Dementia diagnosis between cure and care.
Policies, practices and ethical issues in the swiss cantons.

Scientific Report

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SUMMARY

Dementia diagnosis raises a range of political and normative questions. Its implementation involves both the health and care sectors and entails various practical dilemmas. This study aims to identify how the Swiss cantons handle dementia diagnosis and the main ethical issues raised in this context.

Background

The number of dementia patients will increase in the coming years in Switzerland. To prepare the healthcare system for this challenge, the National Dementia Strategy 2014-2019 emphasises early diagnosis and appropriate support for concerned people and their families. Early diagnosis benefits, however, are still debated and the cantons, which are mostly in charge of health and care policies, have adopted different approaches. Data on the concrete implementation of diagnosis remain scant.

Goals

This project aims to shed light on the implementation of diagnosis in Switzerland, the diversity of cantonal diagnosis governance, and the ethical issues that professionals confront in their diagnosis practices. The following questions are adressed: (1) What are the characteristics of the dementia diagnosis network in Switzerland ? (2) How do different cantons implement early diagnosis policy ? (3) What are the key ethical dilemmas related to diagnosis practices ?

Methods

This is a multilevel study, based on a mixed qualitative-quantitative methodology. We first conducted a literature review on the benefits and drawbacks as well as ethical issues of early diagnosis, and we produced cantonal reports of the 26 cantonal diagnosis policies, based on an

extensive desk research. On this basis, we addressed an online survey to specialised institutions providing dementia diagnosis in the swiss cantons. Finally, we conducted cantonal case studies in four cantons that have adopted a dementia cantonal strategie (Saint-Gall, Tessin, Vaud, Zürich). These case studies articulated a public policy analysis and an exploration of practical and ethical dilemmas reported by health and social professional in selected diagnosis institutions (mainly Memory Clinics).

Main results

Early diagnosis is promoted by institutions which practice this diagnosis, but professional are still confronted with many ethical issues. Models of diagnosis policy and governance vary at the cantonal level in level of centralization, specificities in spezialied actors' network and anchoring in health and/or social care. Health professionals are mainly confronted with social implications of diagnosis for the persons and their families, especially shortages in long term care and driving licence management. There is a need (and a strong potential) for increasing coordination between health diagnosis structures and social/care organisations. Moreover, many issues are related to how best to protect and promote patient autonomy at each step in a diagnostic process.

Benefits

The plurality of cantonal dementia policies leads to unequal access and blind spots. In this context, our results contribute to the diffusion of intercantonal knowledge on dementia diagnosis practices and debates and cantonal governance. By highlighting the salience of ethical issues in medical practice related to social and care issues, they contribute to define priorities for improving dementia policies and developing tools for decision-making at the professional level.

Research report

(1) Aims, objectives and relevance of the research project

Dementia is a key challenge for health and social policy in the developed world, as it is related to population aging. The Swiss Alzheimer's Association (2021) estimates that 146'500 people live with dementia in Switzerland (half without a formal diagnosis; 95% over the age of 65); by 2050, this number might reach 315'400. The cost of dementia in Switzerland is estimated at 11.8 billions CHF, about half of which is informal unpaid care provided by families. So far, no curative treatment for dementia exists and the efficacy of existing medication in slowing its progress is very limited. In this context, early diagnosis and post-diagnostic support were defined as key features in the first Swiss National Dementia Strategy 2014–2019. This was intended to enhance patients' autonomy and quality of life, as well as to contribute to cost containment. This federal policy was backed by shared recommendations for dementia diagnosis made by an interdisciplinary alliance of specialists (Bürge and al. 2018).

However, due to the Swiss federal structure, most health and care policies are cantonal competences. The private sector and informal care are also particularly important. In practice, the concrete steering and implementation of dementia diagnosis across Switzerland are thus characterised by a high degree of diversity. Professionals confront ethical issues regarding early diagnosis in a complex context of diagnosis practices. This context is fragmented and insufficiently documented. Data and publications on cantonal dementia care policies are scant, as is reliable information on the practical and ethical issues related to the implementation of dementia diagnosis.

