

## Chapter 4

# Tracking the occupational exposure of cancer patients: the Giscop93 survey

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Although the SUMER survey (Medical Surveillance of Occupational Risks) has since 1994 made it possible to monitor some 20 occupational carcinogenic exposures in France on the basis of a representative sample of the working population, there is no institutional, centralised and accessible record of occupational exposure to the numerous carcinogens present in the working environment since the early 20<sup>th</sup> century. In the absence of readily understandable information for workers on the risks to which they have been exposed and given the decades which generally separate the time of exposure and the outbreak of cancer, it is often difficult for patients to make the link between work and health. Perceptions associated with the main causes of cancer – smoking, drinking and more recently, ‘bad luck’<sup>1</sup> – are very often brought to patients’ attention, and to that of their doctors, who rarely refer to an occupational origin when diagnosing cancer. Yet though the knowledge accumulated on the carcinogenic risks associated with different sectors of activity and jobs is considerable, the mechanisms for concealing the role of working conditions in changes in the incidence of, and mortality due to, cancer are very effective. Of these, job precariousness and the individualisation of the link with work modify power relationships between employers and employees, aggravating the social inequalities of exposure while at the same time making traceability more and more unlikely in view of the piecemeal and adaptable nature of working careers.

In view of all this, a research project concentrating on action was established in the early 2000s in the French *département* of Seine-Saint-Denis (Réseau Scop93 2005; Thébault-Mony 2008). Led by public health researchers in association with hospital doctors, local authorities and a group of experts in occupational health and sickness insurance, this project used an original survey methodology (see Box 1) in order to update the exposure situations encountered by cancer patients throughout their working life. Based on this revelation of exposures which would otherwise have remained largely unknown to the patients themselves, the objective was then to identify the factors aiding or hampering access to the right to financial compensation with respect to the occupational disease<sup>2</sup>. This contribution attempts to set out a number of strengths, but also limitations, of the procedure implemented for reconstructing exposure.

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1. See the arguments put forward by an article published in the prestigious scientific review *Science* (Tomasetti and Vogelstein 2015).
  2. See the contribution of Anne Marchand in this piece.

**Box 1 Giscop93 survey**

Since March 2002, three hospital departments have been collaborating closely with the Scientific Interest Group on Cancers of Occupational Origin in Seine-Saint-Denis (Giscop93). These departments are referring patients suffering from tumours of the respiratory, urinary or haematological tracts to Giscop93. With their agreement, these patients are contacted by the Giscop team to be interviewed by a sociologist on their careers. These interviews are intended primarily to reconstruct patient careers, documenting the work performed in each position, including the environment in which it was done. Each interview is then submitted to a multidisciplinary expert committee tasked with examining the description of each position with respect to a list of 54 carcinogens acknowledged as being present in the working environment. The experts also examine the eligibility of patients for an occupational disease claim, following this up by prospectively monitoring patients with regard to claiming and being awarded compensation.

**1. Territorial base**

Very densely populated, the *département* of Seine-Saint-Denis has a high proportion of migrants and blue-collar workers in its working population. It has a long industrial history characterised by small and medium-sized enterprises in addition to the presence of several emblematic plants<sup>3</sup>. Since the 70s, the *département* has also been characterised by an excessive number of deaths from lung, pleural and bladder cancers. However, as in the other Île-de-France *départements*, no cancer register has yet been set up. The *département* could therefore assume a pilot role in the monitoring of occupational cancers, testing the implementation of an information system at national level. It was on this basis that the local scheme was established, in an attempt to ensure proximity to health, occupational health and compensation players.

**2. Cancer as a sentinel for a lack of prevention**

Taking inspiration from the concept of occupational “sentinel health events” (SHE[O]) proposed in 1983 by Rutstein et al., cancer is considered here to be a sentinel event in itself, putting researchers on the track of work-related carcinogenic exposure, aside from the application of any filter associated with the work activity. Patient recruitment took place through partner hospital departments (oncology, pneumology, urology departments) not specialised in occupational pathologies. Any person newly diagnosed with primary cancer of the respiratory, urinary or haematological tracts and residing in Seine-Saint-Denis was eligible for the survey.

3. To cite just a few examples: the Mécano plant and the Babcock and Wilcox foundries in la Courneuve, the Illustration printing works in Bobigny, PSA Peugeot-Citroën in Saint-Ouen and then Aulnay-sous-Bois, Saint-Gobins in Aubervilliers, Christophe in Saint-Denis, Idéal Standard and more recently L'Oréal in Aulnay-sous-Bois.

### **3. The patient as the expert**

The survey was built around an aspect key to the whole research: reconstructing a patient's working career. In an interview, a patient is invited to describe, job by job, position by position, the work performed, quite often far removed from the tasks suggested by the simple job title. Separate importance is attached to the environment in which the work was performed. The experience accumulated by the interviewer during interviews allows him to help patients recall details of possible importance in the carcinogen identification phase, meaning that reconstruction is conducted as closely as possible to the reality of patients' individual work.

