

# Infrastructures of schizophrenia: transforming psychiatric diagnoses at the local and global level in the twentieth century

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**Abstract:** This article uses the concept of infrastructures of diagnosis to propose a framework for telling the history of schizophrenia as a global entity in the twentieth century. Infrastructures of diagnosis include the material and architectural arrangements, legal prescriptions and professional models that organize the way patients come to clinics and navigate in the world of schizophrenia, as well as clinicians organize their diagnostic work. They organize the way schizophrenia was identified as a disorder. The article then explores three moments in the history of the infrastructures of the diagnosis of schizophrenia in the twentieth century. The first is German psychiatrist Kurt Schneider's discussion of first and second rank symptoms in the interwar period. The second is the work on the criteria for defining schizophrenia in the framework of the WHO International Pilot Study of Schizophrenia at the turn of the 1970s. The last moment concerns recent discussions on deconstructing psychosis in the framework of the development of the fifth edition of DSM.

**Keywords:** schizophrenia, infrastructures, psychiatric diagnosis, history of psychiatry

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## **Infrastructures of schizophrenia: transforming psychiatric diagnoses at the local and global level in the twentieth century**

When in 1954 the American psychiatric profession developed one of its innumerable quarrels over the meaning of schizophrenia, a participant to the discussion proposed to write to Manfred Bleuler, the son of the originator of the concept, Eugen Bleuler, and his successor at the Zurich university psychiatric clinic on the Burghölzli hill, to ask his opinion on the “diagnostic criteria which had been established at Burghölzli with reference to the diagnosis of schizophrenia, schizoid states “pseudoneurotic schizophrenia”, and allied conditions”(Johnson, 1954) . In his response, published in the *American Journal of Psychiatry*, Manfred Bleuler took pain at explaining the meaning of the various labels crafted by his father, recalling the ways these labels were used at Burghölzli (Bleuler, 1954). For mid-century psychiatrists, the truth of schizophrenia was to be found in a single place. The intimate connection Manfred Bleuler had with his father’s work had made him a guardian of the clinical tradition Eugen Bleuler had created, a role he would keep until his death in 1994. This role entailed both moral and scientific dimensions. Bleuler personified a humanistic vision of schizophrenia, a vision that had roots in his long term study of the course of the disorder as well as in the bond he had created with his patients and their families over his life spent at Burghölzli since his childhood. (see for instance: Rosenthal, 1974)

My point in recalling this episode is to stress the fact that schizophrenia has always been, in a certain sense, a global category: a category which circulated in and was shaped by networks of people extending over continents. A crucial question for a global history of schizophrenia then relates to the shape of these networks: both their extension and the type of channel they were for a variety of entities. Where was schizophrenia used as a concept? What sorts of concepts and instruments were mobilized in these settings to diagnose and discuss schizophrenia? Who were the authorities in these discussions and how did their authority extend to various contexts? And how did the replies to these questions impact the very nature of schizophrenia as an entity? In this article I would like to insist on the materiality of the professional and scientific networks behind schizophrenia. Networks are not only a matter of circulating people, ideas, and things. They also involve in decisive ways a series of infrastructures and more generally material arrangements which make these circulations simply possible. These infrastructures were not only necessary in order to transport people, things and concepts. They also helped these people, objects and concepts retain a meaning across contexts.

By insisting on these dimensions I wish to offer a new framework for understanding the history of schizophrenia in twentieth century. There are a number of good historical, anthropological and sociological analyses of the changing phenomena that have been labelled as schizophrenia across the twentieth century. (Woods, 2011; McNally, 2016; Noll, 1992; 2011; Barrett, 1996; Garrabé, 2003; Guillemain, 2018; Bernet, 2013) Most of this scholarship focused on the changing representations of both schizophrenia and the people concerned: which symptoms defined schizophrenia and schizophrenic patients; what sort of person these were. By contrast the question that interests me in this article is the ways in which clinicians identified the disorder they were calling schizophrenia. What were the structural, institutional and practical conditions that framed the clinical experience of schizophrenia at each single moment? I draw on research of infrastructures and more generally on the insistence in Science and Technology Studies (STS) on the material dimensions of clinical work in

order to highlight both the highly contingent nature of clinical judgment and the way it is structured by the conditions of psychiatric work. With this inquiry I do not intend to downplay the argument that fundamental human processes are behind schizophrenia. (Jenkins and Barrett, 2004) Rather I see the analysis as an attempt to offer another supplementary perspective on the social life of that disorder.

Outlining an account of the changing infrastructures of psychiatric diagnosis across the twentieth century would by far exceed both my capacity and the scope of this article. Rather my strategy will be to illustrate aspects of this analysis by focusing on three moments in the history of the diagnosis of schizophrenia in the twentieth century. The first is German psychiatrist Kurt Schneider's discussion of first and second rank symptoms in the interwar period. The second is the work on the criteria for defining schizophrenia in the framework of the WHO International Pilot Study of Schizophrenia at the turn of the 1970s. The last moment concerns recent discussions on deconstructing psychosis in the framework of the development of the fifth edition of DSM. I take these discussions as revelatory moments in which the arguments that are exchanged, the nature of the criteria and the type of the definitions they offer, make visible the infrastructures behind diagnostic work. Before turning to these analyses, the first section of the article offers some broad theoretical and historiographical considerations on the changing infrastructures of psychiatric diagnosis in the twentieth century.<sup>1</sup>

