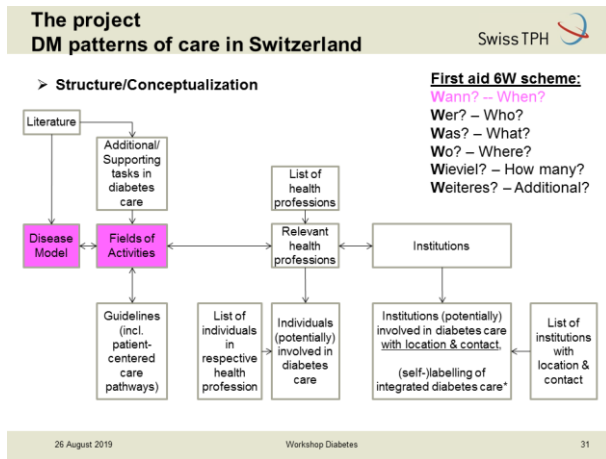


First aid 6W scheme:
 Wann? – When?
 Wer? – Who?
 Was? – What?
 Wo? – Where?
 Wieviel? – How many?
 Weiteres? – Additional?

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The project DM patterns of care in Switzerland

Swiss TPH 

➤ Structure/Conceptualization

- More systematic
- Better validity (correctness and consistency of content)
- Better reliability (replicability)
- Interlinkages clearer
- Clearer "...overview of diabetes healthcare providers and services to inform health professionals, politicians, patients and other partners..." ?
- Look-up tool ?
- If conceptualization/definition of "integrated diabetes care" clearer (more on that later!):
 - Survey among institutions and respective entries/"labelling" in database – quality of care/"marketing" aspect ?
 - Transparency/Decision support for patients, payer, politicians... ?
- (Transferable... ?)

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Workshop Diabetes

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This Workshop

Swiss TPH 

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Stakeholder Database

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- 1) Any major stakeholder category missing?
A=Patients; B=Health Care Providers; C=Health Insurance;
D=Administration; E=Academia/Experts
- 2) Classification (*high, medium, low*) of stakeholder relevance (*diabetes key expertise/activities/involvement -- also in light of our project*) ok?
- 3) Any specific stakeholder missing (obviously physiotherapy with physioswiss as stakeholder under B--practice)?
- 4) Other comments?

→ see XLS

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Health Care Database

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Healthcare database

➤ Healthcare providers:

- 1) Identical to section B in stakeholder database!
- 2) Do lists of individuals in resp. health professions exist (optimally with exhaustive and mutually exclusive categorization)?
Accessible?
If not, what else could be used?
- 3) Do lists of resp. healthcare institutions exist (optimally with exhaustive and mutually exclusive categorization)?
Accessible?
If not, what else could be used?

→ for relevance, see the revised/ proposed "Structure/Conceptualisation" (slides 28-38)

→ see XLS

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Health Care Database

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Healthcare database

➤ Guidelines:

- 1) All guidelines from FMH online platform (www.guidelines.fmh.ch) – additional, publicly available guidelines – optimally also in a repository?
- 2) Is it true that ca. 1/3 are expired? Any new editions of the expired ones?
- 3) Has anyone access to Nr. 11 ("PizolCare: Patientenpfad Diabetes mellitus") and could share it with us?
- 4) Any idea/"feeling" about application relevance and utilization frequency/compliance with these publicly available guidelines?
- 5) Any idea/"feeling" about application relevance and utilization frequency/compliance with not publicly available guidelines, i.e. internal guidelines within GP networks, hospitals, etc.?

→ see XLS

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Quantitative Data Database

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➤ DALYs time-based measure of health loss and calculated – for a certain population, year, and sequela – as follows:

- DALYs = YLL + YLD
- YLL = Years of life lost (due to premature death)
= $N * L$
- YLD = Years lived with disability
= $P * DW$ ($\approx I * D * DW$)

- N = Number of deaths
- L = (Standard) Life expectancy at age of death
- P = Prevalence
- DW = Disability weight (scale from 0=full health to 1=death; analogy disability insurance IV/AI)
- (• I = Incidence)
- (• D = Duration)
- (• R = Remission/Cure rate)

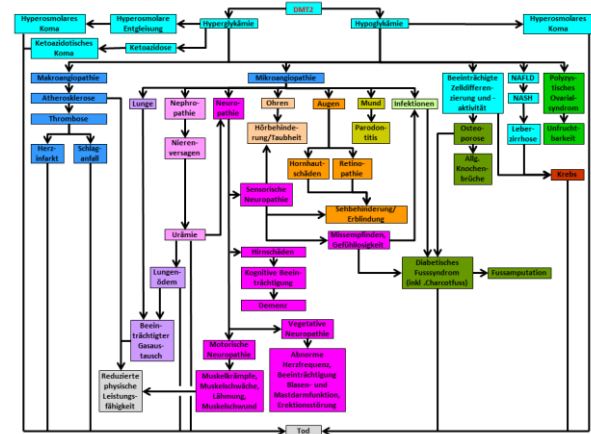
Qualitative model for progression of condition / causally attributable sequelae