This project aimed to contribute to shed light on the concrete implementation of dementia diagnosis in Switzerland, map the diversity of cantonal diagnosis policies, and identify the main ethical dilemmas confronting professionals in the context of their diagnostic practices. Empirical exploration aimed to improve our theorical understanding of how dilemmas in medical practice relate to socio-political and institutional contexts. In this perspective, we addressed the following questions:

(1) What are the characteristics of the dementia diagnosis network in Switzerland ?

(2) How do different cantons formulate and implement early diagnosis policy ?

(3) What are the key ethical dilemmas related to (early) diagnosis practices ?

These national and cantonal results are particularly relevant in the context of the Swiss health care system, because the diversity of cantonal dementia policies and the structural barriers to coordination of health care services make it difficult to produce a coherent national response. Moreover, this system has so far focused on cure more than care; this makes it ill equipped for dealing with "chronic" patient populations. In this context, we aim to contribute to the diffusion of intercantonal knowledge on dementia diagnosis policies and practices as well as to the definition of the policy priorities in the field.

(2) Research design, theoretical frame, methods and data used

Theorical frame

Two models of dementia are opposed in the litterature. In the prevailing '*biomedical model'* ("cure") the persons concerned are patient suffering from a specific disease that should be treated – and if possible cured- in the health system. By contrast, the *'social model'* of dementia emphasizes the social experience of dementia and social construction of disabilities, as well as the rights and voices of people concerned. Remaining abilities, participation in decision-making, community care, and social inclusion are key elements here.

In practice, *dementia diagnosis policies* combine elements of both models. These public policies are located at the articulation of health and long term care systems. The cure-care divide can be observed in the three dimensions of cantonal policies: institutional (cantonal governance and power structures); service provision (actors' network; services provision & coordination); and discursive (policy content and debates about dementia diagnosis).

At the clinical level, dementia diagnosis is a process with five stages: (1) Entry into specialised diagnosis institutions (2) First consultation and further assessments (3) Making the diagnosis (4) Disclosure of the diagnosis (5) Care plan definition and post-diagnostic support. Along these steps, professionals are confronted with a range of ethical dilemmas. In the perspective of pragmatic sociology, those practical dilemmas need to be understood with regards to different contexts of meaning. Our general hypothesis is that these contexts of meaning are shaped by dementia *diagnosis policy*. More precisely, we hypothesise that the content and salience of the dilemmas are shaped by the articulation of the cure/care divide specific to each dementia cantonal policy. From an ethical point of view, those dilemmas refer to the specific conditions of vulnerability of both the people concerned and their family carers. Understanding them allows for the possibility of grounding appropriate answers in a normative perspective, taking into account the emancipatory dimension of the social model.

Research design

This is a multilevel study, based on a mixed qualitative-quantitative methodology. We followed five main steps:

• We first built a framework of the main *ethical issues associated with dementia diagnosis based on a literature review* (annexe 1), to help us make sense of the planned fieldwork data and conduct normative evaluation of diagnosis policies.

• Second, we produced a *systematic cantonal mapping of the 26 cantonal diagnosis policies and networks*, based on an extensive desk research (26 cantonal profiles)

• Third, we developed on *online survey,* addressed to specialised institutions identifiyed through the cantonal mapping as providing dementia diagnosis in the 26 Swiss cantons.

• Fourth we conducted *four cantonal case studies* in cantons that have adopted a cantonal strategies (annexe 3). Case selection was based on the cantonal mapping, following a 'similar systems design'. These case studies articulated a *public policy analysis* and an exploration of *practical and ethical dilemmas* reported by health and social professional in selected diagnosis institutions (mainly Memory Clinics).

• Finally, we conducted a multi-level comparative analysis and started with the theorical integration of results (this last step will be continued through publications).