### **4. Multidisciplinary expertise in exposure**

The variety of work situations and the diversity of carcinogens produced and used in industrial companies mean that a multidisciplinary group of experts is required – occupational doctors, prevention engineers, industrial hygienists, members of a CHSCT [Safety, Hygiene and Working Conditions Committee], sociologists, etc. – to reconstruct patients' exposure. On the basis of the detailed account of the work performed and the experts' knowledge of prevailing working conditions at the times and in the employment areas concerned, the group identifies the following for each position: the carcinogens, their probability of occurrence and other normal descriptors of exposure (intensity, frequency, duration, peaks). More than 54 proven or suspected carcinogens are taken into account.

### **5. Necessary cooperation**

The acquisition of knowledge on occupational exposure is thus based on a combination of a patient's recorded work experience and an in-depth examination thereof by the multidisciplinary group of experts. With each party contributing knowledge and skills, this combination uncovers situations not usually accessible under the normal approach of retrospectively evaluating exposure (see Box 2). Surveys using questionnaires are generally based on the principle that people have been given comprehensive and readily understandable information on their exposure, a situation found to be the exception. Moreover, the job-exposure matrices offer mean indicators masking the variety of situations. What is more, they are only available for some of the many known carcinogens, primarily asbestos.

**Box 2 Indirect exposure, ancillary activities**

Ms P. worked from 1959 to 1965 as a security guard for the Seigneurie company in Bobigny. 'The company is a paint factory [...] which employed about 300 people at that time, mainly manual workers and secretaries. It was a huge hangar covering almost two hectares. Machines made the paint, which was then poured into tins before being dispatched all over the place. The workers had to spray the drums of paint night and day with jets of water to prevent them 'exploding'. These drums contained toxic products. Her work involved recording the arrivals and departures of trucks in the warehouse. She had a lodge at the entrance to the hangar, about ten metres away from where the trucks arrived. [...] The patient lived in this lodge until 1975 [...]. A large sliding door allowed trucks to enter the warehouse. The patient sometimes went out onto the loading bay for a 'stroll', passing close to the drums of paint. A ventilation system evacuated fumes via the roof but the patient said that the paint smells were still very strong.' On the basis of this account, the experts identified two indirect exposures: benzene in the mixtures (solvents), and diesel exhaust fumes.

Between 1969 and 1986, Mr E worked as a sealing contractor for about 20 companies in the Paris region. 'The patient's work consisted in sealing the flat roofs of new buildings through applying bitumen. [...] The patient also had to carry out a whole range of ancillary work to finish sealing the roofs. He had to install rainwater drain pipes made of lead. He had to strip the lead with 'stearin', an acid which attacked the surface. The patient also applied tin solders to the lead pipes, as well as making expansion joints with lead. [...] He made trim from zinc or copper. Zinc or copper sheets were bent using a bending machine and then he had to apply hydrochloric acid solders with a soldering iron operating on propane gas. [...] Occasionally, four or five times a year, he repainted terraces. [...] The patient had little protection equipment at any of these sites. He wore leather and fabric gloves to handle the bitumen. He wore overalls, which he washed at home. There was often bitumen stuck to them. He washed his hands with a detergent, a special soap based on solvent or spirit. He often used spirit to remove traces of bitumen on his hands or face.' In addition to his exposure to bitumen (PAH) [polycyclic aromatic hydrocarbons], the experts identified three exposures associated with ancillary activities: benzenes in mixtures (solvents), strong acids and lead.

**6. Careers at the heart of the survey**

Workplaces were examined one by one and exposure identified with respect to the working situations specific to a patient at a given moment - proximity to other sets of jobs in construction and public works, activities of a client enterprise as part of industrial cleaning, etc. As far as possible, the group of experts looked at the whole record of working life, taking account of changes in the labour market and work organisation in order to assess the conditions under which each job was performed. In doing so, the survey revealed a social division of risks (see Box 3), still seen in current SUMER surveys (Cavet and Leonard 2013).

**Box 3 Social inequalities with respect to carcinogenic work**

Affected mainly by respiratory cancers, a very large proportion of patients, especially skilled workers, had been exposed to at least one carcinogen (almost 90% of men and 65% of women), with more than half of the workplaces characterized by multi-exposure\*. This proportion was 12 times higher than among managers and professionals. The survey also makes it possible to assess the effects of the increasing use of sub-contracting and temporary work on the social division of risks. In fact, the careers of almost one in four patients are 'temp careers': low-skilled work characterised by flexibility, instability and lack of continuity. Male patients with such careers, predominant among those starting work since the 1970s, were more likely to have histories burdened by exposure (an accumulation of five carcinogens or more over the entire career) than those pursuing high-skilled, stable and continuous careers. These results suggest that the precariousness of careers noted since the application of the principle of flexibility (Appay and Thébaud-Mony 1997) is reflected in a deterioration in working conditions and is contributing to the development of social inequalities with respect to cancer.