Quantitative data
REMINDER

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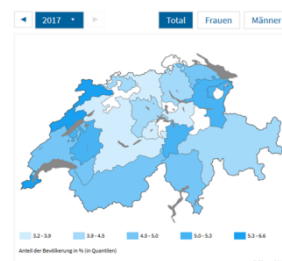
Quantitative Data Database

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Example

Häufigkeit von Diabetes mellitus

Prozent der Bevölkerung



"Dieser Indikator basiert auf der Schweizerischen Gesundheitsbefragung. (...) Die für diesen Indikator verwendete Frage aus der Schweizerischen Gesundheitsbefragung (TDIAB01) lautet: <Hat Ihnen ein Arzt schon einmal gesagt, Sie hätten Diabetes bzw. Sie seien zuckerkrank?>
JA / NEIN / WEISS NICHT / KEINE ANTWORT> "

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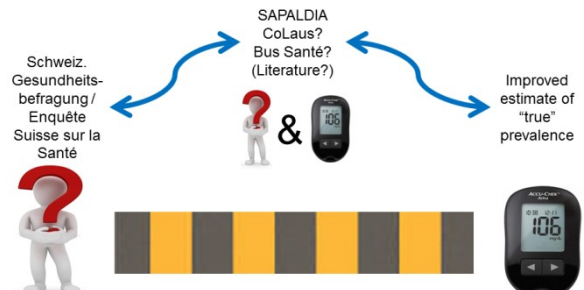
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Quantitative Data Database

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"Crosswalk" self-reported prevalence ↔ objectively diagnosed prevalence to correct for underdiagnosis



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Quantitative Data Database

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1) What is your impression/comments on the thus far listed potential data sources:

- i. Can you rule out some of them for the respective purpose(s) as you know them (e.g. wrong content, not available at the needed level of disaggregation, very poor quality, extremely small sample sizes, not/hardly accessible, etc.)?
- ii. Where do you see a good chances of success?

2) Do you know any other potentially useful data source(s) and what they could be used for in the disease burden assessment?

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Questions from my side

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"Be close to patients and practitioners!"

Jan P. Vandenbroucke



- 1) What do you think about the revised structure/conceptualization/6W scheme?
 - i. Useful for patients, providers, politicians, other partners?
 - ii. Any reservations/concerns about feasibility?
- 2) What do you think about the disease models / causal webs? OK? Something important missing?
- 3) What do you think about the GBD/BoD approach?
 - i. In general, useful or not – also in the Swiss context?
 - ii. Which aspects most/least useful?

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This Workshop

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Reminder

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BREAK



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Integrated diabetes care

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- Generally, no clear consensus and definition of "integrated care" exists thus far
- "Integrated diabetes care" desirable...
 - ...but what does it mean?
 - ...relevant and operationalizable criteria/definition?
 - ...how to capture thus defined, available integrated diabetes care initiatives?
 - ...additional useful characteristics to well describe the identified integrated diabetes care initiatives?
- Considered as good starting point: shared article on the first Swiss Survey on Integrated Care (SSIC), published in Health Policy last year
 - Most happy to have the senior author of this article with us today, Prof. Peytremann-Bridevaux!



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Integrated diabetes care

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- According to the article, SSIC used to following inclusion criteria to define "integrated care initiatives":
 - Formalization (formal written agreement between organizations/institutions)
 - Integration at healthcare services level (at least 2; e.g. physician-led primary care, non-physician-led primary care, specialized medical outpatient service, home care, community services, etc.)
 - Integration at healthcare professionals level (at least 2; e.g. specialist physician, GP, general nurse, specialist nurse, FaGE (assistant en soins et santé)/MPA (assistant médicales), nutritionist, pharmacist, optometrist, physiotherapist, etc.)
 - Ongoing