Methods and data

This project was based on the following data:
• We conducted a *literature review of ethical issues* (started in 2018, updated in April 2021) focusing on publications in English published since 2013 (annexe 1).
• A *cantonal database* was elaborated in 2019 based on extensive desk-research involving several hundreds of policy documents, legal documents, official and organisational websites, parliamentary documents and media reports. (26 cantonal profiles + comparative synthesis).
• *Our Online survey*, carried out in 2020, was addressed to specialised institutions from all 26 cantons providing dementia diagnosis and assessed characteristics of the structures, diagnostic practices, and attitudes towards early dementia diagnosis (annexe 2).
• The *cantonal case studies* were conducted in Saint-Gall, Tessin, Vaud and Zürich between January 2020 and August 2021 (annexe 3). They are based on an analysis of *secondary literature* on cantonal health, care and dementia policies • a *print media analysis* of cantonal dementia policies and practices; a *documentary analysis* and *semi-structured in-depth interviews with the key actors of the diagnosis network*. Two different topic guides were used (one for the policy level, one for the practice level).

(3) Results and highlights

1. Caracteristics of the dementia diagnosis network in Switzerland

Our national questionnaire (n: 113; RR 58%) provided new insights about the network of institutions providing diagnosis in Switzerland and its main characteristics with regards to the cure-care divide. 72 % of respondents are German-speaking, 23 % French-speaking, 5 % Italian-speaking. The great majority of diagnosis institutions are public structures (78.9%), mostly financed by public funding. Memory centres represent 40 % of the structures. The others are specialised hospital units, including geriatric units (23%), neurological units (14%) and psycho-geriatric units (13%). With regards to professional disciplines, neuropsychology is represented in almost 80% of institutions, geriatrics or neurology in about 60% and psychogeriatrics in about 40%. Psychiatry is present in half of the Swiss German institutions, but only in about 20% of the French speaking. Social work is present in about a quarter of the institutions, but is relatively rare in the French speaking part (11%).

Diagnosis activities: care pathway, migration and informal care as acknowledged issues.
Most of the structures include both screening services and postdiagnosis services, in addition to specialised diagnosis services. But post-diagnosis services are more frequent in the French-speaking region (more than 80% of institutions) than in the German-speaking one (64%). Most diagnosing institutions (66%) propose services for *informal carers*, with the highest proportion in the German speaking area and the lowest in Ticino (half of the institutions). Most institutions also have internal (about half of the institutions) and/or external translation and intercultural communication services for *migrants.*

Reported problems in diagnosis practices: importance of social & care issues
The main reported problems in the practice of diagnosis are related to the limitations of the biomedical model as well as to social issues, especially the shortcomings of social care support. On the medical side, among the 6 most cited answers, we observe that most respondents

consider the *lack of drug-based treatments* (57%) as one of the main problems. This issue is mentioned more often by French and Italian speaking institutions than by the German speaking ones. Overall, almost 40% mention *uncertainties regarding the formulation of the diagnosis* and 25% the *lack of non-drug-based therapy.* On the social side, almost half of the respondents mention *the handling of driving license issue* as one of the main problems, and a quarter cited the *lack of social support for informal carers* or *insufficient funding of the diagnosis by health insurances.*

Collaborations in the health & care network: strong potential for increased cure-care cooperation

The three-quarter of institutions providing diagnosis declare collaboration with *public health authorities,* 30% on a regular basis. Among them, the satisfaction rate is very high (88%). A strong dissatisfaction is, however, reported on collaboration with *health insurances* (60% of dissatisfaction on average, and up to 90% in the French speaking regions).

The cooperation *within the medical network* is quite strong and satisfactory for the diagnosis institutions. The responding organisations most frequently collaborate with (other) hospital units and GPs (almost 80%, with a satisfaction rate around 90%). With regards to the collaboration with the *actors of the care and social network*, the potential for improvement appears to be large. Less than half of the participants collaborate frequently with *associations* (44%), and a quarter with *social services* (25%), with satisfaction rates of 93% and 82% respectively. Almost 20% of the participants never collaborate with social services.