## **Infrastructures of psychiatric diagnosis**

This article proceeds from the assumption that what is global in a condition such as schizophrenia derives as much if not more from shared infrastructures of clinical work as it does from shared understandings and representations, circulating numbers and concepts, common biological and psychological processes. I draw my understanding of infrastructures from Susan Leigh Star's and colleague pioneering work on information systems (Star, 1999; Star and Ruhleder, 1996; Bowker, et al., 2016). Infrastructures are things that are embedded and transparent, that are learned as part of becoming a member of a community, that extend over several sites and are, and that only comes to the fore when they break down. They can be found virtually everywhere there is work. Social science interest in infrastructures derived from an attention paid to mundane and taken for granted dimensions of professional and scientific work, many of which related to the use and maintenance of infrastructures. (Graham and Thrift, 2007; Lynch, 1993)

Geoff Bowker and Leigh Star's own work on the International Classification of Disease offers a series of analytical clue as well as a series of concrete examples on some infrastructures behind that lay behind diagnostic work. (Bowker and Star, 1999) In the line of decades of research on categories and labelling, one of their central questions was how people managed to map a complex reality onto a limited set of categories. I suggest in this article to expand the analysis to a wider range of infrastructures that contribute to organize and shape practices in the field of schizophrenia. These infrastructures do not only consist in the instruments that are specifically used to sort pathological conditions and disease entities, but they also encompass a range of material and architectural

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<sup>1</sup> This article is based on several lines of research that I have been following over the last six years on the history and current status of early psychosis. These include archival work on schizophrenia research in France, Germany and the United States, as well as a multisite ethnography of schizophrenia research in France and Germany. In particular this My participation to this world also entailed attending international conferences as well as interviewing leaders in the field of schizophrenia research at the international level as well as participation as a sociologist into a collaborative research with a French research team.

arrangements, legal prescriptions and professional models that organize the way patients come to clinics and navigate in the world of schizophrenia, as well as professionals organize their work. Among these infrastructures are the paper technologies and informatics infrastructures that are used to record clinical notes (Hess and Mendelsohn, 2010; Borck and Schäfer, 2015; Berg, 1996), the architectural and institutional models that structure the landscape of mental health institutions (Keating and Cambrosio, 2003; Laget and Laroche, 2012), or the professional standards as well as legal models that define the role and scope of mental health professions (Freidson, 1970; Abbott, 1988).

By insisting on infrastructures I do not want to reduce diagnosis making to the mere application of routine procedures that would be solidified in these infrastructures. A key theme in the analysis of infrastructures is in fact the gap between their normative dimensions and the creativity of social practices. On another hand while infrastructures impose their structure on work activities they themselves derive from the way this work is thought of and conducted. We may also think of the relationship between infrastructures and clinical work with the help of the notion of moral economies as it was defined by historian of science Lorraine Daston. In science Daston defined moral economies as “webs of affect-saturated values that stand and function in well-defined relationship to one another” and that are integral to the very ways in which scientific research is done. (Daston, 1995) In the same way, in the field of psychiatric work, a given infrastructure both reflects and shapes a series of moral values and norms that organize the ways in which clinicians conceive of themselves and behave as professionals. For instance the development of an array of tests and interview schedule was founded on a new ethos of exactitude and discipline that profoundly affected both the psychiatric profession and its relationship to its patients.

With the concept infrastructures I also insist on the incremental nature of changes in the domain of psychiatric diagnosis across the last century. A central theme in the history of schizophrenia is the impact of past descriptions of the disorder on current concepts. The distinction German psychiatrist Emil Kraepelin made between dementia praecox and manic depressive continues to be called upon in virtually every discussion of the diagnostic problems of schizophrenia and in 2011 the centenary of the publication of Eugen Bleuler’s *Schizophrenie*, which introduced the term, was celebrated with due recognition of the enduring influence of a classic (Carpenter, 2011). Such celebrations represent more than rhetorical deference due to a glorious past. Many clinicians and theoreticians seek the truth of the disorder in observations published decades ago that seem to embody their authors’ clinical concepts. While one may want to see in this enduring influence the acumen of past clinicians, it also reflects the permanence of some core dimension of the infrastructures of diagnoses across the century. Despite decades of deinstitutionalization and more broadly transformations as a result of an expanding field of psychopharmacology and transforming societies, psychiatric practices are still structured by the institutional and normative arrangements that were created in the 19<sup>th</sup> century in most European and American countries. Both the sort of phenomena that are labelled schizophrenia and the way they are remain intimately related to what they used to be a century ago.

By contrast one might want to see in the advent of the biomedical complex in the second half of the twentieth century a series of epochal transformations that have profoundly affected psychiatric diagnosis making. The creation of new psychopharmacological therapies, the multiplication of tests and scales, the development imaging and genetic engineering not only molecularized the representations of psychiatric disorders. STS scholars Peter Keating and Alberto Cambrosio would

perhaps argue that these developments were behind the emergence of new arrangements between laboratory techniques and clinical practices taking place on “biomedical platforms” (Keating and Cambrosio, 2000; 2003). While I agree with them that we should be watchful for the new ways of practicing psychiatry that are emerging within the biomedical complex, I do not believe that these are necessarily based on a dilution of the clinical gaze. On the one hand the psychiatric research complex has had a major impact in transforming diagnosis making over the last decades through the dissemination of schedules and guidelines or the multiplication of reference centers that tend to create new polarities in the landscape of mental healthcare. On another hand, contrary to Keating and Cambrosio’s observations in the field of cancer, psychiatric disease entities notoriously resist reduction to biomarkers. Even in research settings a striking dimension of psychiatric decision making remains its reliance on clinical judgment. Despite a number of prophetic calls the impact of genetics or brain imaging might not be so much to challenge psychiatric expertise than to negotiate it in new ways.