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Integrated diabetes care

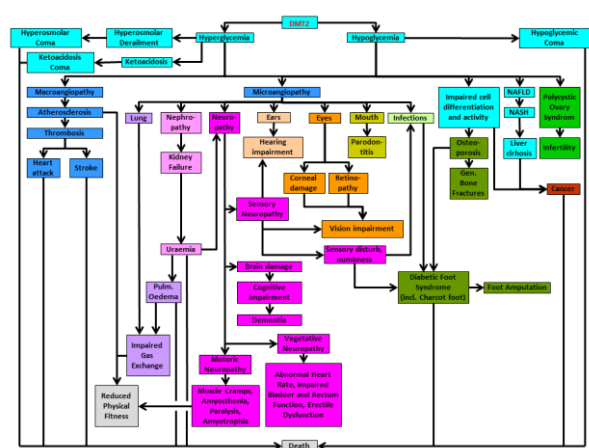
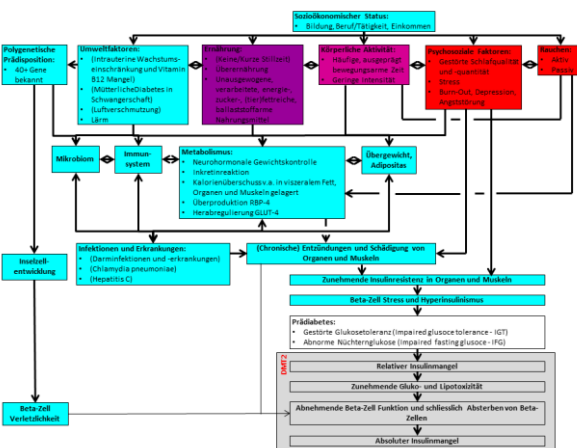
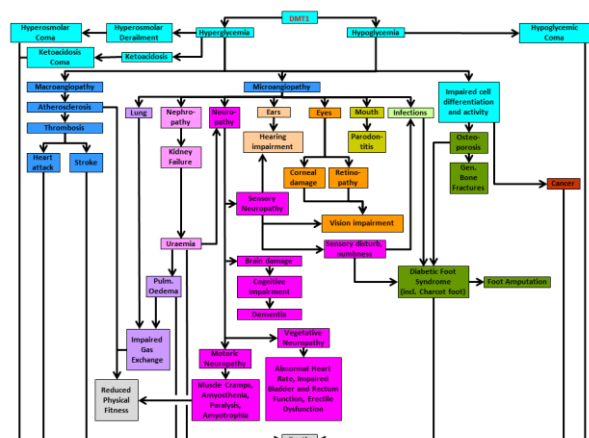
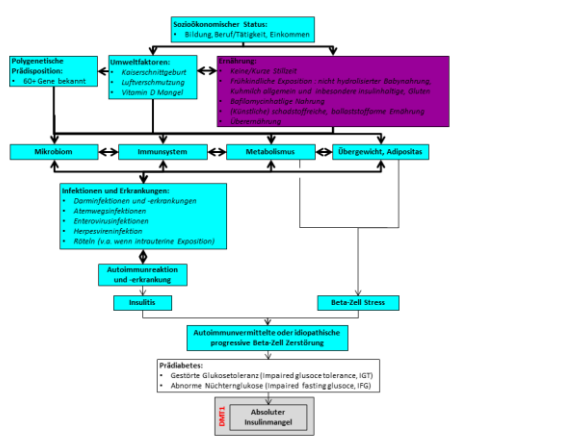
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- According to the article, SSIC used several exclusion criteria to define "integrated care initiatives", probably most relevant for this work:
 - "Provision of 'usual care' (such as multidisciplinary diabetic teams, tumor boards, pain centers, wound centers, memory centers)"
- Questions to Prof. Peytremann-Bridevaux – not to be lazy, but pragmatic:
 - Due to the aforementioned exclusion criteria, one could probably not 'simply' draw a subset of the SSIC to obtain a good overview of "integrated diabetes care" initiatives – one would miss those who have already become "usual care"; correct?
 - If one could 'simply' draw such a subset to obtain a good overview of "integrated diabetes care" initiatives, this would be a strong argument for adopting the exact same definition/criteria as in the SSIC...
- Otherwise – as aforementioned and to all: What would be relevant and operationalizable criteria/definition for "Integrated diabetes care"?

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Further stakeholder consultation

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➤ For first considerations, switch to XLS

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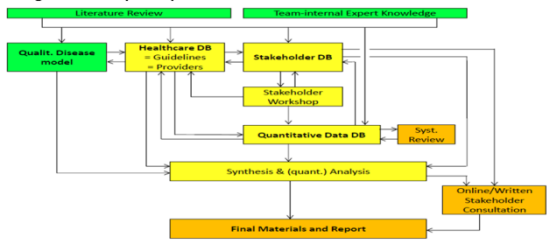
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Next steps



- Digest
- Send workshop participants material
- Further stakeholder consultation – Incl. workshop participants again, if ok
- Final synthesis & (quant.) analysis & write up and share final material again with all participants

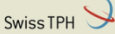


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Thank you



- Ok, if we approach you also after the workshop with limited, targeted questions, if need be?
 - Would be most grateful – and one essential goal is to start and maintain stakeholder dialogue as...

“Be close to patients and practitioners!”

Jan P. Vandenbroucke



THANK YOU !!!

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