2. Differences in cantonal dementia diagnosis policies

Half of the canton without a dementia strategy

There still are pronounced differences in the levels of institutionalisation of dementia policy in the Swiss cantons: In 2019, half of the 26 cantons had an explicit dementia strategy (BL, BS, GE, LU, NW/OW, SG, TG, TI, UR, VD, VS, ZH). In 8 cantons, some elements addressing dementia can be found in some policy documents (AG, BE, FR, NE, SH, SO and partially in AR & JU). 5 cantons (AI, GL, GR, SZ, ZG) had no strategy or strategic elements for addressing dementia at all. The National Dementia Strategy 2014-2019 is mentioned as having determined or influenced the process of developing cantonal strategies in the 13 cantons that do have some version of a dementia policy (with the exception of VD, where the cantonal strategy was adopted in 2010, before the National Strategy).

These dementia strategies are part of the cantonal Health Departments or health services (health, public health, "cantonal physician" service). Saint Gall is an exception: its strategy is governed by the Social office, part of the Internal Affairs Department.

Different types of governance for dementia diagnosis in the cantons

Dementia diagnosis is caught in the multilevel governance regime, typical of the Swiss federal system. Federal policies, notably in the domain of health care insurance, long-term care financing, and the growing national structuration of medical specialties and network of memory clinics play a structuring role. However, the autonomy of cantonal and local authorities, as well as the very differentiated traditions and development of the cure and care systems locally and regionally, all strongly influence the governance of dementia diagnosis. Among the cantons with a dementia strategy, different diagnosis models can be distinguished on the basis of case

studies *(annexe 3*). These models are structured by cantonal dementia policies, level of cantonal centralization, specificities in the specialized actors' network, logic of coordination of the cure and care systems, and the debates about dementia diagnosis.

• *TICINO: The community based timely diagnosis model.*
InTicino, some institutions had introduced the notion of *timely* (rather than early) dementia diagnosis before the canton elaborated a cantonal dementia strategy in 2014. The strategy promotes the development of diverse medical specialty regional centers, public or private, with a particular focus on research-based service development. This diversity may lead to some complementarities at cantonal level, but the decentralization of the health and care systems causes inequalities at local level. The coordination of services appears rather weak, both at cantonal level and in most localities. The cantonal context is marked by the influence of geriatrics in both diagnosis and post-diagnosis support and the early recognition on both social and medical dimension of dementia care. Families' role is acknowledged, and Ticino was precursor in providing financial contribution for hiring a relative. An informal carer policy was, however, defined only recently, which may justify the general weak support granted to family carers. A debate about the tension between early and timely diagnosis had structured the dynamics of the cantonal network, as part of the actors are opposed to asymptomatic diagnosis.

• *VAUD: The delegated and centralized early diagnosis model.*
In Vaud, the drafting of a dementia strategy and an informal carers' policy has taken place at an early stage before the Federal Strategy. The cantonal strategy has organized the delegation of dementia diagnosis to a specialized MC implanted in the Lausanne university hospital. This center has promoted *early diagnosis* and the homogenization of diagnosis norms in the other public MC of the whole cantonal territory. Mostly influenced by neurologists, this MC promotes co-ordinations between cure and long-term care provision. The structure of the cure and care system is not centralized per se in Vaud, but the cantonal administration provides financing and guidance aiming at an active homogenization of both the diagnosis and post-diagnosis policies. Debates on the importance of prevention and early diagnosis, in contrast to a priority given to care played a structuring role in the actors of this diagnosis network.