In the line of these remarks a major theme in the history of schizophrenia is the possibility to produce universal knowledge on the disorder through localized experience. In the past phenomenological approaches have promoted the role of the clinician’s personality in the evaluation of symptoms, and some of these approaches even asserted that diagnosing schizophrenia relied on a “praecox feeling” that could not be objectified (Rümke, 1990). If these ideas may have receded in the recent period, they have not disappeared and one may argue that they continue to shape the perspectives of many clinicians over the disease. They reflect the enduring tension between the lack of specificity of the disorder and the irreducible experience represented by its encounter. Schizophrenia was from the beginning and still is at once a vague and unmistakable thing. The equation many people still see between schizophrenia and madness is a dimension of this. Yet schizophrenia is something else than pure madness. It is the attempt at framing madness within biomedical reason. This tension shaped schizophrenia as both a global and a local entity throughout the last century. The question for historians is how this experience has been shaped by the social, material, organization and institutional organization of psychiatric work. I now turn to the first moment of my analysis.

## **Clinical schizophrenia in the interwar period**

In his *Klinische Psychopathologie* published between 1939 and 1950, probably one of the most influential book on schizophrenia in the 20<sup>th</sup> century after Bleuler’s *Dementia praecox oder Gruppe der Schizophrenie*, Kurt Schneider pointed to the particular position schizophrenia occupied in psychopathology (Schneider, 1950). In the domain of so-called endogenous psychoses, schizophrenia was the remaining option once a clinician was sure the condition was not manic depression (Schneider, 1950:11). Yet at the same time Schneider also suggested that schizophrenia could be ascertained in many cases on the basis of the presence of specific symptoms (Schneider, 1950:138-139). These perspectives were less contradictory than it may seem. In Schneider’s view schizophrenia was conceived of in relation to other disorders; it was a salient pattern against the background of the ordered set of pathological phenomena that constituted the realm of psychiatry.

This take on schizophrenia reflected Schneider’s wider position on diagnosis. Schneider saw individual psychiatric disorders as “types”, in the sense given by Max Weber to that concept, which helped organize psychiatric diagnosis making but should not be taken at its face value. “With this [notion], the classification of endogenous psychoses will be more relative, with this notion ‘accuracy’

loses its strength, the struggle between systems and schools loses its pungency, with this notion for instance it does not make sense any more to fight over the question of whether regression melancholia 'belongs' to manic depressive madness, but the question is only whether it is practical to count it as such, or whether it is handier not to do it." (Schneider, 1925) In this perspective diagnostic criteria did not aim at ascertaining a diagnosis. Rather they helped a clinician recognize a condition in order to take action. The "first rank" and "second rank criteria" he listed for the diagnosis of schizophrenia followed this philosophy. (Schneider, 1950; also see: Cutting, 2015) They were a list of symptoms which were typically there in patients with the disorder and as such they indicated the presence of that disorder when they were there, but they were neither a sufficient nor a necessary condition for it.

Schneider's relativistic stance on diagnosis is usually taken as an expression of the influence of phenomenology over his thinking. A colleague and friend of Karl Jaspers, his psychopathology was also influenced by his reading of Max Scheler as a philosophy student in Tübingen. (Cutting, et al., 2016) More pragmatically his intellectual project also reflected a concept of mental disorders where the main question was not so much whether a case was schizophrenia or another psychosis, but whether it was madness or not. (on this way of framing the problem of psychiatric diagnosis, see: Noll, 2018) This explained his and his fellow psychiatrists' ways of thinking about classification. The key, central category for mid twentieth German psychiatrists was that of "endogenous psychoses". These were characterized within two series of distinctions. On the one hand psychoses distinguished themselves from psychopathy or abnormal personalities: while psychopathy was conceived of as a deviation from the normal, psychoses were seen as illnesses resulting from an underlying pathological process. On another hand, within the realm of psychoses, German psychiatrists distinguished between organic psychoses, for which a biological cause was known, and endogenous psychoses for which there was no known biological etiology. Diagnosing organic psychoses was supposed to be relatively straightforward: by definition they relied on the presence of a number of definite signs, which could be ascertained by biological testing properly done. By contrast the identification of endogenous psychoses relied on an ability to decipher less univocal psychological and behavioral signs that was the realm of psychiatry. (Henckes and Rzesnitzek, 2018)

The role of forensic psychiatry was determinant in this way of thinking (Hess, 2015). In the mid-twentieth century the main use of psychiatric classifications was still to decide about the fate of a patient in the asylum system or in the court. This is why they were highly idiosyncratic. The way psychiatrists addressed the problem of nosology was shaped by the specific institutional and judicial arrangements on which the psychiatric system was founded at the national level. These arrangements were in turn reflected in the paper technologies in use locally. Local ways of doing with these technologies remain to be investigated by the historiography. (Hess and Mendelsohn, 2010) In France, for instance, the "certificates" psychiatrists had to write to justify a decision to commit a patient aimed less at labeling a disorder than at making explicit the arguments for or against seclusion. (on the creation of the psychiatric certificate: Castel, 1988:139-141) Clinicians had to provide a short description of the disorder in order to justify confinement. This created a style of writing that consisted in picturing traits in order to produce a global impression of the case. Diagnosis was not the determinant feature and as a result it was virtually absent from medical records. By contrast the specific take German psychiatrists had on diagnosis was shaped by the organization of the university clinic, a urban institution created at the end of 19<sup>th</sup> century that served both as an entry in the psychiatric system for patients, as a training center for medical students and as a