\* Exposure to at least two hazards from a list of about 50 proven or possible carcinogens.

## 7. Surveying cancer patients

The context of cancer, a fatal diagnosis turning patients' lives upside down, necessarily impacts information gathering, as it is impossible for some patients to be surveyed in view of the priority given to care, or even due to premature death. It is difficult to make sense of detailed reconstructions of working careers in view of the perceptions patients have of their work and the probable causes of their illness. Physical and mental exhaustion are often barriers to this laborious reconstruction exercise. And it can be just as difficult for the interviewers, having to find the right balance between empathy and impartiality, listening to the person and striving for thoroughness, a task which continually requires judgements and adjustments [Lanna 2013].

## 8. Heterogeneity factors

The evaluation of exposure is based on three overlapping sets of knowledge: that of the patient about his work, that of the interviewer about the conduct of the interview and that of the group of experts about exposure situations. Some accounts of jobs are more substantial than others, depending on the context mentioned above, but also depending on the ease with which the patient can talk about his work and his command of French. Over the 14 years of the survey, interviews have been conducted by a series of interviewers, with varied experience with respect to the requirements of research relating to aspects positioned at the intersection of serious illness and work. The conduct of interviews and the encoding of working careers are subject to an ever-changing protocol. At the same time, some 10 occupational health professionals are needed in the joint expert sessions to examine the exposure. The composition of the group of experts

has fluctuated over time, practices have developed, introducing an inevitable degree of variability in the evaluation process.

## 9. A 'non-representative' sample but an exemplary scheme

Though the surveyed sample can in no way be claimed to be representative – in the statistical sense of the term – of all cancer patients in France and even less of the general population, the survey nevertheless documents a broad range of exposure situations occurring between the 1940s and now and associated with highly unequal positions in the social division of work. Sub-contractors, temporary employees, unqualified cleaning and maintenance workers and migrants have been largely ignored in typical epidemiological studies, which usually concentrate on populations of stable and permanent workers. The situations identified in the particular context of Seine-Saint-Denis thus have overall relevance, revealing prevention shortcomings, all the more pronounced when they concern people whose careers involve some kind of precarity. They also illustrate the inadequacy and unequal nature of the criteria for awarding compensation with respect in particular to the multi-exposure situations experienced by a number of these patients. Finally, and this is particularly important, the results show that it is possible to reconstruct carcinogenic workplace exposures, even ones way back in the past, despite institutional amnesia and the disappearance of records and despite the fragility of our working group (see Box 4).

### Box 4 Impossible to preserve a working group

Despite repeated financial backing from a local authority (the Seine-Saint-Denis General Council), the Ministry of Labour and the Départemental League for the Fight against Cancer, the team behind the day-to-day running of the survey scheme is hit by great fluctuation. A real-life example of the 'precariousness of jobs in the higher education and research sector', Giscop93 has for several years been suffering the effects of project-based research financing, as well as the red tape inherent to this sector.

Team members are caught in a system of individual and collective constraints: replacement of part of the team every year, the challenges of multi-disciplinary working, domineering relationships within the academic sphere, the positioning of socially-engaged researchers, a lack of clarity on possible career progression\*, etc. The continuity and quality of the work can only be assured at the cost of significant concessions by all concerned in order to maintain a fragile balance between participation in the survey work, including all its invisible dimensions, and involvement in particular research aspects.

\*Due both to the chronic lack of financial resources and, since 2012 the Sauvadet Act which imposes a cumulative 3-year maximum for a fixed-term contract and is applied by most higher education and research institutions to non-permanent staff.

Table 1 Differences in the Giscop93 survey with respect to the usual approaches

Divergences and limitations with respect to the usual approaches	Advantages in terms of knowledge acquisition
<b>Recruitment of cancer patients, with no control group</b>	
Does not provide for studying the aetiology of the disease	Cancer as a sentinel with respect to past exposure and access to workers' rights
<b>Patients treated in public hospitals in Seine-Saint-Denis</b>	
Little social diversity: 60% blue-collars, 18% white-collars	'Magnifying glass' effect on a socially less advantaged population, which is also that affected most by cancer
<b>Exclusive study of working life</b>	
No procedure for estimating attributable risks	Detailed career and access to actual work activity
<b>Exclusive research of known carcinogens</b>	
No procedure for identifying new risk factors	Identification of prevention failure situations
<b>Great majority of patients 'exposed'</b>	
Under-representation of non-exposed people and work situations	Diversity in terms of duration, intensity, multi-exposures, etc.
<b>Longitudinal retrospective approach</b>	
Effects of selection (inclusion only of survivors)	Inclusion of the diachronic dimension of careers
<b>Piecemeal career accounts and evidence</b>	
Incomplete or imprecise career accounts, skewed memory	Reliance on workers' memories of their work, but lack of administrative evidence remains a problem for compensation
<b>Deletion of records relating to exposure</b>	
Little company history, lack of evidence of exposure (attestations)	Cooperation between patients and experts, search for specific data (archives, trade unions, etc.)

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