• *ZURICH:*
The integrated care urban model of diagnosis In the canton -and particularly the city- of Zurich, advanced medical institutions had developed specific capacities in the domain of dementia diagnosis. The City of Zurich developed *early detection* – including diagnosis at home and active identification of isolated persons with dementia via specific services or the Spitex. The cost reduction of this model enables the City to develop *active detection* and to improve the quality of long-term services for people with dementia. Long term care policies are decentralized to the local authorities, and the model developed by the City of Zurich could only rarely be emulated by other local authorities. This implies a rather high level of inequalities both for patients and for family carers. Amongst practitioners of dementia diagnosis, two visions of diagnosis can be contrasted. For some pragmatist practitioners, in specific cases of isolated persons at an advanced stage in dementia, anamnesis, cognitive and neuro-psychological tests as well as a quick inspection of the state of the household can ground a dementia diagnosis. Other practitioners advocate the systematic unfolding of all steps and techniques recommended by medical specialists, including labor testing and IRM for instance, in all cases.

• *ST-GALLEN:*
The decentralized un-coordinated model of diagnosis In the canton of St. Gallen, the dementia strategy aims at informing and giving responsabilities the actors of the health and social domains. Dementia diagnosis and long-term care are within the competencies of the cantonal social bureau. The cantonal health department is particularly weakly structured. Both health and social systems are decentralized. There is no attempt by the health department at homogenizing diagnosis practices over the cantonal territory. At local level, actors have developed efficient diagnosis procedures and/or pathways to support patients and family carers. Some local authorities have joined their efforts to finance common structures of diagnosis and follow-up of the patients and of the family carers, in some cases, with the support of the high-level St. Gallen MC. However, the isolation of the various local configurations leads to important level of inequalities among patients and caregivers over the cantonal territory. There is an important debate at cantonal level about the ongoing process of closing of local or regional hospitals, guided by a cost reduction strategy, which has consequences on the availability of specialized dementia diagnosis (MC).

3. Ethical issues related to early diagnosis practices

Literature reviews on ethical issues

We conducted two literature reviews. The first was a narrative review, to provide an overview of ethical issues associated with early diagnosis of dementia in the literature. We found that the issues mentioned in the literature fall into five categories: 1) the nature of dementia as a medical condition and scientific uncertainty, 2) benefits and drawbacks of early diagnosis, 3) screening for dementia, 4) disclosure of the diagnosis, and 5) self-determination and respect for persons. (*annexe 1)*
The second literature review was a systematic review of reasons to further explore the second category (benefits and drawbacks of early diagnosis), to provide greater clarity to clinicians regarding the care for patients facing the choice for or against early diagnosis. In this second review, we found that the potential consequences of early diagnosis for the patients, their family, health professionals, and society as a whole, vary widely and can sometimes conflict. Consequently, and also as a consequence of considerable cantonal differences between diagnosis policies and practices identified in our case studies, general recommendations for or against early diagnosis are difficult to make. Rather, to ensure that early dementia diagnosis is practiced in a person-centred manner, we suggest that a set of specific questions needs to be asked at the point in time when diagnosis first becomes possible. These questions can be used to identify potential alignments and misalignments of interests between the affected parties, as a tool for decision-making at both individual and collective levels. (Gurau, Lucas, Hurst; *forthcoming*)

The position of institutions with regards to early diagnosis: persisting tensions

The promotion of early diagnosis is largely supported by the institutions providing diagnosis in Switzerland. Only 2% consider that there is no need to promote early diagnosis and none consider that this should be avoided. For almost 3/4 of respondents, early diagnosis should be promoted for *all people potentially affected by dementia*, while 1/4 think it more appropriate to target specific categories of people. There is no significant difference by linguistic region.

However, for a large majority of respondents (70%), testing for pre-clinical signs of dementia (*via* biomarkers) should be proposed only in *specific cases.*
The *main reasons* cited in favour of early diagnosis are related to social issues, and not mainly to medical treatment (curative or not): the quality of life of patients and their family, patients' autonomy, the possibility to organise social care. These arguments are directly in line with the ones put forward by the National Dementia Strategy. Despite this overall support for early diagnosis, we show four open issues regarding its implementation:

• *Emotional impact of early diagnosis appears uncertain*: The "reduction of stress and uncertainty for patients/their families" is the first most cited argument in favour of early diagnosis (69% of participants), but 60% also mention the "risk of negative emotions for patients/their families" among the three most important reasons *against* early diagnosis.