research institution. (Engstrom, 2004; Hess and Ledebur, 2012) In this system diagnosis was a crucial instrument at the juncture of knowledge making and patient management, a position that was reflected in the very structures of German medical records (Henckes and Rzesnitzek, 2018; Keuck, 2018). The differential understanding of schizophrenia between both countries reflected these two widely different infrastructures: in France many psychiatrists saw schizophrenia as a catch all category that blurred the subtleties of individual tableaux and schizophrenia only made its way in French diagnostic practices after the 1930s (Guillemain, 2018); by contrast schizophrenia had established itself as the determinant category for German psychiatric thinking from the 1910s.

The circulation of knowledge and categories was shaped by the specificities of local infrastructures of psychiatric work. Categories and classifications were useful for communicating across contexts and the first efforts at crafting an international classification of madness can be traced back to the late 19<sup>th</sup> century. Yet locally what was important were the ways in which singular concepts found a niche in the institutional infrastructure of psychiatric work. While the diffusion of categories in the colonial world also followed this pattern, it was also shaped by the specific relationships colonial administrations had with autochthone people, its goals as well as the shape local colonial and indigenous infrastructures. Speculations about and research on the universal nature of dementia praecox famously began with Emil Kraepelin's journey to Indonesia in 1904. (Bendick, 1989) However colonial psychopathologies were shaped by a melting pot of influences which included metropolitan theories as well as vernacular concepts, resulting in hybridity rather than translation. (Ernst, 1997; Vaughan, 1991; Sadowsky, 1999) The identity of schizophrenia as a disorder across contexts made in fact little sense in a world where classifications were so much related to the local infrastructures of healthcare.

### **Schizophrenia redefined by the research complex in the 1960s and 1970s**

The International Pilot Study of Schizophrenia (IPSS) is usually considered as a decisive moment in the history of transcultural psychiatry: the demonstration that schizophrenia affected people in the same ways in all parts of the globe; the proof of the global nature of mental disorders. (Patel, et al., 2013) Another less commented aspect of IPSS is its role in the emergence of a new concept of schizophrenia characterized as the conjunction of two syndromes, one consisting of "positive symptoms", the second of "negative symptoms". (Strauss, et al., 1974) This concept would become the main framework for the research on the disorder for the next forty years. (Marneros, et al., 1991) These two aspects reflected the profound changes in the ways psychiatry addressed its entities in general and schizophrenia in particular from the 1960s on. While what counted for Schneider and his contemporaries was the position of a category in a classification, the main question raised by schizophrenia was now its internal consistency. In this new problematization a key role was played by an emerging infrastructure of institutions, protocols and technologies supporting schizophrenia research.

Schizophrenia research was in a sense a typically American cause. It reflected both the importance taken by schizophrenia in the American intellectual and cultural life and the specific ways in which biomedical research was funded in this country. (Woods, 2011; Metzl, 2009) The creation of the National Institute of Health and then of institutes dedicated to research on specific health conditions is usually interpreted as the governmental response to increasing public demands from for public funding of biomedicine: while successive US governments rejected the idea of creating a universal healthcare coverage at the scale of the country, funding research seemed less expensive than

funding care. (Starr, 1982; Harden, 1986; Hannaway, 2008) When the National Institute of Mental Health was created in 1949 its main task was to monitor the reform of the US psychiatric system. (Farreras, et al., 2004; Grob, 2008) By the 1950s it had established a series of intramural research units devoted to basic as well as clinical research and was funding a wide range of projects across the US as part of its extramural program.

The idea that the research effort in the field of mental health should focus on singular disorders rather than on mental health in general began to be expressed in the late 1950s. At that time schizophrenia already attracted a significant share of the research money distributed by the NIMH, but it was not singled out among the numerous programs coordinated by NIMH grantees. (Studies of Schizophrenia, 1954) Highlighting schizophrenia was thought of as a way of prioritizing research on a particularly dreadful disorder as well as a way of promoting psychiatric research and demonstrating to the congressmen who voted the budget of the NIMH the utility of the money spent for it: while mental health was a rather abstract concept, schizophrenia pointed to the tens of thousands people affected by the disorder who for the most part lived on state or federal money. In 1957 in a letter to the editor of the American Journal of Psychiatry, psychiatrist Stanley R Dean thus proposed that a program of research for schizophrenia was established at the NIMH: "Until now, public support has been directed towards the all-inclusive field of mental health. But psychiatry has long outgrown such swaddling clothes, and the phrase "mental health" now seems too diffuse, too ambiguous, too inadequate to clothe its constituent parts. That is especially true of one of its largest segments – schizophrenia – which many believe may provide the key to all mental disease. It is therefore deserving of much closer public and even professional scrutiny than it has previously received." (Dean, 1957)

Dean subsequently contributed to raise funds for schizophrenia research and he created an award for outstanding researchers. (Dean, 1979) These efforts and others led to organize and institutionalize the field of schizophrenia research. By the mid-1960s a series of funding bodies including the NIMH and several private foundations were significantly involved in that effort. In 1966 a reorganization of the NIMH led to the creation of a bureau specifically dedicated to coordinating work in the field, the Center for the Studies of Schizophrenia (CSS). (Mosher and Feinsilver, 1970) The role of the CSS was to produce coherence among programs and foster synergies between researchers. The Center organized meetings between researchers and monitored a series of programs while its head advocated the cause of schizophrenia among NIMH officials and the wider public. In 1969 the CSS also created the *Schizophrenia Bulletin* which rapidly developed into the major journal in the field. By the end of the 1970s schizophrenia was the sole psychiatric disorder with a significant coordinated research effort specifically devoted to it. In other countries schizophrenia research never reached this level of institutionalization but it also distinguished itself as a key fundraiser cause.

In a way the main question asked by schizophrenia research was what had become of a disorder that had lost its natural boundaries. The demise of the psychiatric institution beginning in the 1950s in the US and the advent of neuroleptic treatment in 1952 had blurred the symptomatic tableau of schizophrenia. Chronic schizophrenia did no longer mean the catastrophic course resulting in a combination of delusional states and intellectual deterioration that had been observed earlier. (Strauss and Carpenter, 1974) On another hand some forms of schizophrenia became harder to distinguish from a wealth of conditions located on the side of personality disorders with which they



shared many traits. (Gunderson, et al., 1975) An answer to these evolutions was the rejection of diagnosis, a temptation that had a strong appeal on the European continent to psychiatrists with a variety of theoretical orientations. (Pilgrim, 2007; Henckes, 2014) In the US the same phenomena had as a consequence an extensive understanding of the label, which was used for an ever increasing group of patients, a problem that began to cause a stir among the psychiatric profession in the 1960s and eventually became a major impetus behind both diagnosis research and the larger movement that led to the DSMIII. (Demazeux, 2013; Decker, 2013)

In this context the objective of schizophrenia research was to identify core phenomena that would help better characterize and understand the disorder. A basic methodological approach was to constitute samples of patients and to test them against controls for a variety of psychological and biological variables. (Mosher and Feinsilver, 1970) The idea that schizophrenia was processual and that the processes behind the disorder would be better identified when observed through time also led to the success of longitudinal approaches. In these approaches researchers sought to create samples of patients either suffering from schizophrenia or supposed to develop schizophrenia in order to test them repeatedly and see how the disorder was evolving. Research on subjects at high risk of schizophrenia, which would become one of the main programs of the NIMH in the field of schizophrenia in the 1970s, typically exemplified this approach: in this research patients supposed to be particularly at risk of schizophrenia were followed from childhood to adulthood to observe the disorder as it blossomed. (Reinholdt, 2018) High risk subjects were chosen among children of patients with schizophrenia, a condition that was known to be associated with a heightened probability to develop the disorder since the work of European geneticists in the immediate post-war period. Other longitudinal studies conducted in the US and German speaking countries also looked at the long term prognosis of the disorder. (Bleuler and Uchtenhagen, 1972; Huber, et al., 1979) These researches stressed the diversity of schizophrenia both synchronically and diachronically. Yet the objective was to channel diversity rather than suppressing it.

In contrast with earlier discussions over diagnosis in Germany, a characteristic of schizophrenia research in the 1960s was that it was in a sense working from within a clinical definition of the disorder. The diagnosis of schizophrenia was a departure point for research protocols. Another central feature was that it did not seek to suppress the variety of perspectives upon the disorder. A key challenge of schizophrenia research was the increasingly diverging perspectives taken by different segments of the psy world over the nature and mechanisms of the disorder. Schizophrenia research seemed to be a chaos of programs, theories and hypotheses, institutions and actors that barely converged. However until the mid 1970s NIMH officials did not seek to suppress this diversity. Rather the strategy was to aggregate the different perspectives in order to derive the best from each of them. This was true of both the intramural program of the Institute which was thought of as an interdisciplinary endeavor, and its extramural research which extended to all the sensibilities in the profession. As Robert Cohen, the Director of Clinical Research at the NIMH wrote in his 1960 annual report:

*The interaction at the regular staff conferences over the eight years of our existence has had a noticeable impact. The individual social or biological scientist no longer approaches a representative problem even in his own discipline without some consideration of its broader implications. Such thinking, by taking into account a wider range of possibilities, leads to a more critical evaluation of the phenomena we are attempting to understand. As the range and depth of our studies show, this*

*atmosphere has not had a stifling effect upon individual initiative; rather, it has promoted careful attention to methodology, precise evaluation of results, and, what is most important, a search for more powerful conceptualizations. (National Institute of Mental Health, 1960:[590])*

Another aspect of this way of thinking was that clinicians were left to decide about the definition and limits of schizophrenia. Until the 1970s and the work on Research Diagnostic Criteria, attempts at standardizing diagnosis were limited to the collection of data. The first questionnaires that circulated in the 1950s were used to structure clinical interviews and make sure that all the relevant data was collected. Clinicians were needed to pass questionnaires and to make a diagnostic decision. Diagnostic standardization organized the perspective of clinicians but it did not seek to suppress it.