•*Patient autonomy is only partly fostered:* The second most cited reason in favour of early diagnosis (59% of participants) is that "it allows appropriate legal measures (for instance advanced directives, or wills)". This argument supports the goal of improving patient autonomy as promoted by National Strategy. However, other answers shows that this value is embraced with some ambivalence. For instance, most institutions consider that patient request is *not* a condition for clinical screening for cognitive impairments (only 4% deem a clinical screening justified only if requested by the patient). Families are more systematically part of decision-making than patients are: over 90% of respondents state that patients' family members are *always* included in the decision to continue the diagnostic process after the initial consultation, but only 77% consider that *patients* should always be included. Finally, only 60% indicate that the diagnosis is *always communicated first* to the patient her- or himself.

• *Usefulness of early diagnosis in absence of curative treatment is questioned by a significant minority:* Among the main arguments against early diagnosis, 45% of respondents agree that it is currently "of little use in the absence of effective treatment". Slowing down the illness is mentioned as a reason in favour of early diagnosis by only 30% of participants.

• *Ambivalent evaluation of impact of diagnosis on social conditions of patients:* Almost half the respondents consider that early diagnosis is to be promoted as it "allows for the timely setting up of domiciliary care/social assistance". This argument is more often brought forward in the French speaking region (75% of participants) than in the German speaking regions (50%). On the other hand, 45% of respondents mention the "risks of stigmatisation/ discrimination of the affected people" as one of the three main reasons *against* early diagnosis.

Main ethical issues identified in MC practices in cantonal contexts
At the cantonal level, we showed that shared practical dilemmas remain that need to be settled by the health professionals and that these issues attach to the different steps of the diagnostics process. Some issues (or framing) also appear to be specific to cantonal contexts.

(1) Access to diagnosis:
Reluctance towards dementia diagnosis and the high level of non-uptake of early diagnosis services is considered an important issue in the four cantons. The access and specific needs of some groups – such as the migrant population – is strongly thematised in Saint Gall but does

not appear to be salient in other cantonal contexts. The under-recognised potential of Spitex workers in dementia screening has been thematised in all the cantons. At the level of practices, the main shared issue is GPs' reluctance to send their patients for (early) diagnosis. Explanations of this shared issue are specific to cantonal contexts. In VD, the fact that GPs send patients to MC for driving certification is mentioned as an important problem for the MC.

(2) First consultation and decision of further investigations:
Professionals in Vaud, Ticino and Zürich (missing data for St.-Gall) experience the three same practical issues during this step, routinely confronting them with ethical dilemmas:

(a) Should investigations be continued in the absence of a request (or in case of refusal) from the patient him/herself ? Opinions differ on what is a *good* decision in this case.

(b) Should investigations be continued by means of biomarkers? While this decision is mentioned as a tricky one in the three contexts, the frame of the problem differs. Professionals seem to be torn between the high expectations of patients towards early diagnosis and the unavailabilty of medical treatment (TI), or the uncertainty of results (risks) (Zü and VD). The intrusive character of such investigations is also part of the equation.

(c) Tensions between patients and their relatives with regard to their respective evaluations of the situation is defined as a tricky issue for professionals in the three cantons.

(3) Making the diagnosis:
The making of the dementia diagnosis itself appears as an object of interrogation in some cantons (missing data for St.-Gall), related to its uncertainty and/or its necessity:

(a) The uncertainty of Alzheimer's diagnosis in thematised is an issue in the practices of professionals in TI and VD. In TI, both the uncertainty of the *diagnosis* itself (probability) and of the *prognosis* (a 'pending diagnosis') are mentioned as a tricky issue. In VD, *comparabilty* of the neurophysiological tests of people with different educational levels is said to challenge medical norms, while *compatibility* between biomarker results and neuropsychological results is a source of uncertainty. *Biomarkers* are described as reducing diagnostic uncertainty in one context (TI), and as increasing uncertainty in another (VD).