The work undertaken in the framework of the IPSS reflected this style of doing research. Even before investigating the prevalence of the disorder in different parts of the world, the first objective of the study was to evaluate the possibility to conduct epidemiological research in a transcultural context. (World Health Organization., 1973:3-4) The study relied on clinical evaluations conducted simultaneously in nine centers by teams consisting of local clinicians. To ensure that local teams would diagnose the same phenomena, they were required to use the same instrument for collecting the data, namely the Present State Examination. Discussions over the comparability of the results of the different centers of the study usually focus on the translation of the instruments used for clinical interviews. However another source of variability came from the fact that local clinicians were left alone to make diagnostic decisions. While the investigators tried to harmonize diagnostic practices both within and between centers by organizing sessions where clinicians were asked to diagnose together the same patients, the procedure left much room for the expression of the idiosyncrasies of individual clinicians. In a subsequent phase of the analysis a factor analysis was applied to the data collected to create different groupings of patients. Clinical judgment was required at all stages of the procedure, from the definition of variables to the final validation, but the procedure introduced some standardization in the ways patients were classified. The main outcome of all this work was the delimitation of a core group of patients defined by the fact that they were labelled with schizophrenia by local clinicians as well as by the statistical calculation. This “concordant group of schizophrenics” was judged sufficiently coherent to demonstrate the consistency of diagnostic procedures across centers and to validate the research.

The very existence of that group relied on the shared assumption that there existed something called schizophrenia that could be recognized by every clinician across the world. Work on positive and negative symptoms of schizophrenia by the US team of the IPSS followed on a similar philosophy. The method consisted in analyzing the frequency of a series of symptoms among the US patients of the study. (Bartko, et al., 1974) These were then allocated to subgroups reflecting different distributions of the symptoms as demonstrated by a cluster analysis. Eventually the symptoms were grouped into categories that contributed more or less to each group. The analysis thus suggested the existence of three categories of symptoms: positive and negative symptoms, and disorders of personal relationship. Eventually the author suggested that they reflected different processes behind schizophrenia. (Strauss, et al., 1974) In the end the research did not so much aim at decomposing schizophrenia than it sought to test its internal consistency.

## Databased schizophrenia in the early 21<sup>st</sup> century

In the early 21<sup>st</sup> century schizophrenia may be losing its preeminent position in global mental health. Multiple causes contribute to this phenomenon: contestations of the label by both researchers and service users across the world (Lasalvia, et al., 2015; van Os, 2009), results from basic research demonstrating the continuum between schizophrenia and both other psychotic disorders and normal conditions (Tamminga, 2010), as well as findings suggesting that schizophrenia is not the first contributor to the burden of psychiatric disorders, including in southern countries (Whiteford, et al., 2013). Behind all these phenomena lay new ways of mapping psychopathological phenomena onto new infrastructures, namely databases. These in turn organize new representations of psychopathologies that challenge the very idea of psychiatric disorders. Yet despite these challenges the schizophrenia label continues to be needed to characterize a range of seemingly irreducible clinical experiences. This creates a series of tensions that profoundly affect current debates over the diagnosis.

Databases are the main infrastructures behind a new organizational form that emerged and came to organize the field of psychiatric research over the last two decades, namely the research consortium. Consortia may be defined as collaborative networks of researchers sharing similar methodologies. While such networks existed since the 1950s in other branches of medicine, and most notably in cancer (Keating and Cambrosio, 2012), in psychiatry the origin of consortium research may be traced back to the first collaborative clinical trials organized under the aegis of the NIMH in the early 1960s. (The National Institute of Mental Health Psychopharmacology Service Center Collaborative Study Group, 1964) However these first collaborative studies were planned to work on the short term with definite research objectives, even though with time some of them came to constitute databases that were made available for further analyses. By contrast consortium research had a wider scope and it was based on much looser organizations. Moreover its field was not restricted to treatment research but rather encompassed more generally research on etiology. In the field of schizophrenia one of the early examples was a consortium created in 1973 as an umbrella for the high risk studies funded by the NIMH (Garmezy and Phipps-Yonas, 1984). In the spirit of 1960s and 1970s schizophrenia research this early consortium aimed at fostering discussions among its members about methods and results. Research teams did not share data and as we mentioned above they had widely divergent views over both the nature of the disorder and the processes they were interested in. In fact members of the consortium only had contacts on the occasion of meetings organized more or less regularly. Except for a series of special issues of the *Schizophrenia Bulletin*, the only joint publication was an edited book with chapters from single projects published in 1984. (Watt, 1984)

Later consortia shared the same philosophy but they managed to produce a much higher degree of integration among participating centers. The ultimate objective was to mutualize data in order to increase their analytical power. Several factors accounted for the creation of those consortia, including the availability of funding at the Federal or international level, the new possibilities opened by communication technologies as well as the need to create larger samples of patients to strengthen analyses as new methodologies were developed. In the 1980s genetics provided the first such consortia under the aegis of the NIMH genetics initiative with the objective to map the genes involved in major psychiatric disorders. While the first of these consortia gathered a small number of centers, by 2007 consortium research in the field of psychiatric genetics entered a new dimension with the creation of the Psychiatric Genomics Consortium (PGC) as part of the broader Genetic

Association Information Network (The GAIN Collaborative Research Group, 2007). Described by one of its protagonist as the coming of “big science” to psychiatry (Sullivan, 2010) this creation aimed at powering GWAS study of major psychiatric disorders. The GPC now claims to be the biggest consortium in the field of schizophrenia research with more than 800 participating teams and a total number of more than 900 000 individuals involved as research subjects<sup>2</sup>.

In the subsequent years brain imaging also produced a need for similar collaborations and more and more consortia came to be created with a variety of research goals and methodological designs, often aggregating several more or less independent sub-groups. One of the biggest consortia working in the field of schizophrenia studies in Europe in recent years, the EU-GEI study, is in fact a big coalition of research groups from all over Europe funded by the Seventh Framework Program of the European Union. Its website indicates as its broad objective to investigate “the interactive genetic, clinical and environmental determinants, involved in the development, severity and outcome of schizophrenia”<sup>3</sup>, however this objective conceals several relatively independent scientific agendas led by its various subgroups.

A crucial ingredient of consortium research is the ability to share large sets of data within extended networks of researchers. Beyond databases, communication technologies and laboratory techniques, the infrastructures that make this happen include an array of standardized tests, interview schedules and questionnaires that are used to generate data from clinical interviews. Using these infrastructures requires large amount of calibration work from participating researchers to ensure the comparability of local data sets: harmonization of criteria, training sessions, supervision, and ongoing quality control. In fact the standardization of data collection is a trend that affects psychiatric research beyond consortia. To enable replication or the inclusion of published results in meta-analyses, journals tend to require from researchers that they make their data available for further analyses. While there are usually a number of tests or interview schedules available in the literature to assess a given psychopathology domain or psychological function, researchers are also encouraged to use a small number of standard instruments even though they may find that these instruments are less handy than others or that they do not correspond to their own concept of the phenomena. In a sense the whole field of psychiatric research may be now seen as a giant consortium.

As a result, it has become nearly impossible to map the field. This observation does not so much refer to the size of the psychiatric research industry although it has more than significantly increased over the last quarter century. The total budget of NIMH was multiplied by three between 1993 and 2017, from half a billion USD to more than 1,5 billion USD. In Europe funding opportunities have multiplied at the level of both States and the European Union in the wake of the Lisbon strategy launched in 2000 (Keeling, 2006). Several journals are now publishing research exclusively on schizophrenia and this condition is also the *raison d’être* of several research associations worldwide including the Schizophrenia International Research Society. Yet mental health research continues to attract modest amounts of funding particularly from private interests (Forsman, et al., 2014). In the field of schizophrenia, the total number of studies is limited and most studies are small in scale. The

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<sup>2</sup> <https://www.med.unc.edu/pgc>, consulted 05/09/2018. Other figures are mentioned in other publications however, a variation that might be explained by the fact that participating to the consortium is a relatively informal process. See below.

<sup>3</sup> See: <http://www.eu-gei.eu/about-the-project>, consulted 05/09/2018.

complexities of the field rather derive from its loose organization. Participation to a consortium often means little more than sending data to a centralized bureau which will be then in charge of dispatching it for analysis to statisticians. The whole process might be relatively informal. Local participating teams usually only need to add to an ongoing study protocol a series of tests required by the consortium and revise their inclusion criteria. Contact between teams may be limited to a few training sessions to use specific instruments and a series of emails upon sending data.

For patients this turns participation to research into a particularly opaque experience. Patients may be included at the same time in several studies corresponding to several consortia. Their data may circulate in widely different networks in which they will be submitted to different types of analyses. Some of these analyses may take place years after inclusion and may concern questions that are only remotely related to the reason they had been indicated on inclusion. Even though patients are supposed to sign a consent form for each study they are in, they usually have limited awareness of the way their data will be used.

For participating clinicians and scientists, networking is a central activity at all levels. Local groups need to be integrated into international consortia to simply exist in the world of psychiatric research. Participation to these consortia gives them access to publications in major journals and, as a result, to funding. On another hand they also need to keep contact with the local infrastructure of psychiatric care in order to get access to patients. Most of psychiatric research centers rely on primary care services for recruiting patients, to which they need to demonstrate their usefulness. Diagnosis and more generally evaluations are the primary products they can offer them. Some of them provide expert care to patients but they rarely do in the long term.

There are also several ways of organizing these networks. For instance two competing clinical and research networks have been created in the early 2010s in France under the leadership of the two main figures of psychiatric research in the country. These networks now gather most psychiatric teams in French university hospitals. They are competing for funding as well as for patients. Both aim at creating large databases that may fuel future analyses and generate new research hypotheses. The first is organized around a series of pathology-oriented reference centers established in University clinics. These reference centers offer standardized assessments to patients addressed by community services but they do not provide treatments. The second network is somewhat looser. It is organized in the framework of a *Groupe de Recherche* which provide both a framework for launching collaborative projects and a database infrastructure set up to collect data from individual centers. Despite this competition, teams from both networks often contribute to the same international consortia and they sometime have to cooperate within single projects. Another model has been established in Germany in the 2000s where the main psychiatry university departments organized in a series of pathology oriented networks. The schizophrenia network was described to me as a loose organization that aimed at creating synergies among participating teams and fostering collaboration in consortium projects. However the network has played an important role over the years as a window of German schizophrenia research and its chair has been also chairing the workgroup in charge of the definition of psychotic disorders in the ICD11 and he also participated to the workgroup on the same issue for the DSM5.

While earlier schizophrenia research sought to aggregate singular perspectives on schizophrenia, consortium research seeks to create new perspectives from within the data accumulated. If the

efforts of clinicians and researchers previously aimed at stabilizing a familiar schizophrenic tableau, the objective is now to destabilize this tableau in order to generate a better representation of the patients' conditions. Several iconic projects have embodied this ambition in recent years including the controversial RDOC project launched by the former director of the NIMH (Insel, et al., 2010) or a range of even more speculative endeavors in the field of "phenomics" (Cuesta and Peralta, 2008). These projects are developed amidst concerns over the "validity" of clinical categories such as schizophrenia. (Tsuang, et al., 2000) Yet interest in this research also derives from the recognition of the limits of available psychopharmaceutical treatments on a wide share of symptoms. The head of the clinic where I was conducting my observations titled one of her projects: "Better descriptions for better treatments". Diagnosis research is in fact closely with research on new therapeutic strategies such as psychedelic drugs, various types of brain stimulation technologies or cognitive-based psychotherapeutic intervention.