(b) The necessity of making an early diagnosis is questioned in TI and Zü, but in different ways. In TI, the necessity of diagnosis itself is questioned with regards to the *absence of treatment*. The importance of a non-curative treatment and care system is described as more important than the diagnosis. In Zü, by contrast, the *necessity of an acute diagnosis* is questioned, in favour of a '*pragmatic' diagnosis* that can be realised in the LTC network.

(4) *Disclosure of the diagnosis:*
Three main issues are mentioned in connection to the disclosure of diagnosis (missing data for St.-Gall):

(a) The *lack of time* with regards to the large agenda is a shared issue. The emotional load of disclosure interferes with the reception of other information, and with the organisation of a care pathway. Professionals thus face a dilemma (VD; Zü). In VD, the most acute dilemma is between disclosure of the diagnosis and disclosure of consequences for the *driving license.*

(b) An other shared issue is *the place of informal carers*. In TI particularly, this issue appears salient: professionals describe tensions between family and patient requests. The autonomy of the patient is seen as sometimes clashing with the principle of non-maleficence. Moreover, professionals face a double loyalty and fear losing the alliance with the family.

(5) *Care pathways organisation:*
In care planning and organisation of post-diagnostic support, two shared issues emerged:

(a) How to *address the social needs* of the patients and their family in the context of insufficient care and social services ? The issue is framed in terms of justice and territorial inequality. In St Gall, a related issue is *how to identify those social needs.*

(b) *How to deal with advanced directives* ? The necessity to talk about advanced directives is uncertain in the absence of patient request, and this conversation implies a direct confrontation with death early in the patient trajectory.

Forthcoming results are related to the further elaboration of the typology of cantonal diagnosis governance, to the analysis of dilemmas in terms of values, and to the improved theorical understanding of the relation between ethical dilemmas and their political contexts.

These results directly contribute to the goals of the NRP 74. They provide *new insights* into the diagnosis institutions network, practices and opinions related to dementia (early) diagnosis - and reveal the main dimensions behind cantonal diagnosis governance diversity. By pointing out persisting cleavages, main services shortcomings and salient ethical issues, they can also contribute to *define priorities* for improving the contexts of diagnosis and developing tools for decision-making in professional level. A such, they contribute to an *evidence-based inter-cantal dialogue,* based on best practices sharing.

4. Three main messages

1. The plurality of diagnosis policies at cantonal and local level are benefits of the Swiss federal system. Different models of diagnosis are debated and implemented. However, the lack of reciprocal knowledge of specific instruments and developments is a shortcoming. Diagnosis access and social implications for patients and their families depend on cantonal or local policy contexts, with top-down governance for example leading to general practitioner reluctance to refer in some contexts. Hence, favouring the dissemination of best practices and facilitating dialogue on the still dividing issues should be an objective of the Federal Office of Public Health and its National Platform Dementia. Attention could also be directed to issues that appear as blind spots: support for patients is much less thematized than support for families, particularly as regards social rather than therapeutic support; territorial inequalities are problematized but social inequality less so.

2. During the diagnosis process, professionals of health structures are mainly confronted with the social implications of diagnosis for both the persons and their families. Many of the dilemmas refer to the people reluctance to enter into a diagnosis process, to the shortcomings in long term care and support for families and to the driving licence

management. There is a need (and a strong potential) for increasing coordination between diagnosis structures and social organisations, as well as to reinforce social work and support into the health structures.

3. The promotion of early diagnosis is largely supported by the institutions which practice this diagnosis, but professional are still confronted to many ethical issues regarding diagnosis. Several of these issues are related to questions regarding how to best protect and promote, patient autonomy at each step in a diagnostic and management process which provides multiple opportunities for failure to foster autonomy, self-determination, and even self-regard, especially for later stages when cognitive decline is advanced.