While the prospect for a radical transformation of psychopathology might be far ahead, this research already begins to destabilize the ways clinicians and patients are used to understand and deal with psychopathological conditions. An aspect of these evolutions is the role in the diagnosis and treatment of schizophrenia of what sociologist David Armstrong called "distal symptoms", that is symptoms such as functioning, quality of life or even cognitive symptoms that are revealed by questionnaires and scales (Armstrong, et al., 2007). As I was told by a psychiatrist in the center where I was conducting my fieldwork: "We are working with a new symptomatology". This center is now known for treating schizophrenia with off label prescriptions of Methylphenidate, a drug normally used in attention deficit disorders. Standard treatment procedures for schizophrenia also include motivational group techniques and cognitive remediation that are used to help patients cope with their lack of concentration or difficulty with planning and organization.

Researchers seek to reach these objectives by generating large amounts of data that can be computed with new types of statistical analyses, such as machine learning or Bayesian techniques. The nature, the quality as well as the quantity of data are crucial to the process. The limited number of included subjects in most studies is compensated by the large numbers of data that can be generated for each single patient thanks to an accumulation of tests. It is not rare that recruited patients have to undergo week-long sessions of tests and interviews. On another hand the quality of the data also relies on the way researchers are disciplined to administer tests and report the results of their observations in the shared database. This involves an amount of tedious work to supervising the group, correcting the data, looking for missing data that is performed by the clinicians themselves or by a data manager.

Good data also means that patients have to satisfy to stringent inclusion criteria. As Steven Epstein forcefully demonstrated a politics of inclusion determines with whom and for whom biomedical research is conducted (Epstein, 2007). An aspect of this politics concerns the psychopathological conditions that are researched. This is why disease entities continue to play a key role in the organization of the research. In order to be able to demonstrate the presence teams need to recruit patients presenting neat psychopathological tableaux. This requirement contradicts the notion that psychiatric diagnoses lack validity: in many respect they are the unique valid ways of constituting samples. In order to overcome this contradiction, some publications are now arguing for the creation of samples of "unselected patients" that would not correspond to given tableaux. (Uher, 2013) Another tendency is to create transdiagnostic samples of patients on the basis of symptomatic

criteria. The emergence of a series of entities such as attenuated psychosis that are defined by the mere presence of a series of symptoms is an aspect of this trend.

This is only one aspect of the tensions that arise between the relentless logic of categorical thinking and the type of representations that is emerging from the research. These tensions are expressed in different ways. Locally, in research centers, an aspect is the gap between the way patients are evaluated for research and the clinical discussions they are stimulating. Robert Barrett's analysis of the construction of schizophrenia as a case situated at a distance from the patient might be useful here. (Barrett, 1996) Another tension derives from the fact that most of the research is concentrated in European, North American and to a lesser extent East Asian institutions. Patients from southern countries are underrepresented in the research and while there is a growing awareness of the cultural dimensions of psychiatric disorders, including in the DSM5, this has had little impact on the way mental illness is approached within research.

All these tensions surfaced in the debates over the definition of schizophrenia in the DSM5. Interestingly enough, for the first time the work group in charge of the question included non American psychiatrists. Some of them are fierce advocates of a "Deconstruction" of psychosis that would lead to abandon the concept of schizophrenia. Much of these discussions focused on the introduction on forms of "dimensionality" in the structure of the DSM. However there are many ways to understand the idea: one might be to use "dimensions" to organize the description of psychopathological conditions; one might also reorganize the descriptions of psychopathological conditions in order to stress the "continuum" between these conditions or the "spectrum" they constitute. Both solutions may have immense consequence for the ways we conceive of psychiatric disorders and treat them. In a 2014 editorial announcing the intention of his journal to publish studies on the boundaries between schizophrenia and bipolar disorder, the editor of *Schizophrenia Bulletin* summarized his position as: "We intend to broaden the mission without damaging the brand." (Carpenter, 2014) As this quote hinted this is more than an issue of the valid basis for diagnosing people. The question is also that of the very image of the disorder in the wider public.

## Conclusion

In this paper I have tried to offer a prismatic view on the changing status of schizophrenia over the last century. I have suggested that a focus on the changing clinical and research infrastructures might help shed a new light on these transformations. What is at stake in this story is the very sort of entity that schizophrenia has been through time: not only the symptoms, signs, criteria and more generally the wider clinical and social representations that defined it, but the inner and outer consistency of that category and its position in psychopathology at large. While schizophrenia represented in many ways the archetype of asylum pathology in the first half of the twentieth century, deinstitutionalization and the emergence and development of a research complex is now producing new definitions of the very sort of phenomena that once constituted the disorder.

There is much more to tell about the infrastructures of psychiatric diagnosis than I was able to do in this article. Rather than drawing a full picture I have attempted to heuristically delineate a framework that may be used for further research. At the same time I have also sought to highlight a series of discussions and debates that relate to the enduring difficulty of objectifying psychiatric diagnoses. While we need detailed studies of the very ways in which clinical work and psychiatric

research have been done in various ways in a diversity of settings by different types of collective I hope to have outlined a first roadmap for these futures studies.

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